Communication, Cognitive Functioning, and Feeding and Swallowing Information Needs of Caregivers of Individuals Diagnosed with Alzheimer's Disease Within a Support Group Setting

by
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Thesis presented in fulfilment of the requirements for the degree of Master of Speech, Language and Hearing Therapy in the Faculty of Medicine and Health Sciences at Stellenbosch University

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April 2022

DECLARATION

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ABSTRACT

Background: The number of individuals with Alzheimer's disease will rise significantly in the coming years. This is a concern as Alzheimer's disease affects numerous functions within the scope of the speech-language therapist. However, due to the limited number of speech-language therapists in South Africa, individual speech and language therapy is not a viable option. Support groups may be a more optimal way of providing speech and language therapy service-related information. Objectives: The study aimed to determine the speech therapy-related information needs of caregivers of individuals with Alzheimer's disease, as well as their preferred support group structure. The study further aimed to describe common speech and language therapy-related points of discussion at support groups and the current structure of support groups in the Western Cape. Method: A convergent parallel mixed method research design was used, and qualitative and quantitative data were collected simultaneously. Semi-structured interviews were conducted with caregivers of individuals with Alzheimer's disease, whilst an online survey was used to collect data from support group facilitators. Results: The results indicated that caregivers had both directly stated, as well as indirectly stated information and support needs. Caregivers had more directly stated information and support needs about cognitive functioning than communication or feeding and swallowing. Their information and support needs were influenced by the current level of functioning of the individual with AD, caregivers' perceptions about the features of AD and their management, as well as acceptance of these difficulties. Caregivers did, however, have more indirectly stated information needs about communication as well as feeding and swallowing. There were also discrepancies identified between caregivers' support group structure preferences and the current support group structure in the Western Cape. Conclusion: The factors driving caregivers' information and support needs guide the information provided at support groups. As much information and support needs are indirectly stated, these needs may likely not be expressed in support groups. Subsequently, caregivers' knowledge about these areas of difficulty may remain limited. This may negatively affect caregiver understanding-and management of these difficulties. Furthermore, accessibility of support groups may be negatively impacted by the discrepancies between caregiver preferences and current support group structure.

Keywords: Alzheimer's disease, speech and language therapy, South Africa, support groups

ABSTRAK

Agtergrond: Die aantal individue met Alzheimer's se siekte sal beduidend toeneem in die komende jare. Dit is kommerwekkend aangesien Alzheimer's se siekte verskeie funksies binne die omvang van die spraak-taal terapeut se fokus affekteer. Weens die beperkte getal spraak-taal terapeute in Suid-Afrika, is individuele spraakterapie nie 'n haalbare opsie nie. Ondersteuningsgroepe mag 'n meer optimale manier wees vir die oordra van spraak- en taal terapie diens-verwante inligting. Doelwitte: Die studie poog om die spraakterapie-verwante inligtingsbehoeftes van versorgers van individue met Alzheimer's se siekte, asook die ondersteuningsgroep struktuur wat hulle verkies, te bepaal. Die studie beskryf ook algemene spraakterapie-verwante besprekingspunte in ondersteuningsgroepe en die huidige struktuur van ondersteuningsgroepe in die Wes-Kaap. Metode: 'n Konvergente parallelle gemengde metode navorsingsontwerp is gebruik en kwalitatiewe en kwantitatiewe data is gelyktydig versamel. Semi-gestruktureerde onderhoude is gevoer met versorgers van individue met Alzheimer's se siekte, terwyl 'n aanlyn opname gebruik is om data van ondersteuningsgroep fasiliteerders te versamel. Resultate: Die resultate dui aan dat versorgers beide direk-gestelde, asook indirek-gestelde inligtings- en ondersteuningsbehoeftes het. Versorgers het meer direk-gestelde inligting- en ondersteuningsbehoeftes oor kognitiewe funksionering as oor kommunikasie of voeding en sluk. Versorgers se inligting- en ondersteuningsbehoeftes is beïnvloed deur die huidige vlak van funksionering van die individu met Alzheimer's se siekte, versorgers se persepsies oor die kenmerke van Alzheimer's se siekte en die behandeling daarvan, asook aanvaarding van probleme. Indirek-gestelde inligtingsbehoeftes was meer oor kommunikasie asook voeding en sluk. Teenstrydighede tussen versorgers se ondersteuningsgroepstruktuur voorkeure en die huidige struktuur van ondersteuningsgroepe in die Wes-Kaap is ook identifiseer. Gevolgtrekking: Die faktore wat versorgers se inligting- en ondersteuningbehoeftes dryf, bepaal die inligting wat by ondersteuningsgroepe verskaf word. Aangesien inligting- en ondersteuningsbehoeftes dikwels indirek gestel word, word hierdie behoeftes moontlik nie in ondersteuningsgroepe uitgespel nie. Gevolglik kan versorgers se kennis van hierdie probleemareas beperk bly. Dit kan 'n negatiewe effek op versorgers se begrip- en behandeling van hierdie probleme hê. Verder, weens die teenstrydighede tussen versorgers se voorkeure en die huidige ondersteuningsgroep struktuur, kan toeganklikheid van ondersteuningsgroepe negatief beïnvloed word.

Sleutelwoorde: Alzheimer's se siekte, spraak- en taal terapie, Suid-Afrika, ondersteuningsgroepe

ACKNOWLEDGEMENTS

I would like to express my appreciation to the following individuals and organizations:

- Mrs. Alida de Beer and Mrs. Faeza Bardien for your guidance during the writing of this dissertation. Thank you for sharing your abundance of knowledge and experience and for your unwavering commitment to this project.
- Ms. Ashley Gaskin for the editing of this dissertation.
- The Health Research Ethics Committee and Western Cape Department of Health for providing clearance for this research project.
- Thank you to the support group facilitators from Dementia SA, Alzheimer's South Africa, Livewell Group, as well as Mrs. Lauren Carter and the support group facilitators from the remaining three sites who took time to participate in this study.
- Thank you to the caregivers who shared their experiences.
- Thank you to my family and wonderful partner for their words of encouragement, patience and support throughout the writing of this dissertation. Without you this dissertation would not have been possible.

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LIST OF ABBREVIATIONS

AD – Alzheimer’s disease

ASHA – American Speech-Language-Hearing Association

CG – Caregiver

DSM-5 – Diagnostic and Statistical Manual of Mental Disorders

EBP – Evidence-based practice

HPCSA – Health Professions Council of South Africa

NCD – Neurocognitive disorder

PBE – Practice-based evidence

PTs – Physiotherapists

OTs – Occupational therapists

SGF – Support group facilitator

SLT – Speech-language therapist

SLTS – Speech and language therapy services

WHO –World Health Organization

INTRODUCTION

The number of individuals with major neurocognitive disorder (NCD), previously known as dementia, is growing rapidly globally. The prevalence of dementia has been reported to double every twenty years (Cheng, 2017). Dementia is a progressive syndrome leading to the deterioration of cognitive functioning, including "memory, speech, reasoning, intellectual function, and/or spatiotemporal perception" (Sousa et al., 2020, p.1). In 2013, the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) replaced the term 'dementia' with 'major neurocognitive disorder' although the term dementia is still accepted (Dementia Australia, 2018). Dementia is an umbrella term used to "describe a clinical syndrome of progressive cognitive decline, but its subtypes are classified according to the cause of dementia" (Duong et al., 2017, p.119). Subtypes of dementia include Alzheimer's Disease (AD), vascular dementia, Lewy Body dementia and frontotemporal dementia (Duong et al., 2017). AD is the most common form of dementia (Fried-Oken et al., 2009; Raggi et al., 2015) accounting for up to 75% of cases (Qiu et al., 2009).

AD can be defined as a neurodegenerative disorder characterized by progressively declining cognitive and functional skills, with associated behavioural changes (Apostolova, 2016). AD can be divided into the early, middle and late stages. Throughout these stages, the number and severity of difficulties increase. AD can last for up to twenty years (Alzheimer's Association, n.d.), with the middle stage of AD lasting the longest, between two to ten years, while the late stage lasts one to three years (Klimova et al., 2015). The most prominent symptom of AD is memory difficulties, which already presents in the early stage (Apostolova, 2016). As the individual with AD is aware of their difficulties at this stage of progression, they may experience secondary behavioural symptoms such as depression and anxiety (Klimova et al., 2015). Additional behavioural difficulties include fear and apathy (Klimova et al., 2015). As the disease progresses into the middle stage, the individual with AD may also experience orientation difficulties (Klimova et al., 2015). Although language difficulties may be present in the early stage, these difficulties are not as prevalent as cognitive difficulties, and only occur in eight to 10 percent of individuals with AD in the early stage of the disease (Groves-Wright et al., 2004). However, as the disease progresses, language difficulties become much more severe and all aspects of language become affected (de Lira et al., 2011). Swallowing difficulties are also associated with AD and increases in severity over the course of the progression of the disease (Humbert et al., 2010; Sheikhany et al., 2019). As AD accounts for most dementia cases and the term 'dementia' is often synonymously used to refer to AD (Sachdev et al., 2014), research that focuses on both dementia and AD will be included in this dissertation, however, reference will predominantly be made to 'AD'.

There are several AD risk factors including older age (Meyer et al., 2016), poor socio-economic circumstances, chronic lifestyle diseases (Crous-Bou et al., 2017; Kalaria et al., 2008), and obesity (Crous-Bou et al., 2017; Kalaria et al., 2008; Kivipelto et al., 2005), as well as low levels of education and illiteracy (Kalaria et al., 2008). These risk factors are all particularly relevant in the South African context. The increased number of South Africans at risk of developing AD is cause for concern as the treatment and care required places significant burden on an already severely resource constrained healthcare system.

AD management involves medical management provided by medical doctors, specifically psychiatrists, and behavioural management provided by allied healthcare workers. Behavioural management provided by the speech-language therapist (SLT) often focuses on providing caregivers (CGs) with individualized strategies for communication, cognitive functioning and feeding and swallowing difficulties, and to provide stimulation to the individual with AD (American Speech-Language-Hearing Association [ASHA], n.d.). Although SLTs play a crucial role in AD management, there is a large mismatch in the number of SLTs in relation to the South African population size (Pillay et al., 2020). Furthermore, the number of available mental health facilities in South Africa are limited, for example the Western Cape having only four mental health hospitals available (Franken et al., 2019). This lack of resources may impede adequate service delivery within the South African context.

In the South African context, the individual with AD and their CGs may be placed in an unfavourable position to access healthcare resources and treatment due to the restricted available healthcare resources in South Africa, the growing global prevalence of dementia and consequently AD, as well as the significant number of South Africans at risk of developing AD. This is cause for concern as CGs of individuals with dementia have high levels of burden of care (Diel et al., 2010), which may be exacerbated by a lack of access to healthcare resources. Burden of care refers to the physical, social, psychological, and financial impact of care (Dang et al., 2008). In the remainder of this dissertation, the term 'burden' will be used. CG burden may be reduced through the provision of educational interventions as well as support (Granbo et al., 2019). Due to the lack of healthcare staff to provide these interventions, alternative means of providing this service need to be investigated.

Support groups could provide a feasible method for contributing to this needed service, as it has shown to hold several benefits for CGs of individuals with AD, including perceived social network and support (Morrow-Odom & Robbins, 2012). Support groups are also beneficial as they can provide peer support, skills training, and education, which is most likely to improve CG outcomes (Donath et al., 2019). As one-on-one speech and language therapy services (SLTS) cannot provide peer support, the importance of support groups is highlighted. Educational interventions, which can be provided through support groups, are crucial, however, limited research is available on the SLTS-related information needs of CGs of individuals with AD. It is therefore likely that CG information needs may not be met in existing service delivery models. A scoping review by Soong et al. (2020), which included research conducted between 2002-2018, showed that CGs have information needs regarding the disease, healthcare services, patient care and CG self-care. This study, however, included limited and non-specific communication-related information needs, while CGs' information needs relating to cognitive functioning, as well as feeding and swallowing, were not identified. The limited research on CGs' SLTS-related information needs may result in unmet information and support needs. This in turn may affect CGs' understanding and management of communication, cognitive functioning, and feeding and swallowing difficulties experienced by the individual with AD. Furthermore, limited research has been conducted on the support group structure preferences of South African CGs of individuals with AD, which may affect the optimization of these services in the South African context. This may impede access to and attendance of support groups, which in turn may influence the ability of the CG to obtain peer support, skills training, and information. The lack of research on CGs' SLTS-related information needs, and the importance of providing CGs with adequate information and support led to the following research question: "What are the communication, cognitive functioning and feeding and swallowing information needs of CGs of individuals diagnosed with AD within a support group setting?"

CHAPTER 1: LITERATURE REVIEW

Globally, an estimated 50 million individuals are living with dementia, and this number has been predicted to rise to 152 million by the year 2050 (Soong et al., 2020). This can largely be attributed to the reported doubling in the prevalence of dementia every 20 years due to an increase in global aging (Cheng, 2017) and the growth in the global elderly population (Wortley et al., 2017). The World Health Organization (WHO) has suggested that three quarters of individuals 60 years and older will be living in developing countries by the year 2050 (Kalaria et al., 2008). The aging population in South Africa is also one of the most rapidly growing within Africa (Zikali, 2018a). Considering that the estimated prevalence of dementia in South Africa was 2.2 million in 2011 (Alzheimer's South Africa, n.d.), this number is expected to rise exponentially. In the next 35 years, a predicted threefold increase of AD in individuals 80 years and older, and approximately a twofold increase in individuals above the age of 65 years is predicted (Klimova et al., 2015). Consequently, South Africa will have a large elderly population at increased risk of developing AD. Additional AD risk factors include poor socio-economic circumstances, chronic lifestyle diseases (Crous-Bou et al., 2017; Kalaria et al., 2008), obesity (Crous-Bou et al., 2017; Kalaria et al., 2008; Kivipelto et al., 2005), low levels of education and high levels of illiteracy (Kalaria et al., 2008). The risk posed by poor socio-economic circumstances is a particular concern in South Africa. It is estimated that 55.5% of South Africans live in poverty, with approximately 13.8 million living on less than R441 per person per month (Omarjee, 2017). The increased risk of developing AD associated with poor socio-economic circumstances is largely attributed to its association with modifiable risk factors (Deckers et al., 2019).

Modifiable risk factors include, amongst others, hypertension and type-2 diabetes (Deckers et al., 2019). Hypertension has been shown to be more common in lower socio-economic groups (Anstey et al., 2019). The South African Demographic and Health Survey of 2016 found a 48.2% prevalence rate of hypertension in this population (Kandala et al., 2021). A higher incidence and prevalence of type-2 diabetes has also been found to be associated with lower income (Hill et al., 2013). Individuals with type-2 diabetes have a minimum twofold increased risk of developing AD (Chatterjee & Mudher, 2018). In South Africa, 3.5 million individuals are diagnosed with diabetes and a further five million are pre-diabetic (Ottermann, 2012). The risk factors of being overweight or obese is also a concern as this is the case for one third of South African men and 70% of South African women (World Heart Federation, n.d.).

AD risk is also increased for individuals with less than a high school education. This is attributed to the lack of improvement of cognitive reserves and neural connections, which are usually developed with higher levels of education. The onset of AD may be reduced if an individual has higher cognitive reserves, as enough brain cells will be reserved despite brain cell degeneration or neuropathology (Meyer et al., 2016). The South African education statistics indicated that a significant number of 16-18 years olds are not in educational facilities (South African Market Insights, 2020), which could result in an increased AD risk later in life. Similarly, another risk factor relevant to South Africa and associated with education is literacy (Kalaria et al., 2008). Although the literacy levels in South Africa are increasing, in 2019, the illiteracy rate of South African men was 11.6% and 12.5% for South African women (Khuluvhe, 2021). The large number of South Africans at an increased risk for developing AD is concerning as the disease results in several difficulties which progressively become more severe, eventually leaving the individual completely dependent on others. AD affects various SLTS-related aspects of function, including communication, cognitive functioning, and feeding and swallowing. The difficulties associated with these areas of functioning are caused by changes in the cortex as well as neurotransmitter levels.

The progressive deterioration of language function of the individual with AD is attributed to neuronal loss (Helmes & Østbye, 2002), whereas cognitive difficulties experienced are attributed to cortical changes as well as changes in neurotransmitter levels (Epelbaum et al., 2009; Heneka et al., 2010; Seyedabadi et al., 2014). Acetylcholine and serotonin play critical roles in memory and learning, with a negative effect on these processes when levels are reduced (Seyedabadi et al., 2014). The reduction of the neurotransmitter somatostatin in certain areas of the brain is also related to cognitive decline (Epelbaum et al., 2009). It has also been reported that reduced norepinephrine correlates with cognitive impairment (Heneka et al., 2010). Several cortical areas which play a crucial role in swallowing are affected by AD. AD results in cortical-brainstem connectivity problems (Suh et al., 2009) as well as degeneration in the insula, frontal anterior cingulate cortex, motor cortical areas, sensory motor cortical areas, and supplementary motor areas which could negatively impact swallowing ability (Seçil et al., 2016). The abovementioned changes to communication, cognitive functioning, and swallowing ability cause individuals with AD to become increasingly dependent on others, specifically their primary CGs, as the disease progresses through the early, middle, and late stages.

Although the individual with AD is still able to function independently during the early stage of AD (Alzheimer's Association, n.d.), cognitive decline is already present (Alzheimer's Association, n.d.). Short and medium-term memory is typically affected first (Klimova et al., 2015). Difficulty performing complex activities has also been reported, which could include fulfilling their duties in a professional capacity (Klimova et al., 2015). Executive functions refer to complex cognitive processes which guide behaviour. Executive functioning difficulties are also associated with the early stage (Satler et al., 2017), and include planning difficulties, which impairs the ability of the individual with AD to perform activities of daily living (ADL) (Satler et al., 2017). Cognitive functioning is more severely affected in the early stage than language (Brookshire, 2015), however, eight to 10 percent of individuals in this stage experience language difficulties (Groves-Wright et al., 2004). Language difficulties could include word retrieval deficits (de Lira et al., 2011; Savundranayagam & Orange, 2014), dysfluency, and challenges with higher order spoken and written language comprehension (Ferris & Farlow, 2013). Phonology and syntax have been reported to remain preserved during this stage (Ferris & Farlow, 2013). As a result of the individual with AD's awareness of the difficulties experienced during this stage, behavioural symptoms, including depression and anxiety, may occur. Diminished interest, sense of fear, and apathy are also associated with this stage (Klimova et al., 2015). Anosognosia is also a common symptom in individuals with AD and refers to being unaware of impairment (Maki et al., 2012) or denying cognitive, functional, or behavioural impairments (Al-Aloucy et al., 2011).

During the middle stage, difficulty with the recall of personal history and long-term memory problems occur (Alzheimer's Association, n.d.). Repetition of questions is a common occurrence in individuals with AD and is attributed to difficulty with learning, retaining, and recalling novel information, and is exacerbated by attention difficulties. Immediate environmental factors may also play a role in the cause of question repetition (Hamdy et al., 2018). For example, while watching a violent movie, the individual with AD may repeatedly ask questions about safety. Events which cause the individual with AD anxiety may also result in question repetition (Hamdy et al., 2018). During this stage, the individual with AD may still be able to complete ADL, however, assistance with these tasks is now required (Alzheimer's Association, n.d.). Orientation difficulties in both unfamiliar and familiar environments may occur and the individual with AD may no longer be oriented to time and place (Klimova et al., 2015). Communication difficulties become more severe, with additional components of language affected in comparison to the early stage. Word retrieval difficulty becomes more severe and expressive output can be incoherent and fragmented (de Lira et al., 2011). Severe verbal dysfluency as well as semantic and literal paraphasias also occur (Ferris & Farlow, 2013). Comprehension is more significantly affected, resulting in repetition of words, sounds, or sentences and difficulty with multi-step commands is expected. Avoidance of conversations in which several communication partners are present is also common. Pragmatic difficulties, such as poor topic maintenance, may also occur (Savundranayagam & Orange, 2014).

During the late stage, cognitive difficulties are evident in the lack of awareness of surroundings or recent experiences (Alzheimer's Association, n.d.). In this stage all aspects of language are affected (de Lira et al., 2011). Echolalia and stereotypical utterances may be the only communication used by the individual with AD (Ferris & Farlow, 2013), rendering spontaneous output limited and often incomprehensible. Palillalia, which refers to verbal repetition, may also occur (Savundranayagam & Orange, 2014). Verbal output may consist of a single word per day (Kim & Bayles, 2007), highlighting the severe language difficulties associated with late-stage AD. Poor receptive language is also characteristic of this stage (Savundranayagam & Orange, 2014). The individual with AD is completely unable to engage in conversation due to the severe receptive language deficits as well as the inability to produce meaningful verbal output. Another aspect which is progressively affected is feeding and swallowing.

Although swallowing changes occur in the normal aging adult population, this must be distinguished from the abnormal swallowing patterns seen in individuals with AD. Both the oral and pharyngeal phase of swallowing may be affected. Oral phase difficulties such as chewing disorders are observed in individuals with dementia (Re et al., 2018). Pharyngeal stage changes may include delayed initiation of the pharyngeal swallow, a reduction in hyolaryngeal movement, an increase in penetration and tracheal aspiration, as well as increased pharyngeal residue (Affoo et al., 2013). As with communication and cognitive functioning, different swallowing changes are associated with the three stages of AD. Delayed swallowing onset and lingual difficulties may be present in the early stage of AD. During the middle stage of AD, difficulties may be present in the oral stage, as well as during pharyngeal bolus clearance and upper oesophageal sphincter opening. Humbert et al. (2010) reported that aspiration was noted with instrumental assessment during the middle stage of AD. In the late stage, oral apraxia may be present, and the only safe consistencies may include thickened liquids or items with jelly-like consistencies (Sheikhany et al., 2019).

Throughout the progression of AD, communication and cognitive difficulties also influence oral intake. The individual with AD may have difficulty expressing needs (Savundranayagam & Orange, 2014), such as hunger or thirst, which may reduce oral intake. Attention and memory impairment may also affect nutritional intake (Easterling & Robbins, 2008), as reduced interest in food, poor coordination with eating, and reduced self-feeding may be expected (Chen et al., 2016). Ten times more individuals with dementia are admitted to hospital due to dehydration, anorexia, and/or malnourishment than individuals of the same age without dementia (Abdelhamid et al., 2016). During the later stages of AD, malnutrition and weight loss are also common (Lee & Kolasa, 2011). Despite this, the use of feeding tubes is contraindicated for this population due to the risks of aspiration. Compared to those who were fed orally, Ijapoo and Ijapoo (2019) found that aspiration pneumonia occurred twice as frequently in individuals with late-stage AD who were fed via feeding tubes, with increased presence of oropharyngeal secretions containing gram-negative bacteria associated with higher risk for aspiration pneumonia. Quality of life is also not improved by using feeding tubes in this population (Groher & Crary, 2016).

It is evident that the progression of communication, cognitive functioning, and feeding and swallowing difficulties results in growing dependency on the CG of the individual with AD. The CG has many responsibilities during the progression of the disease, including providing assistance to the individual with AD and monitoring their activity. The individual with AD may require assistance with completing personal care and medication management (Chaudhuri & Das, 2006). An important part of treatment of AD is providing cognitive-communicative stimulation (ASHA, n.d.), which requires assistance from the CG. AD-related communication difficulties result in several negative effects on both the CG and the individual with AD. Therefore, it may be useful for the CG to utilize strategies which optimize verbal communication (Egan et al., 2010). Another potential responsibility of the CG is the management of feeding and swallowing difficulties, which could include specific preparation of foods, diet modifications, taste enhancements, environmental changes during meals, providing supervision during meals, and the use of cues during meals (Groher & Crary, 2016; Harwood, 2014). As the individual with AD's ability to perform ADL decreases, the CG will be responsible for preparing meals in accordance with their swallowing ability and need and will also be responsible for making mealtime adjustments. Evidently, the CG's responsibilities are expected to increase significantly in number and intensity as the disease progresses and dependency increases. It is, therefore, important to consider the effect that AD has on the CG.

A study conducted by Diel et al. (2010) revealed that 71.4% of CGs of individuals with dementia had moderate burden levels, while 28.6% had moderate to severe burden levels. This is a concerning finding as a strong link exists between burden and depression. Burden increases depression risk, and depression increases the subjective burden experience (Dang et al., 2008). Several factors contribute to CG burden.

One of the significant factors contributing to CG burden is the relationship between the CG and the individual with AD. Children caring for a live-in parent with AD experience increased objective burden when compared to live-in spousal CGs (Raccichini et al., 2009). Children of individuals with AD also experience higher levels of stress and unhappiness than spousal CGs (Blieszner &

Shifflett, 1990). The sex of the CG and presence of anosognosia are additional factors which can affect CG burden. Female live-in CGs show higher levels of emotional burden when compared to their male counterparts, which can be attributed to the difference in coping strategies between males and females (Raccichini et al., 2009). The burden levels of CGs who are related to the individual with AD, is significantly affected by the presence of anosognosia (Al-Aloucy et al., 2011) as the individual with AD may perform unsafe tasks or resist treatment due to the lack of awareness of their impairment (Rymer et al., 2002). Living with the individual with AD also influences CG burden. CGs living with the individual with AD may experience higher CG burden compared to non-live-in CGs (Raccichini et al., 2009). A study conducted in 2015 revealed that 87.7% of live-in CG participants experienced distress (Raggi et al., 2015). A daughter who lived with her mother with AD, and served as her informal CG, reflected this: "*She picked on me because I was the caretaker. She perceived me as not being a good child, but my siblings were glorified, as they came to visit and went home, whereas I was the one who was with her 24/7… Shortly before my mother's last days, I was hospitalized. The doctors locked me up in the psychiatric unit and loaded me up with medications. The doctor said I was "struck by stress*." (Wegierek, 2012, p.465).

CGs of individuals with dementia have been reported to visit doctors 46% more often than non-CGs and have a 63% higher mortality risk compared to non-CGs (Dang et al., 2008). The social effects of caregiving include feelings of isolation, loneliness, anger, frustration, guilt, and feelings of being overwhelmed (Dang et al., 2008). CGs may experience several direct and indirect financial effects, including time spent on caregiving activities, loss of CG income, health costs related to being a CG, as well as additional caregiving services required for the individual with AD. Approximately half of CGs reduce the number of hours they work, and a further 18% stop working altogether (Dang et al., 2008). Common psychological effects on the CG include anxiety and depression (Dang et al., 2008). Cheng (2017) found a prevalence of 34% depressive symptoms and 44% anxiety symptoms in CGs of individuals with AD, with the incidence increasing to 37% for depression symptoms and 55% for anxiety disorders over a 24-month period (Cheng, 2017). A daughter-CG explains the experience. "*I was helping my mother and I was ruining my own life. Both of us were getting worse and worse. Over time, my body became hers. She needed my hands, my legs, and even my mind, with nothing left for me. I served it all to her without missing a beat, never thinking of the consequences for myself.*" (Wegierek, 2012, p.464).

CGs may also experience negative psychological effects due to communication, cognitive functioning, and feeding and swallowing difficulties of the individual with AD. CGs experience communication difficulties as a stressful symptom, and these difficulties may lead to conflict between CG and patient. The effects thereof include feelings of isolation or even depression for either or both the individual with AD and the CG (Egan et al., 2010). Communication related difficulties may also result in changes in the quality of their relationship. Behavioural problems, which cause significant stress to the CG, may result from communication difficulties (Savundranayagam et al., 2005). The CG may view communication difficulties and resulting behavioural symptoms as being deliberate, compared to difficulties with ADL (Savundranayagam et al., 2005). CGs may also perceive behavioural symptoms resulting from communication difficulties as attempts to frustrate and challenge them (Savundranayagam et al., 2005).

CG burden has also been found to be associated with the patient's level of cognitive functioning (Germain et al., 2009). Cognitive impairment does not contribute to CG burden to the same extent as factors such as behavioural symptoms, however, these impairments still impact the CG (Germain et al., 2009). Berry (2014) suggested that the probability of CGs developing extreme stress and depression is increased by behaviours associated with orientation difficulties, such as wandering off, in the individual with AD. Davis (2007) reported that CG burden may also be influenced by behaviours associated with executive functioning difficulties such as repetition of actions and poor insight.

The presence of feeding and swallowing difficulties also has an impact on CG burden. CGs of individuals with dementia have described mealtimes as a pleasurable activity and an activity which helps the individual with dementia remain socially connected with their family, even if communication difficulties are present (Keller et al., 2007). This may, however, be negatively impacted by the presence of feeding and swallowing difficulties. The inability of the individual with AD to adhere to the social norms around mealtimes may negatively impact the social experience of mealtimes and reduce social outings in which food is involved. Increased burden levels have been found in family CGs of individuals who have dysphagia, especially with deteriorating feeding behaviours, as is the case with AD. CGs have concerns regarding aspects such as nutritional intake as well as the risk of choking (Namasivayam-MacDonald & Shune, 2020). The significant impact of AD on the CG is evident, and these effects may be increased in the South African context as informal CGs may remain the primary CG for an extended period due to factors preventing placement of the individual with AD in a formal care facility.

On average, informal CGs provide care for individuals with AD for roughly five years (Brookshire, 2015; Dang et al., 2008) as the individual with AD often spends their final years of life in a formal facility (Brookshire, 2015). In most instances in South Africa, however, this is not a viable option due to the high cost of care facilities, especially when considering the high levels of poverty of the South African population. Poor accessibility is further exacerbated by a lack of available care facilities in South Africa due to long waiting lists at retirement homes (Borochowitz, 2011). Of the South African elderly population requiring 24-hour care, only 2% receive this service (de Jager et al., 2015). Additionally, individuals with AD who obtain placement at a retirement home may be requested to leave if they inconvenience other residents (du Preez, 2018). As a result, it is most probable that many individuals with AD in South Africa will be cared for in the community by an informal CG, for the duration of the disease. Adequate support and management are, therefore, essential to alleviate the effect of the disease on the CG.

AD management takes on two forms, namely, medical intervention and/or behavioural management. Medical intervention involves pharmacological management, however, due to the limited number of psychiatric facilities in the Western Cape (Franken et al., 2019), access to these services may be limited. Behavioural management includes the involvement of allied healthcare professionals, including occupational therapists (OTs), physiotherapists (PTs) and SLTs. Behavioural management is focused on both the individual with AD as well as their CG. In this population, OTs focus on ADL, making environmental alterations and behavioural changes, providing cognitive stimulation, improving CG knowledge (Schmid et al., 2015), and preventing and treating neuropsychiatric symptoms (Fraker et al., 2013). PTs provide intervention to the AD population for difficulties pertaining to reduced strength and range of movement, posture, balance dysfunction, and coordination, as well as for improving ADL engagement. PTs also assist in pain management of the individual with AD (Kaur et al., 2013). The SLT is responsible for the management of cognitive-communicative difficulties as well as dysphagia. This includes counselling the CG and providing indirect intervention through working with the CG (ASHA, n.d.).

Healthcare resource restrictions in South Africa may, however, influence the delivery of one-on-one behavioural intervention. The limited number of SLTs, specifically, pose a barrier to service delivery. There are currently 39 SLTs per one million South Africans (Pillay et al., 2020). Service delivery through one-on-one interventions is thus not a viable option for the AD population due to the lack of SLTs, as well as the financial impact of individual care on the healthcare system. Therefore, support groups may be a more feasible option through which to provide information to CGs about SLTS-related difficulties, as support groups could address many individuals simultaneously, often without any cost to the CG and without waiting lists. It is crucial for CGs to have a means of obtaining this information as knowledge has been shown to reduce CG burden

(Schindler et al., 2012). In addition to providing information, support groups are an appropriate alternative to one-on-one interventions due to other factors.

Accessing intervention via support groups is a cost-effective option (Gräßel et al., 2010), as support groups are often free of charge, which is preferable for South African CGs due to the high poverty levels in South Africa. Support groups also contribute to increased emotional, social and peer support (Killen et al., 2016), while skills training and education is also provided. Integrating these components has been shown to have the most likely potential for improving CG outcomes (Donath et al., 2019). Emotional support is a crucial part of service delivery to the CG, as a reduction in depression of CGs who attend AD support groups has been found, which was attributed to sharing common experiences afforded by a support group (Morrow-Odom & Robbins, 2012; Killen et al., 2016). Support groups also decrease feelings of isolation (Killen et al., 2016) through access to peer support, which one-on-one SLTS is unable to provide. Although skills training is a crucial aspect of intervention, one must distinguish skills training which can be provided at a support group level from that which should be addressed at an individual level. Stimulation strategies are aimed at delaying impairment, while support strategies are specific to the individual with AD's level of functioning and severity of difficulties. Therefore, the types of difficulties must be carefully evaluated to select appropriate strategies (Lanzi et al., 2017). Stimulation strategies can be applied and discussed in a support group format as they are less specific (Kim et al., 2017), while the involvement of the SLT is required to assess the difficulties of the individual with AD to provide appropriate support strategies in relation to their level of functioning and severity of difficulties. Family education is another important management aspect of AD within the scope of the SLT (Bourgeois, 2019) and it is a means of addressing CG knowledge, however, the limited number of SLTs in South Africa highlights the importance of addressing CG education within the support group setting.

Research has indicated that increased CG knowledge reduces CG burden levels (Schindler et al., 2012). CGs' information needs must therefore be understood to ensure that they receive the information they require. The need for access to adequate information is further highlighted as informal CGs typically do not have knowledge or training in providing care to an individual with AD. It is, therefore, important that CGs receive adequate information, to ensure that high-quality care is provided (Soong et al., 2020). Although the information needs of CGs of individuals with AD have been investigated, limited research focusing on the SLTS-related information needs of CGs of individuals with AD has been conducted. A recent scoping review conducted by Soong et al. (2020) provides valuable insight into CGs' information needs.

Soong et al. (2020) investigated dementia-related CG information needs through a scoping review which included 20 studies and 4140 participants. The four themes regarding information needs that emerged were: (1) disease-specific information needs, (2) information needs pertaining to healthcare services, (3) the provision of patient care, and (4) CG self-care (Soong et al., 2020). Within each of these themes, specific information needs were identified. Disease-specific information needs most commonly found by Soong et al. (2020) included aspects such as dementia-related information and treatment options, while additional information needs included prognosis, medication, and experimental treatment and trials. Information needs relating to healthcare services predominantly included how to use services and the types of services available (Soong et al., 2020). Most of the reported information needs within the theme of patient care included the provision of general care, managing behaviours, and concerns about safety, while some evidence showed a need for information relating to management of communication difficulties, and medical information (Soong et al., 2020). The primary information need, within the theme of CG self-care pertained to stress management. Additional CG self-care information needs included, amongst others, pension entitlements and managing emotions experienced by the CG (Soong et al., 2020). It is noteworthy that CGs of individuals with dementia who were in the early stages expressed more information needs pertaining to disease-specific information than CGs of individuals with dementia in the later stages. This demonstrates that disease severity, therefore, influences information needs (Soong et al., 2020). It should be noted that the current literature considers the need for support to manage difficulties as an information need. However, it may be important to distinguish between information and support needs. Support needs refer to ways of managing symptoms whereas information needs may be considered to be aspects such as the cause of symptoms or about the progression of symptoms.

It is evident that there are a broad range of studies pertaining to CG information needs, however, communication-related information needs were only identified in two of studies in the scoping review by Soong et al (2020). While 74% of CGs in the study conducted by Killen et al. (2016) reported that information about communication difficulties and the management thereof would be beneficial, 46% of participants in a study conducted by Edelman et al. (2006) expressed the need for information about ways in which to improve communication. This clearly demonstrates that CGs do not only require information, but also support and stimulation strategies relating to communication difficulties. However, these studies do not provide detailed information regarding the aspects of communication for which the CGs required information and support. It is also noteworthy that the studies included in the Soong et al. (2020) scoping review did not report information needs pertaining to cognitive functioning or feeding and swallowing difficulties. Furthermore, the scoping review investigated research published in English, from predominantly higher-income countries. Therefore, the results may not be relevant in the South African context. Thus, although a wealth of information exists about a broad range of aspects related to the information needs of CGs of individuals with dementia, the limited research about CGs' information needs pertaining specifically to communication, cognitive functioning, and feeding and swallowing, demonstrate a need for research on this topic.

This need for research is supported by the significant impact of the disease on the CG, who fulfils a crucial role in management. Due to their role in management, it is imperative that CGs' information needs are investigated to ensure that they have the information required to inform the care they provide to the individual with AD. In addition, the limited information about CGs' SLTS-related information needs may negatively impact CG well-being and burden levels due to the effect of knowledge on CG burden (Schindler et al., 2012). The limited research on the topic also has implications for the content and conversations included in support groups.

As limited research on the SLTS-related information needs of CGs of individuals with AD is available, the content and conversations in support group sessions about these topics cannot be guided by evidence-based practice (EBP). EBP entails the use of current research in combination with clinical judgment and client preferences to guide clinical decision making (Greenwell & Walsh, 2021). The limited research on the topic implies that support group facilitators (SGFs) utilize practice-based evidence (PBE) to inform their discussions of SLTS-related difficulties. PBE entails obtaining data in real-life situations about which practices work, who the practice works with and how practices can be adapted (Chorzempa et al., 2018). The use of PBE is of particular concern in the AD population as CGs of individuals with dementia's information needs are often indirectly, rather than directly stated (McCabe et al., 2016). Drawing from the available research, SGFs may be aware that CGs require information about communication difficulties, the management thereof (Killen et al., 2016) and guidance on improving communication (Edelman et al., 2006). However, the research cannot adequately inform the discussion around communication-related information needs as the research does not provide insight into the specific aspects of communication that CGs require information about. In addition, the lack of research about specific information needs pertaining to cognitive functioning and feeding and swallowing demonstrates that EBP cannot be used to inform the content and conversations about these topics within the support group as limited information is available. This may result in unmet information needs on the part of the CG.

Although research on SLTS-related information needs of CGs of individuals with AD is limited, information about support group structure is available. The structure of support groups must be considered to promote the accessibility of these groups as this service fulfils an important role in the provision of both information and support to the CGs of individuals with AD.

Factors to consider regarding support group structure include location, time of day of the support group, duration, frequency, group size and attendance of the individual with AD. The preferred location may be influenced by attendee age. Retired attendees may prefer religious buildings or community centres, whereas working-age attendees may be more accepting of educational buildings or hospital settings (Morrow-Odom & Robbins, 2012). The age of attendees can influence the time of day most appropriate for the support group meeting to be held. Day-time support groups may be more suited for retired CGs, whereas late afternoon or evening groups may be more suited to employed CGs. Evening groups also allow more CGs to attend the support group as a family or community member can tend to the individual with AD after hours, thereby allowing the CG to attend the group (LaMore, 2011). Support groups have been reported to typically last for approximately an hour and a half (Morrow-Odom & Robbins, 2012). It is recommended that support groups should be held twice a month for familial live-in CGs to improves the chance of CGs being able to attend a minimum of one session a month (Steffen & Magnum, 2012). Morrow-Odom and Robbins (2012) suggested that groups of ten members are small enough to allow everyone to be actively involved during the session, while more than ten attendees may not allow all the attendees an opportunity to raise their concerns. LaMore (2011) recommended groups of six to 12 attendees. Since the various stages of AD are characterized by different difficulties, attendees may be served better if divided into groups according to the stage of the disease of their loved one, which could also help manage group size (Morrow-Odom & Robbins, 2012). This is further supported by the findings of Soong et al. (2020), which demonstrated that severity of the disease, which implies stage of progression, influences CGs' information needs. Service delivery could also be improved by dividing support groups according to the CG's relationship with the individual with AD, which may improve group connection as participants share similar experiences (Golden & Lund, 2009). Considering the importance of peer support (Donath et al., 2019), division of attendees according to their relationship with the individual with AD may also provide a more optimal support system through a closer match of CGs with their peers. CGs also often prefer that the individual with AD not attend the support group sessions, as their absence allows the CG with a place to discuss concerns, as well as their feelings (Morrow-Odom & Robbins, 2012).

In conclusion, the prevalence and incidence of dementia is rising globally. This is alarming in the South African context due to the significant number of South Africans who present with AD risk factors, such as chronic lifestyle diseases. The degenerative nature of the disease results in progressively increasing CG dependence. AD impacts the CG in various ways, and this impact may be more significant in a resource-constrained, developing context like South Africa. This is attributed to the high cost of care and limited access to formal care services, combined with poverty which predicts that care by informal CGs is likely required throughout the progression of the disease. This may result in significant CG burden with potentially negative effects, such as anxiety and depression. Several healthcare professionals, including SLTs, can be involved in management of AD. However, the lack of SLTs in South Africa highlights that group-based intervention is more viable compared to one-on-one SLTS sessions. Research has demonstrated the benefits of support groups which include lower intervention cost (Gräßel et al., 2010), increased social network and social support, reduction in depression (Morrow-Odom & Robbins, 2012), and peer support. Although one-on-one speech therapy sessions can provide CGs with skills training and education, peer support cannot be achieved in one-on-one sessions. Although the importance of providing information to CG is shown in the literature (Donath et al., 2019), it is crucial to understand CGs' information needs to optimally serve them. Past research has investigated CGs' information needs with themes emerging pertaining to the disease, healthcare services, patient care, and CG self-care (Soong et al., 2020). Although a broad range of information needs have been identified in existing research, there is limited research on CGs' SLTS-related information needs. This may hinder adequate information provision in this regard and thereby influence CG burden. This demonstrates the need for research on the SLTS-related information needs of South African CGs of individuals with AD within the support group setting. Consideration must also be given to support group structure preferences to ensure that CGs are able to optimally access support groups and benefit from the peer support, skills training, and education afforded by the support group setting.

This has informed the research question of the current study: "What are the communication, cognitive functioning and feeding and swallowing information needs of CGs of individuals diagnosed with AD within a support group setting?"

This led to the current research objectives:

1. To investigate the communication information needs of the CGs.
2. To investigate the cognitive functioning information needs of the CGs.
3. To investigate the feeding and swallowing information needs of the CGs.
4. To investigate the support group structure that the CGs prefer.

5. To describe the SLTS-related aspects that are common points of discussion in support groups.
6. To describe the current support group structure in relation to the preferences of the CGs.

CHAPTER 2: METHODOLOGY

This chapter provides an overview of the research methods employed in the current study. This includes information relating to the research design, study setting, participants and sampling. The chapter further describes the data collection instruments, the procedure for data collection and analysis, as well as the ethical processes followed.

2.1. Research design

The current study made use of a convergent parallel mixed method research design. In accordance with this design, the data in the qualitative and quantitative phase were collected simultaneously but analysed separately and then merged for interpretation and discussion. This design allows the researcher to draw on the strengths of the two respective methods and allows for the assessment of discrepancies between the results of the qualitative and quantitative phase (Östlund et al., 2010). The use of a mixed method research design was also deemed appropriate as it provides the researcher with a better understanding of the research problem than when utilizing either qualitative or quantitative methods in isolation (Razali et al., 2019). Combining the two methods also strengthens the conclusions which can be drawn from a study (Schoonenboom & Johnson, 2017). This method allowed the researcher to obtain insight into CGs' information needs, as well as the aspects which influences these needs and how they may differ throughout the progression of the disease. Collecting the data simultaneously according to the parallel design also ensured that the time spent on data collection was optimized.

The qualitative phase of the research used a descriptive phenomenological approach. A phenomenological research design allows the researcher to obtain information about the lived experiences of specific individuals (Neubauer et al., 2019). Descriptive phenomenology is used when limited information about a topic is available and the researcher aims to obtain a deeper understanding of the phenomenon through the perspective of the participant (Penner & McClement, 2008). In the current study, SLTS-related information needs arising from the lived experience of being a CG to an individual with AD, as well as preferences regarding support group structure needed, informed the decision to use a descriptive phenomenological approach as it was aimed to obtain in-depth knowledge of this experience. The understanding of these experiences and the needs that arise because of this provide insight into the specific phenomenon (Neubauer et al., 2019). The use of a descriptive phenomenological approach was specifically deemed appropriate as limited research has been conducted on this topic.

The data in the qualitative phase was obtained using semi-structured, in-depth interviews with the primary CGs of individuals diagnosed with AD. A qualitative design for this phase of the study was deemed appropriate as the researcher aimed to obtain information on their experience (Hammarberg et al., 2016), namely the experience of being a CG of an individual diagnosed with AD, and the resulting information needs that may arise from this experience. The use of a semi-structured interview to investigate this experience was relevant as this method allowed the researcher to… *"…1) collect qualitative, open-ended data, 2) to explore participant thoughts, feelings and beliefs about a particular topic; and 3) to delve deeply into personal and sometimes sensitive issues."* (DeJonckheere & Vaughn, 2019, p.2-3). Advantages of interviews in qualitative research include increasing self-awareness, empowering the interviewee, and providing the interviewee with a voice (Parikh, 2013). Qualitative interviews are, however, a very time-consuming process due to time spent on interviews as well as transcript analysis (Bryman, 2012).

An online survey was used as the method of collecting data for the quantitative phase of the study. It focused on the SLTS-related aspects that are common points of discussion in support groups and the current structure of support groups in the Western Cape. An online survey was deemed an appropriate data collection method as the aim was to obtain a large number of responses. Online surveys have been shown to yield higher response rates while reducing the cost to the researcher (Bakla et al., 2013). The use of an online survey is time effective for the SGF, therefore, the likelihood of obtaining responses is increased. The use of an online survey also ensured anonymity of responses. The survey was completed by the SGFs of support groups for CGs of individuals diagnosed with dementia or AD. As the researcher was not present, interviewer effects were not a concern. The risk of variability in the presentation of questions was also eliminated (Bryman, 2012).

The data from both the qualitative and quantitative phase of the study were obtained using an exploratory, cross-sectional research design. The advantages of a cross-sectional research design include the quick nature of data collection as information is obtained at a single point in time (Bless et al., 2013). An exploratory research design is used when little information is currently available on the topic being investigated (Bless et al., 2013). This was appropriate as the SLTS-related information needs and support group structure preferences of CGs of individuals diagnosed with AD in the Western Cape, as well as the SLTS-related aspects that are common points of discussion at support groups and the structure of support groups in the Western Cape, have not previously been investigated.

2.2. Study setting

2.2.1. Qualitative phase

CGs in the qualitative phase of the study were recruited from a government health facility in the Western Cape. This recruitment context was deemed appropriate as 84% of the South African population utilize the public health sector (Maphumulo & Bhengu, 2019). The specific facility was selected as it serves many individuals with AD. This may be attributed to the site having the only geriatric psychiatry unit recognized by the HPCSA (Zikali, 2018b). The neurology and psychiatric departments contacted at other government health facilities reported a limited AD caseload and were thus not feasible as potential research sites. These facilities also referred the researcher to the aforementioned government health facility used in the current study. The facility was also deemed appropriate as it serves one third of the Western Cape (Ras et al., 2011). The areas served are vast and include the Northern Suburbs, Cape Peninsula, Swartland, Western Cape Winelands, the West Coast up to Bitterfontein, Cederberg, and Northern Olifant's Valley (Sr Koek, personal communication, June 25, 2019). The catchment area served by the facility as well as its geriatric psychiatric unit were likely the reasons for referral to the facility by the other government health facilities contacted.

2.2.2. Quantitative phase

Support groups from both non-profit organizations and private facilities were approached for the quantitative phase of the current study due to the limited number of dementia and AD support groups in the Western Cape. This was deemed necessary to ensure an adequate number of participants. AD is also the most common form of dementia, and the inclusion of both dementia and AD support groups was, therefore, deemed appropriate. The support groups at the private facilities included in the current study were open to the general public and not only private healthcare users. SGFs from a total of seven organizations and facilities were included. The information of the support groups included in this study is outlined in Table 1. This reflects the information about the sites during the year 2019 when data was collected.

Table 1

Support group site information

Support group Number	**Total number of support group facilitators**	**Number of years since support group was established**	**Cost**	**Areas covered**
1	11	5-10 years, depending on the site	Free	Cape Town, Durbanville, Fish Hoek, Hermanus, Kleinmond, Langebaan, Milnerton, Panorama, Pinelands, Plumstead, Somerset West, Stellenbosch, Vredehoek
2	1	5 years	Free	Durbanville, Betty's Bay
3	2	< one year	Free	Stellenbosch, Plattekloof, Somerset West
4	2	11 years	Free	Plumstead
5	20	13 years	Free	Bellville, Bergvliet, Elsies River, Fish Hoek, Gordons Bay, Hanover Park, Hermanus, Hout Bay, Kensington, Kleinmond, Kuils River, Langebaan, Milnerton, Pinelands, Plumstead, Strandfontein, Somerset West, Strand, Table View
6	3	16 years	Free	George
7	1	< one year	Free	Pinelands

2.3. Sampling strategy

Non-probability sampling was used for both the qualitative and quantitative phase of the current study. Non-probability sampling is not randomized and relies on the researcher’s judgement to select participants (Showkat & Parveen, 2017). Convenience sampling was used for the qualitative phase and purposive sampling was used for the quantitative phase. These sampling strategies and the rationale for each will be described in more detail below.

2.3.1. Qualitative phase

Convenience sampling was employed for the qualitative phase of the current study. Convenience sampling is a non-probability sampling which entails obtaining participants who are easily available (Stratton, 2021). This sampling procedure was deemed appropriate as the researcher was able to easily access CGs at the government health facility used in this study. The psychiatrists at the facility were asked to identify CGs who met the inclusion criteria and who were willing to participate.

2.3.2. Quantitative phase

Purposive sampling was used for the quantitative phase of this study. Purposive sampling entails selecting participants based on certain qualities. This method was considered appropriate as the researcher was able to select individuals with a specific set of characteristics and who possessed information on the topic due to their knowledge or experience (Etikan et al., 2016; Palinkas et al., 2015). In the current study, these individuals were SGFs who met the inclusion criteria. These SGFs were able to provide valuable information to the research due to both their knowledge and experience within the context.

2.4. Selection criteria

2.4.1. Qualitative phase

For the purpose of the current study, CGs in the qualitative phase had to meet the criteria outlined in Table 2.

Table 2

Qualitative phase inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
Spends 7+ hours/day with the individual with Alzheimer's disease as the primary caregiver	Has previously cared for an individual(s) with Alzheimer's disease
18 years or older	Allied healthcare workers, nurses or medical doctors
Caregivers of individuals within any stage of progression of Alzheimer's disease	The individual with Alzheimer's disease is currently or has previously been seen by a speech-language therapist or other allied health professional
	The caregiver has previously or is currently attending a dementia or Alzheimer's disease support group
	Not proficient in English, Afrikaans or isiXhosa

A primary CG for the purpose of the current study was an individual who spent 7+ hours per day with the individual with AD. In a study by Fisher et al. (2011), it was reported that primary family CGs of individuals with AD spent an average of 9+ hours per day providing care. The time frame of 7+ hours per day accounted for individual differences in caregiving time. CGs had to be 18 years or older to provide informed consent. There was no exclusion criterion for the stage of progression of AD, thus CGs of individuals with AD within any stage of progression were included.

CGs who had previously cared for an individual(s) with AD were excluded from the research as they may have gained information and experience which could influence their information needs. CGs who were allied healthcare workers, nurses and medical doctors were excluded due to their potential background knowledge of the disease which could influence their information needs. CGs were also excluded if the individual with AD for whom they cared were previously or currently managed by a SLT or other allied health professional regarding the AD diagnosis. CGs who had or were already attending a support group regarding the individual with AD were excluded from the study as they may already have received information, which may affect their information needs. Possible CGs not proficient in English, Afrikaans or isiXhosa were excluded from the study. These are the three official provincial languages of the Western Cape (Western Cape Government, n.d.), which was the study setting for this research. This criterion was also included due to the lack of access to translating services in the Western Cape for the additional nine official South African languages.

2.4.2. Quantitative phase

The SGFs for the quantitative phase of the study had to meet the criteria outlined in Table 3.

Table 3

Quantitative phase inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
Must be a facilitator of a support group for caregivers of individuals with dementia or Alzheimer's disease	Not proficient in English, Afrikaans or isiXhosa
Has facilitated the support group for a minimum of five sessions	

In the current study, a SGF was defined as the individual in charge of running the support group, providing information, and answering group questions. As support groups in the Western Cape typically cater to individuals with dementia and not AD in particular, the criteria of including both dementia and AD was used. SGFs were required to complete a screening form to ensure that they met the inclusion criteria. They had to have been the SGF of a support group for CGs of individuals with dementia or AD for at least five sessions. This allowed the SGF to be familiar with the support group structure and allowed them adequate time to build rapport with the attendees, thus ensuring a safe environment in which attendees could ask questions. The five-session period also allowed sufficient time to ensure that they were familiar with questions asked during support group meetings and thus the SLTS-related topics commonly discussed at support groups. SGFs not proficient in English, Afrikaans or isiXhosa were excluded from the study as these are the three official provincial languages of the Western Cape (Western Cape Government, n.d.), as well as due to the lack of access to translating services in the Western Cape for the additional nine official South African languages.

Due to the two sets of participants in the current study, participants in the qualitative phase will henceforth be referred to as a 'CG' while participants in the quantitative phase will be referred to as a 'SGF' to provide clarity to the reader.

2.5. Sample size

2.5.1. Qualitative phase

For qualitative phase, the researcher intended to use data saturation as the primary consideration through which to determine sample size. Data saturation is an important aspect to be considered in determining sample size (Dworkin, 2012). Thus, the aim was to include CGs until data saturation was reached. Data was collected for a period of 43 weeks, however, in that period data saturation was not reached. It was, however, evident that more CGs could not be recruited and subsequently data collection was terminated after the 43-week period. A total of nine possible CGs who could participate in the study were identified at the recruitment site between 7 June 2019 and 1 May 2021. Data collection was interrupted during 2020 due to the COVID-19 pandemic and was restarted in February 2021. This was deemed necessary as the pandemic resulted in the clinic at the government health facility, from which CGs were recruited, being temporary closed. Of the nine CGs who were identified, three were successfully recruited and participated in face-to-face interviews in the qualitative phase of the study. A small sample is typical of qualitative research (Vasileiou et al., 2018). The use of a small sample is supported as qualitative research involves in-depth analysis of interviews and focuses on cases which are rich in information (Vasileiou et al., 2018). Furthermore, fewer participants are needed if a large amount of useable data is collected from the participants (Vasileiou et al., 2018), as was the case with the current study. There were various reasons for the exclusion of the six other CGs identified at the recruitment site. One CG declined participation and one was excluded as she was a nurse. As per the exclusion criteria, allied healthcare workers, nurses or medical doctors were excluded from the current study as they could have more knowledge about AD than the general population, which could influence their information needs and, therefore, impact the results of the study. A third CG was excluded due to their markedly poor speech intelligibility, which resulted in an inability to analyse and transcribe the responses. An additional two CGs were excluded as they reported being unaware of the AD diagnosis. It was explained by the head of the psychogeriatric unit at the recruitment site that CGs frequently ask about the diagnosis at follow up appointments and that the diagnosis often needs to be explained multiple times. Subsequently, these CGs were not included in the study as they stated that they were not aware of the diagnosis. This would defeat the purpose of the interview as they would be unable to reflect on their information needs due to their lack of knowledge of the AD diagnosis. Lastly, one CG declined participation due to the COVID-19 pandemic, despite being offered the option of a telephonic interview.

2.5.2. Quantitative phase

The sample size determinants for the quantitative phase of the study is outlined in Figure 1.

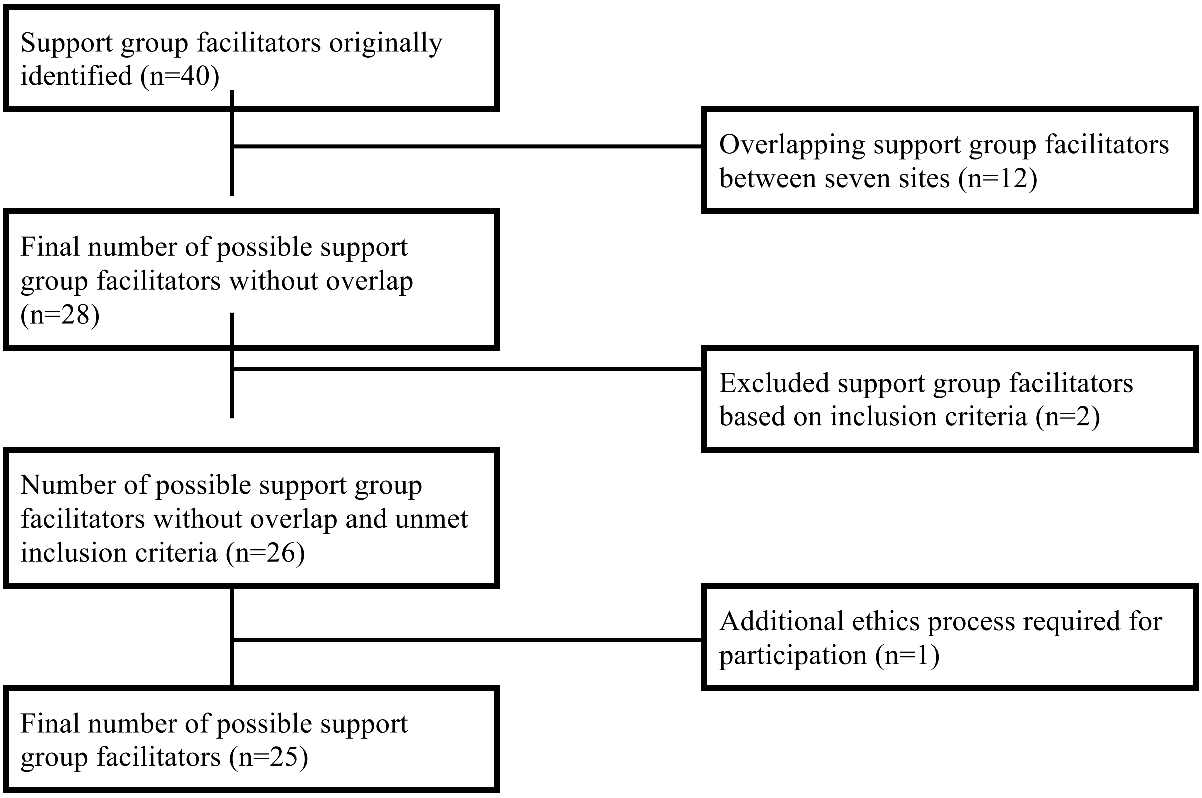

Figure 1

Factors which influenced the final potential sample size for the quantitative phase

The initial total potential sample consisted of 40 SGFs. There were 12 SGFs who were affiliated with more than one site, which reduced the potential sample to a total of 28 SGFs.

Two SGFs could not be included in the study as they had not yet facilitated five sessions as per the inclusion criteria. Another possible SGF required the researcher to complete an additional ethics application process through the Western Cape Department of Health (WCDOH) to grant her permission to participate in the study. Due to the additional time required to obtain ethical clearance to include this SGF in the study, this possible participant was excluded. This resulted in a final number of 25 possible SGFs for this phase of the current study. The final sample was also time bound as SGFs were recruited between March 2019 and August 2019. The number of respondents in a period of five months were therefore included. The SGFs who could possibly be included in the study received regular email or telephonic reminders throughout the data collection period in an attempt to obtain the best possible response rate. Fifteen of 25 identified SGFs, who could make up the sample for the quantitative phase, were included. This reflects a response rate of 60% which is recommended for survey-based quantitative research (Fincham, 2008). There were various reasons for the remaining ten SGFs not being included in the sample. Two of the SGFs indicated they did not wish to participate. Two were unable to participate due to illness in their family. One was unable to participate due to being ill themselves, while another cited unforeseen circumstances. The remaining four did not respond to any of the communication which invited them to participate.

2.6. Materials and instrumentation

2.6.1. Qualitative phase

Semi-structured interview guide

An interview guide (see Appendix A) was used to guide the semi-structured, in-depth interviews with the CGs. The interview guide was used to obtain information regarding the SLTS-related information needs of CGs of individuals with AD as well as information about their support group structure preferences. The interview guide consisted of seven open-ended questions. Each question had related prompts, used by the researcher to guide the interview if the need for clarification of the open-ended question arose. The questions in the interview guide were based on the article by Satler et al. (2017), as well as the literature consulted to compile the self-compiled survey in the quantitative phase, as will be described later in this chapter. The interview guide utilized the guidelines outlined by Turner (2010): questions should be open-ended, questions should be phrased in a neutral manner to avoid wording influencing answers, one question should be posed at a time, and clear wording should be used.

The main themes investigated pertained to communication, cognitive functioning, and feeding and swallowing information needs, as well as preferred support group structure. Question one related to the background information of the CG. Question two focused on background information of the individual with AD. Question three obtained information pertaining to CGs' perception of an ideal support group structure. And question four to seven explored the information CGs wished to receive related to communication, cognitive functioning, and feeding and swallowing.

The interview guide as well as the prompts were compiled in English and translated to Afrikaans by the researcher. The Afrikaans interview guide as well as the prompts were then back translated to English by another qualified SLT, to increase the reliability of the translated interview guide. The original English interview guide and prompts were compared to the back translated document by the researcher. No differences, which caused meaning changes, were present between the original and the back translated document. Thus, no changes were made to the Afrikaans interview guide.

The researcher intended to make use of an isiXhosa translator during the interview process if isiXhosa speaking CGs were identified. However, no CGs identified in this study were isiXhosa speaking.

A voice recorder was used during each interview to allow the researcher to transcribe the interviews verbatim for data analysis. A pen and paper were also used for note taking of important aspects mentioned that the researcher wished to return to during the interview.

2.6.2. Quantitative phase

The self-compiled screening form (see Appendix B) consisted of four closed-ended questions to determine whether SGFs met the inclusion criteria. The self-compiled survey (see Appendix C) used through Google Forms consisted of three sections which was based on the research question, as well as the research objectives and initially consisted of a total of 33 closed-ended questions. The survey contained yes/no questions, single answer multiple choice questions, and one Likert scale question.

The questions focused on background and personal information of the SGF, support group structure, questions received in the support group about common expressive and receptive language difficulties, pragmatic difficulties, signs of feeding and swallowing difficulties, as well as memory difficulties and cognitive stimulation. The survey also investigated whether SGFs felt able to adequately answer these questions. The survey furthermore investigated questions received in the support group about the role of the SLT, the perceived value of having a SLT in the support group, and previous referral of attendees to a SLT.

The survey design and process of validation utilized the procedure set out by Bakla et al. (2013), as outlined in Figure 2.

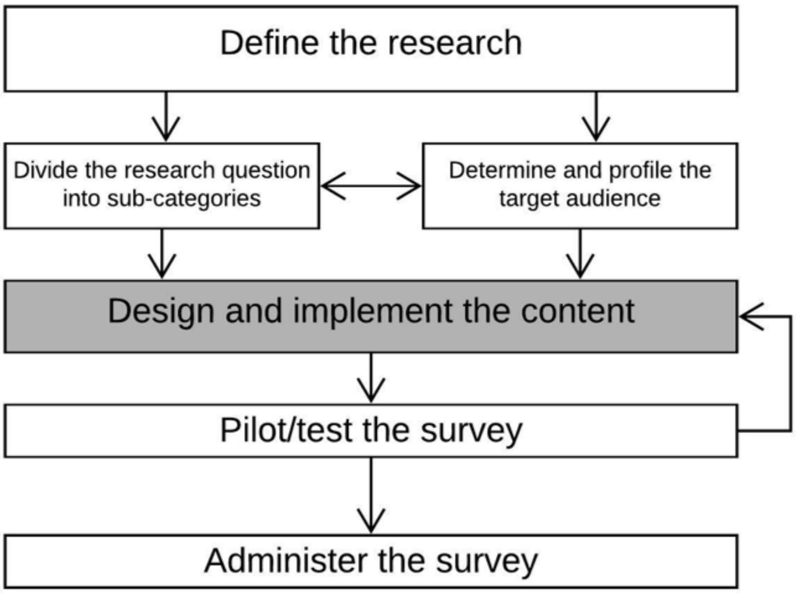

Figure 2

Web-based survey design process

Note: From "Web-based surveys in educational research" by A. Bakla, A. Çekiç, and O. Kösksal, 2013, International Journal of Academic Research, 5(1), p. 8.

Defining the research, sub-categorization of the research question and determining the profile of the target audience: These three sections of the process have been outlined in this chapter and informed the survey design.

Survey design and content: The content of the survey was informed by the research question and study objectives. The current literature was used to guide the questions included into the survey.

Section one contained a single screening question to determine whether the potential participant was a SGF of a support group for CGs of individuals with dementia or AD.

Section two consisted of 14 questions (i.e., questions 2 to 15), pertaining to background and personal information of the SGF, as well as the support group structure. Questions two to five obtained background information about the SGF. Question six pertained to the training received to prepare them for the SGF role. Questions seven to 15 gathered information about the support group structure. This included, the group size, location, the time of week the support group is held, frequency of sessions, the time of day the support group is held, duration of sessions, the presence or absence of the individual with AD, the focus of the support group, as well as the employment status of the attendees. Questions seven to 15 were based on the articles by Morrow-Odom and

Robbins (2012) and LaMore (2011) in which information pertaining to support group structure recommendations are outlined.

Section three consisted of questions 16 to 33, which focused on the SLTS-related questions received in the support group. Questions 16 to 23 related to common expressive and receptive language difficulties, as well as common pragmatic difficulties associated with AD. These questions were based on articles by Ferris and Farlow (2013), de Lira et al. (2011) and Savundranayagam and Orange (2014) in which these communication difficulties related to AD were discussed. Questions 24 and 25 were based on the prevalence of dysphagia as discussed by Groher and Crary (2016). Questions 26 and 27 were based on the research in the literature review on the various types of memory (Alzheimer's Association, n.d.; Klimova et al., 2015) and the effect AD has on the types of memory in the various stages of AD. Questions 28 and 29 were based on the article by Meyer et al. (2016) which pertained to cognitive stimulation of the individual with AD. Questions 30 to 33 were based on information by Dijkstra et al. (2004), Egan et al. (2010), Groher and Crary (2016), Harwood (2014), Klimova et al. (2015), Meyer et al. (2016) and Small et al. (2003), which outlines the manners in which to assist the individual with AD with SLTS-related difficulties. This in turn highlighted the importance of the SLT in the management of the individual with AD. Question 30 and 31 thus focused on questions received during support groups relating to the role of the SLT in AD management. Question 32 investigated the subjective value of possibly having a SLT involved in the support group. Question 33 pertained to the referral of group members to a SLT. Questions 30 to 33 were also based on the article by Morrow-Odom and Robbins (2012) in which the need for openness by the SGF to obtain other expertise in the support group who are more knowledgeable on certain topics is discussed.

The survey was translated from English to Afrikaans by the researcher. The survey was then back translated by another qualified SLT. A phrasing difference was identified between translation and back translation in question 16. Question 16 originally read: "*In die ondersteuningsgroep, is u al gevra oor pasïente wat probleme ervaar om die regte woorde te vind*?" Upon discussion with the SLT who back translated the Afrikaans survey, the question was rephrased as *"In die ondersteuningsgroep, is u al gevra oor pasïente wat probleme ervaar om woorde te vind."* This change demonstrated that the question pertained to word finding difficulties in general, rather than the use of incorrect words. Although the use of incorrect words may be a symptom of word finding difficulty, this is not the only symptom, and this was reflected by the phrasing change.

2.7. Procedure

2.7.1. Pilot study for the qualitative phase

A pilot study was conducted with the first two CGs of individuals with AD who met the inclusion criteria. The first CG in the pilot study was an Afrikaans speaking female caring for her spouse with AD, while the second was an Afrikaans speaking female caring for her aunt with AD. A pilot study was conducted to determine whether the interview guide obtained appropriate and relevant information. Pilot studies may also be used to identify wording issues, assist novice researchers to be better prepared for challenges which may occur during the study, and increases the researcher's confidence in the data collection instrument (Malmqvist et al., 2019). Throughout the interviews, summarizing was utilized to determine accuracy of the understood responses. This enabled the researcher to ensure that questions were understood by CGs in the manner intended. Upon conclusion of the interviews, the CGs were asked whether any questions were unclear or whether there was anything that was not discussed which they felt should have been. The only adjustment to the interview guide based on the pilot study was changing the phrasing "*Tell me about any questions you have about the patient's eating and/or drinking*" to "*tell me about any questions you have about the patient's swallowing ability.*" This was deemed necessary to ensure that the question pertained specifically to feeding and swallowing, as this question was perceived to pertain to diet, when using the original phrasing. However, as the CGs in the pilot study reflected on feeding and swallowing at a later stage in the interview, these interviews were still included into the main study data set.

2.7.2 Expert review for the quantitative phase

An expert review was utilized for the quantitative phase of the current study. An expert review refers to the process in which experts on the topic were asked to review the survey and provide feedback and comments on any problems with the survey, measurement errors or difficulties encountered in answering the questions (Ikart, 2019). The aim was to identify any possible incomplete areas of the survey as well as any problems regarding the phrasing of the questions. Two SGFs who fulfilled the inclusion criteria were included in the expert review of the survey. One SGF was English and the other Afrikaans speaking. Due to the limited number of SGFs in the Western Cape, only two SGFs were included into the expert review.

They were asked to review the survey and comment on the phrasing and clarity of the questions and make recommendations about possible adjustments. They were also asked to comment on the overall completeness of the survey and whether any questions had to be adjusted, added or be removed. Two adjustments were recommended. It was suggested that the aspect of question repetition be added to the survey. One SGF in the expert review noted that CGs often ask why individuals with AD repeat questions which have already been answered. This question was not included in the original survey. Additionally, it was noted that the individual with AD is sometimes present at the support group, rather than never present or always present as per the options in the original survey. This was discussed by the researcher and the two supervisors. There was agreement that the question about the repetition of questions should be added to the survey and informed the addition of question 28 in the final draft of the survey. A follow up question, i.e., question 29, related to the SGFs' perceived ability to respond to this question was also added to the survey. These additional two questions were also back translated using the translation process employed with the initial draft of the survey and are outlined in Table 4 below. The option of '*sometimes present*' was also added to question 12.

Table 4

Expert review question additions

Questions added to the survey following the expert review
1. In the support group, have you been asked why patients repeat questions they have already asked?
2. In your opinion, were you able to answer this question adequately?

The final version of the survey therefore consisted of 35 questions. The SGFs who participated in the expert review did not recommend any word or phrasing changes. Due to the limited number of SGFs in the Western Cape as well as the minimal changes indicated, the two expert reviewers were included into the data sample. They were provided with the additional two questions via email to complete their responses to the survey for inclusion in the final data set.

2.7.3. Main procedure

Written permission to conduct both the qualitative and quantitative phase of the research was first obtained from the Postgraduate Health Research Ethics Committee (HREC)(HREC reference No: S20/12/346) (see Appendix D). Written consent for the qualitative section of the study was also obtained from the WCDOH (see Appendix E & Appendix F), as well as the CEO at the government health facility from which participants for the qualitative phase of the study were recruited (see Appendix G).

2.7.3.1. Qualitative phase

Prior to the start of the study, written permission to conduct the study was obtained from the CEO at the government health facility from which CGs for the qualitative phase of the study were recruited. The head of the psychogeriatric unit at the government health facility was contacted telephonically to explain the study procedure. The researcher then met with the various psychiatrists at the facility during a departmental meeting. They were informed about the aims and objectives of the research, the study procedure, as well as the CG requirement for the research. A printed summary of the research protocol, as well as the inclusion and exclusion criteria, were also provided to them. They were asked to identify possible CGs from their caseload and to obtain written consent to disseminate the CGs' details to the researcher (see Appendix H). This allowed them to disseminate the contact information of the CG, the stage of progression of the individual with AD and the biographical information of the CGs who could potentially be included in the study to the researcher and provide permission for the researcher to contact them telephonically to invite them to participate.

The researcher contacted these CGs telephonically to discuss the aims of the research, the research method as well as the inclusion and exclusion criteria to ensure that the criteria was met. If they qualified to participate based on the criteria and wished to participate, the researcher arranged a convenient location and time to conduct the interviews. Privacy was ensured by meeting in private locations such as a quiet, isolated room at the government health facility. Each interview lasted approximately 45 minutes. Each CG was required to sign the informed consent form (see Appendix I). The individual diagnosed with AD was also required to sign the informed consent form, as information about the difficulties they experience were discussed by their CG and the researcher (see Appendix J). If the individual with AD, due to difficulties associated with AD, was not capable of providing informed consent, the psychiatrist involved in the management of the individual with AD was required to confirm this (see Appendix K). In such cases, the individual with AD's next of kin was asked to provide consent on their behalf (see Appendix L). Once all the necessary informed consent was obtained, the researcher and CG met. Before starting the interview, the CG was again provided with a brief overview of the study.

Despite the government health facility being identified as the optimal site from which to obtain CGs for the qualitative phase of the study, multiple difficulties with the recruitment of CGs were encountered. The limitation that this posed is recognized, however, numerous attempts were made to obtain CGs for the study. The researcher was in frequent contact with the head of the psychogeriatric unit and the psychiatrists who identified CGs who could potentially participate in the study. One challenge which was encountered during data collection was that the psychiatrists at the government health facility changed during the data collection period as psychiatry registrars rotate every three months. Consequently, new psychiatrists were frequently involved in the recruitment process. The researcher and the head of the psychogeriatric unit discussed the difficulties encountered regarding recruitment. The head of the psychogeriatric unit reported that the inclusion and exclusion criteria limited the number of CGs who could be recruited to participate. It was reported that the majority of individuals with AD are managed by primary care workers in the early stages and that the individuals with AD in the late stages who are seen at the recruitment site have already been managed by allied health professionals and were, therefore, excluded as possible participants. It was also reported that the recruitment site typically had more patients with vascular dementia than AD (Prof. Niehaus, personal communication, 31 May 2021). Furthermore, due to the global COVID-19 pandemic, data collection was temporarily ceased in 2020. During the period before temporary cessation of the study, the clinic at the government health facility from which participants were recruited temporarily closed. Once the clinic re-opened, data collection still proved problematic. After 43 weeks, data collection was terminated. This timeline was considered to be a fair amount of time for recruitment.

2.7.3.2. Quantitative phase

Organizations in the Western Cape which advertise their support groups online were approached to participate in the study. The researcher contacted the relevant organizations or SGFs via email or telephonically, depending on the available contact information of each organization or SGF. In instances where organizations were contacted, they provided the researcher with the contact information of the SGFs at their organization. Potential SGFs were emailed by the researcher or contacted telephonically. In the email or during the telephonic conversation, the researcher provided a brief overview of the study, as well as the inclusion and exclusion criteria. Potential SGFs were asked in which language they wanted to complete the survey. Only English and Afrikaans were indicated as their language of choice. All SGFs who agreed to participate in the study were asked to complete the screening form (see Appendix B) as well as the consent form (see Appendix M), and to forward the documents to the researcher. The SGFs were encouraged to contact the researcher if they had any questions or concerns before providing consent. Once the screening form and informed consent form was completed, a link to the online survey was sent via Google Forms.

2.8. Data analysis

2.8.1. Qualitative phase

Thematic analysis was used to analyse the qualitative data obtained from the interviews. Specifically, a deductive approach to data analysis was used. Themes, alternatively referred to as “patterns”, were identified, analysed, and reported. The six steps of analysis, as described by Braun and Clarke (2006), were used and are described below.

Step 1. Familiarization: The first step of the thematic analysis procedure involved verbatim transcription of the interviews. Thereafter, the researcher became familiar with the data obtained. This entailed reading the data multiple times to become immersed in the data. The researcher further actively interpreted the data in the search for patterns during this initial step.

Step 2. Generating initial codes: Initial codes were produced based on the data obtained and by identifying patterns which occurred. Manual coding using a paper-method was used for this process. Codes were extracted and data extracts demonstrating the codes were identified.

Step 3. Searching for themes: Possible themes were then produced, based on the initial codes. Codes were combined to form a theme. Upon completion of this step, numerous possible themes and sub-themes, and the codes which they were comprised of, were identified.

Step 4. Theme revision: The researcher revised the coded data and ensured that a clear pattern was formed with the codes to comprise the theme. Related themes were merged into a single theme and themes without sufficient supportive data were discarded.

Step 5. Theme identification and naming: During this phase, the core of each theme was investigated, and supportive data was organized to form a logical account with a supportive narrative. Themes were examined as separate entities, as well as in conjunction with other themes to ensure the absence of overlap, as well as to identify the story of each theme, and how they related to the research question.

Step 6. Report production: The last step was final analysis, as well as writing themes into a report in the form of the results and discussion sections of this dissertation.

2.8.2. Quantitative phase

Quantitative data obtained was summarized in a Microsoft Excel spreadsheet. The quantitative data was then reflected as descriptive statistics using tables, percentages, graphs, and charts.

Questions received in the support group about SLTS-related difficulties and the number of SGFs who felt able to answer the question were calculated and reflected using graphs and percentages. Descriptions of the current support group structure were identified. The current support group structures used were calculated as percentages. The questions received about the role of the SLT were reflected as percentages. SGFs' perceived value of having a SLT at the group was reflected using a chart and percentages, while the information about referral to a SLT was also reflected using percentages.

2.9. Data management

2.9.1. Qualitative phase

Each transcribed interview conducted was saved as word documents on a password protected laptop. Interview sound files were recorded on a voice recorder and stored in a locked cabinet to which only the researcher had access. Upon completion of the interview transcription, all sound files were permanently deleted from the voice recorder. All CGs who participated received a code instead of using any identifying personal information, allowing for anonymity to be maintained during the data analysis process.

2.9.2. Quantitative phase

All information obtained was automatically saved on Google Forms. The Google account used was password protected. Data was organized in an Excel spreadsheet on a password protected laptop.

2.10. Data dissemination

The information obtained in this study will be disseminated to the support groups that participated in the study. A summary of the results and discussion will be emailed to the SGFs as well as the managers of the organizations. A discussion of the clinical implications and suggestions regarding SLTS-related information provision at the support groups and recommendations to promote support group accessibility will be included. An information session on the results of the study will be held via an online meeting due to the COVID-19 pandemic, to provide the opportunity for discussion of the results and clinical implications, as well as to provide an opportunity for questions to be asked and answered.

Data dissemination will further take place at the Division of Speech-Language and Hearing Therapy Stellenbosch University's research day. Data dissemination at this event will provide the opportunity to inform both qualified clinicians, as well as student SLTs about the information gleaned from the study, which may result in improved information provision to the AD caregiver. Furthermore, the researcher aims to publish an article on the results, giving a wider audience of SLTs access to the information.

2.11. Trustworthiness of the qualitative data

The following aspects of trustworthiness of the data was considered throughout the research process.

2.11.1. Credibility

Credibility in research aims to ensure that research findings reflect the reality of that which is being studied (Bless et al., 2013). To increase credibility in the current study, the researcher used the technique of summarizing during the interviews to ensure that the CGs had been correctly understood. CGs were also encouraged to provide their honest reflections throughout the interview (Shenton, 2004). The risk of social desirability bias was also considered. Attempts at avoiding this was made through the interviewer's constant attempts at remaining reassuring of the CGs' answers and reflections without judgement.

Credibility was further ensured through data immersion as the researcher was familiar with the content of the interviews and as the researcher conducted, transcribed and translated the interviews herself and reviewed it multiple times to ensure a thorough understanding of the interviews. Continued engagement with the data through discussions between the researcher and the supervisors ensured that shared meaning of the data was achieved, which increased the credibility of the study. Results of the interviews were discussed between the researcher and two supervisors to ensure credibility of interpreted results. Investigator triangulation (Korstjens & Moser, 2017) was, therefore, included as the supervisors were directly involved in the analysis of the qualitative data.

2.11.2. Dependability

For research to obtain dependability, all steps of the research method should be clearly outlined and followed (Bless et al., 2013). Detailed descriptions and records of all the phases of the study were kept by the researcher to increase the study's dependability.

2.11.3. Confirmability

To obtain confirmability, other researchers should be able to obtain similar findings if similar research methods are used in a similar context (Bless et al., 2013). Confirmability was achieved through constant reviews of the notes and data by the researcher and the two supervisors of the study.

2.11.4. Reflexivity

Reflexivity entails the self-evaluation of the researcher's outlook and the effects thereof on the research outcomes (Berger, 2015). Attempts to avoid this was made by the two supervisors acting as the auditors to ensure that the outlook of the researcher does not influence the outcomes.

2.12. Reliability and validity of the quantitative data

2.12.1. Reliability

Reliability refers to the ability of an instrument to consistently obtain the same results (Roberts et al., 2006). There was minimal risk of inconsistencies in the presentation of the questions as each SGF received the same instructions and had all questions posed in the same way using the online survey, thus eliminating interviewer bias (Bless et al., 2013). The researcher also did not influence the responses of the SGFs as she was not present during the completion of the survey. This reduced the chance of SGFs giving desirable answers to satisfy the researcher, thereby reducing respondent bias (Bless et al., 2013). Experimenter expectancy bias was also eliminated as the researcher was not present to influence the SGFs through aspects such as facial expressions or tone of voice (Finn, 2006). Facial expressions and tone of voice may influence SGFs' responses as they may feel led to answer questions in a specific way by these factors. Interpretive bias was reduced through the involvement of the two supervisors of the study auditing the research and thereby reducing the risk of interpreting data for the purpose of supporting the researcher's hypothesis. Non-response bias, which refers to the under-representation of specific types of respondents due to non-response (Cheung et al., 2017) was a concern and consequently attempts were made to reduce this through repeated reminders via email or telephonically.

2.12.2. Validity

Validity pertains to whether the conclusions drawn from data reflect reality (McKibben & Silvia, 2016). Internal validity was increased by including the expert review. Replication ability of the study was ensured through detailed descriptions of the research procedure, the use of a survey which can be used in replication, and by providing detailed descriptions of the inclusion and exclusion criteria.

Selection bias was reduced by approaching all known support groups and thereby SGFs in the Western Cape. Data collection bias may have been present, as the survey used in the quantitative section of the study required the SGFs to rely on memory to reflect on their experience (Smith & Noble, 2014). Non-response bias was present in the study as numerous possible SGFs did not reply to the email or refused participation (Bless et al., 2013). Attempts at avoiding non-response bias was made by frequent email and telephonic reminders to SGFs.

2.13. Ethical considerations

2.13.1. Qualitative phase

Permission to conduct the study was obtained from the HREC at Stellenbosch University as well as the WCDOH prior to the commencement of the study. Both confidentiality and anonymity were maintained throughout all the phases of the research to safeguard the rights of the CGs. All CGs, as well as either the individual with AD or their next of kin signed the necessary informed consent forms. This aimed to ensure that the CGs, the individual with AD or their next of kin were aware of the details of the study. Informed consent, the details of the study and the participant's right to withdraw from the study was explained during the process of informed consent. All CGs had the right to withdraw from the study at any point without negative consequences. CGs, the individual with AD, or their next of kin also provided signed informed consent to audio record the interview.

A list of referral numbers (see Appendix N) was made available to the CGs, should they feel the need for further assistance following the interview. The list contains the numbers of the SLTS departments at Tygerberg Hospital, Groote Schuur Hospital and Khayelitsha District Hospital as well as the Tygerberg, Groote Schuur and Khayelitsha Hospitals' adult psychiatry, psychology, and mental health departments. The contact numbers of SLTS departments were made available as the information needs which arose in the interviews fall within the scope of practice of the SLT. Thus, if CGs wished to consult a SLT about the difficulties discussed in the interview, they were able to access these services. The contact numbers of psychiatric and psychological services were made available, as the interviews could elicit emotional responses, which should be dealt with by these professionals.

2.13.2. Quantitative phase

Ethical approval was obtained from the HREC at Stellenbosch University. The principles of biomedical ethics, namely respect for autonomy, beneficence, non-maleficence and justice (Beauchamp & Childress, 2001) were complied with in the current study. Participation in this study was voluntary and SGFs signed a consent form, thereby complying with the biomedical ethics principle of autonomy. In line with this principle, SGFs' participation was voluntary and SGFs were in no way pressurised to participate in the study. Although the informed consent document was sent via email and the researcher was not able to explain the document to the SGFs in person, SGFs were encouraged to contact the researcher should they have any questions or concerns regarding the informed consent document or the study before they consented to participate. The rights of the SGFs were protected and anything which could result in harm was avoided, which complies with the ethical principle of beneficence (Moodley, 2011). In accordance to the principle of non-maleficence, no harm was inflicted on the SGFs. The consent form also outlined that SGFs could withdraw from the study at any time, as per the principal of justice. In further compliance of the principal of justice, confidentiality of SGFs were kept during all phases of the research and all SGFs were treated equally and respectfully whilst respecting the rights of the SGFs (Moodley, 2011). No identifying information about the SGFs were included in this dissertation.

CHAPTER 3: RESULTS

The current study investigated the communication, cognitive functioning, and feeding and swallowing information needs of CGs of individuals diagnosed with AD. The study also obtained information about the support group structure preferred by CGs. The SLTS-related aspects which are common points of discussion at support groups and the structure of support groups in the Western Cape were also determined. A convergent, parallel mixed method research design was used to obtain this information. The qualitative and quantitative data was collected simultaneously, analysed separately, and merged for interpretation and discussion. The qualitative data involved semi-structured interviews with CGs of individuals diagnosed with AD while the quantitative data was collected in the form of an online survey, completed by SGFs.

3.1. Qualitative data

Table 5 outlines the relevant demographic information of the three CGs included in the study.

Table 5

Demographic information: Caregivers

Caregiver	Sex	Participant age	Relationship to individual with Alzheimer's disease	Patient age	Time since diagnosis
CG1	Female	57	Wife	74	5 years
CG2	Female	55	Niece	91	± 3 or 4 years
CG3	Female	62	Wife	67	< 1 year

All three CGs in the current study were female. The age of the CGs ranged from 55 to 62 years. Two CGs were the wives of the individual with AD, while the remaining CG was the niece of the individual with AD. The age of the individuals with AD ranged from 67 to 91 years. The time since the individual with AD had been diagnosed ranged between less than one year to five years prior to the interview. CG3 reported that the individual with AD was diagnosed less than one year before the interview. However, CG3 had noticed symptoms of AD and attempted to obtain a diagnosis for several years before being seen at the recruitment site where a diagnosis of AD was made.

Thematic analysis was used to analyse the interviews conducted with the final three CGs included in the sample. All interviews were conducted in Afrikaans and the translation of the interviews were done by the researcher, who is fully bilingual. The main objectives of this study guided the overarching themes in the data, namely information needs pertaining to communication, cognitive functioning, and feeding and swallowing, as well as preferred support group structure. Although the focus of the study pertained to information needs, analysis of the interviews revealed that the CGs had both information and support needs. In the literature, support needs are typically considered an information need, however, in this study information and support needs were considered separately. In the current study, information needs referred to requests for information about aspects such as the cause of symptoms or about the progression of symptoms, whereas support needs referred to ways of managing symptoms of AD.

Some of the information and support needs were directly stated in the interviews. Others were indirectly stated or interpreted by the researcher during analysis as an indirectly stated need. Analysis of the difficulties that CGs observed in the person with AD whom they cared for, demonstrated an indirectly stated need for information about these difficulties. The perceptions CGs had about the features of AD also reflected a need for information. The CGs' apparent acceptance of the observed difficulties and their perception that no support options were available, was also interpreted as an indirectly stated need for information or support. A need for support was also deemed to be indirectly stated in instances where strategies were employed but considered to be ineffective by the CG. It was interpreted as a need for guidance about additional or alternative support strategies. CG1, CG2 and CG3 will be used to refer to the interviews with the respective CGs included into the current study. This code was given to each of the CGs to allow for anonymity, as well as to distinguish between statements made by each CG. The themes, sub-themes and codes pertaining to the information and support needs which were identified in the interviews are reflected in Table 6.

Table 6

Themes, sub-themes, and codes

Themes	Sub-themes	Codes
Communication	Pragmatics	• Contributes less to conversation • Information needs • Support needs
	Receptive language	• Difficulty understanding • Information needs • Support needs
	Word retrieval	• Word finding difficulties

Cognitive functioning	Short-term memory	• Short-term memory difficulties • Attempted strategies for short-term memory difficulties • Information needs
	Long-term memory	• Long-term memory difficulties • Information needs • Support needs
	Orientation	• Orientation difficulties • Attempted strategies for orientation difficulties • Information needs • Support needs
	Executive functioning	• Planning difficulties • Attempted strategies for planning difficulties • Information needs • Support needs
	Communication and cognitive stimulation	• Support needs for communication stimulation • Support needs for cognitive stimulation
Feeding	Feeding and swallowing difficulties	• Signs of dysphagia • Attempted strategies to facilitate swallowing • Information needs
Emotional impact of Alzheimer's disease-related difficulties	Receptive language	• Emotional impact of receptive language difficulties
	Cognitive functioning	• Emotional impact of memory difficulties • Emotional impact of orientation difficulties
	Feeding and swallowing	• Emotional impact of feeding and swallowing difficulties
Preferred support group structure	Location	• Preference • Reason for preference
	Time of day	• Preference • Reason for preference
	Duration	• Preference • Reason for preference
	Frequency	• Preference • Reason for preference
	Group size	• Preference • Reason for preference
	Patient presence/ absence	• Preference • Reason for preference

3.1.1. Communication

CGs' information and support needs pertaining to communication, as well as supporting quotes translated from English to Afrikaans by the researcher are outlined in Table 7.

Table 7

Sub-themes, codes, and quotes: Communication

Sub-theme	Codes & Quotes
Pragmatics	Contributes less to conversations *CG3:186: ...he doesn't take part in a conversation anymore.* Information needs *CG1:58: Maybe he doesn't have much to speak about because he can't really remember where we were and that he can tell someone...* Support needs *CG3:140: ...no, because I know I won't get my friend back again. So, I have made peace with that.* *CG1:62: What will help for it…is there something that can help?*
Receptive language	Difficulty understanding *CG3:181: ... then I can see it in his eyes, yes. [Referring to patient not understanding]* Information needs *CG1:92 ...must know as soon as possible ...that person won't understand what you are saying…* *CG1:69:…information on how your brain then really works to go wrong.* Support needs *CG1:68: It probably can't change? There probably isn't advice for it.*
Word retrieval	Word finding difficulties *CG3:145: ... and then he can't get to the word.*

3.1.1.1. Pragmatics

Changes to the pragmatic skills of the individual with AD were noticed by CG1 and CG3. It was reported that the individuals with AD had become more passive communication partners as they spoke less, or no longer contributed to conversations. CG1 observed that memory difficulties could be a contributing factor to the individual with AD's reduced ability to engage in conversation. This reflected an indirectly stated need for information about the influence of cognitive skills, such as concentration, attention, and memory on pragmatic skills. CG3 accepted that the individual with AD no longer engaged in conversation and reported that this would not improve, indicating an indirectly stated need for strategies to support pragmatic difficulties. This support need, also applied to CG1 who made a directly stated need for strategies to support the individual with AD with memory difficulties to engage in conversation.

3.1.1.2. Receptive language

CG1 and CG3 noted that they had observed that the individual with AD experiences receptive language difficulties. CG1 discussed the importance of obtaining information about receptive language difficulties at an early stage of AD, to better understand the observed symptoms. CG1 also directly stated the need for information about the cause of receptive language difficulties. It was, however, evident that CGs not only needed information, but also required support. CG1 appeared to assume that there are no strategies to support receptive language difficulties, thus indicating an indirectly stated need for support strategies in this regard.

3.1.1.3. Word retrieval

Although CG3 noted word retrieval difficulties, no directly stated information or support needs were raised. The observation of these difficulties does, however, demonstrate an indirectly stated need for information regarding word retrieval difficulties associated with AD.

3.1.2. Cognitive functioning

CGs' information and support needs pertaining to cognitive functioning are outlined in Table 8 and supporting quotes translated from English to Afrikaans are provided.

Table 8

Sub-themes, codes, and quotes: Cognitive functioning

Sub-theme	Codes & Quotes
Short-term memory	Short-term memory difficulties *CG2:47: ...but things about now? Ha-a. She can't remember that.* *CG2:98: I forgot I asked you. I am going to ask you again.* Attempted strategies for short-term memory difficulties *CG3:111: Sometimes when I give him more than one thing I must cut out a picture and send that along.* Information needs *CG3:93: Whether he will completely forget everything.*
Long-term memory	Long-term memory difficulties *CG1:27: ... he doesn't easily recognize people.*

	CG1:46: It is like a new place that we are going to. Information needs *CG2:53: … why is the memory that it can remember those years' things, but not the things that happen now?* *CG3:213: …and if he will completely forget us.* Support needs *CG1:46: There is probably not help for that? [referring to difficulty recognizing familiar individuals and places]*
Orientation difficulties	Orientation difficulties *CG1:37: He can't remember what day and date it is…* *CG3:153: He doesn't know where he is…* Attempted strategies for orientation difficulties *CG2:138: …when we go out or we drive out we don't want to be away from the house for too long, because she is so used to that environment now.* *CG3:155: Then I will tell him "You are here now" and I will tell him the date.* Information needs *CG3:161: If I could get more information in book form…* Support needs *CG1:71: … what should you do? [Referring to difficulty with orientation to place]*
Executive functioning	Planning difficulties *CG1:56: But he might…be interested in something but doesn't know where to start to do something.* *CG3:72: …he goes to the bathroom … but I noticed the washcloth and the soap is still dry. He does nothing.* Attempted strategies for planning difficulties *CG3:128: … I will put the soap on the washcloth myself and then…I say "right, you continue now."* Information needs *CG2:80: They say you must go live in their world, but how can you live in their world when you see they do something wrong?* Support needs *CG1:56: It would be interesting for me to be able to help him to plan to start something or to do something.*
Communication and cognitive stimulation	Support needs for communication stimulation *CG2:227: …the more you speak with the person with Alzheimer's, the better she can still bring up her speech.* Support needs for cognitive stimulation *CG1:41: …something you give an adult that maybe keeps the brain busy.* *CG3:114: But I have thought about crossword puzzles and things like that.*

3.1.2.1. Short-term memory

Short-term memory difficulties, specifically difficulty remembering recent information, were noted by CG2 and CG3. CG2 also reported that the individual with AD repeated questions and attributed this to memory difficulties. This shows the CG's understanding of the underlying cause of the repetition of questions. CG3 directly stated a need for information about what to expect in the future regarding short-term memory difficulties. This indicates a need for information about the progressions of short-term memory difficulties associated with the various stages of AD. Only CG3 reported attempting strategies to compensate for the short-term memory difficulties observed.

3.1.2.2. Long-term memory

Difficulty with long-term memory were noted by CG1 and CG3. CG1 stated that the individual with AD had difficulty recognizing familiar individuals and places. CG3 noted that the individual with AD had difficulty remembering familiar dates. CG2 had limited information about the reasons why short and long-term memory are affected differently by AD. This CG expressed the need for information about this discrepancy. It was also evident that the progressive nature of long-term memory difficulties is a cause of concern as CG3 directly stated a need for information about what to expect in the future regarding long-term memory. Support needs were indirectly stated when CG1 noted that nothing could be done to support the individual with AD with recognizing familiar individuals and places.

3.1.2.3. Orientation

The individual with AD's difficulty with orientation to time was noticed by CG1 and CG2, while all three CGs observed the difficulty with orientation to place. CG2 and CG3 both attempted strategies to address these orientation difficulties. It included changing their activities to keep the individual with AD in their familiar environment, maintaining a routine and telling the individual with AD their location and the date. CG3 reported that the latter strategy was ineffective because the individual with AD would not be orientated again the following day. This observation by CG3 seems to demonstrate an indirectly stated need for information about the cause of orientation difficulties, since it appears that the CG does not understand why orientation difficulties may persist despite providing orientating information. CG3 further directly stated a need for information regarding orientation difficulties related to AD, while CG1 directly stated a need for support to address the individual with AD's difficulty with orientation to place.

3.1.2.4. Executive functioning

Planning difficulties were identified by CG1 and CG3. These planning difficulties related to task initiation and ADL engagement. CG1 did not appear to notice that the individual she cares for may have difficulty with planning until the topic was prompted in the interview. CG3 attempted strategies to support the observed planning difficulty, but reported that this had been ineffective, which implies an indirectly stated need for support. CG2 directly stated a need for information about how to handle the situation when one observes the individual with AD experiencing difficulty with planning of tasks, while CG1 had a directly stated need for support strategies to initiate tasks.

3.1.2.5. Communication and cognitive stimulation

CG2 noted that the more the individual with AD was spoken to, the better they would maintain their communication ability. Although it is evident that CG2 is aware of the importance of stimulating the individual with AD's language skills, she did not note any specific strategies other than speaking to the individual with AD. This was interpreted as an indirectly stated need for support regarding specific language stimulation. CG1 and CG3 directly stated a need for guidance about cognitive stimulation strategies. It was evident that although these CGs mentioned possible activities that they thought could stimulate cognition, they were uncertain whether these strategies would be beneficial. Their uncertainty further indicated a more indirectly stated support need.

3.1.3. Feeding and swallowing

The information and support needs identified regarding feeding and swallowing, as well as supporting quotes translated from English to Afrikaans are outlined in Table 9.

Table 9

Sub-themes, codes, and quotes: Feeding and swallowing

Sub-theme	Codes & Quotes
Feeding and swallowing difficulties	Signs of dysphagia *CG2:29: Sometimes she swallows and she says the pills are still sitting here [points to throat]…* *CG3: 209: … he eats so slowly.* Attempted strategies to facilitate swallowing *CG2:32: And then I give water again. Then I tell her to tilt her head back.* Information needs *CG2:128: How will we make her swallow it? …What must we do to get that down her throat?*

CG1:82: ... the swallowing I have also read is something that happens that later on the person doesn't know how to swallow.

G1:83: Because then he must probably be fed by tube. Where do you go?

Signs of pharyngeal phase dysphagia were noted by CG2, and signs of oral phase dysphagia by CG3. Despite noticing these difficulties, no immediate questions or concerns were raised regarding these potential signs of dysphagia. This indicates a lack of ability to recognize signs and symptoms of dysphagia and was, therefore, interpreted as an indirectly stated need for information about feeding and swallowing difficulties related to AD. Despite this limited information about feeding and swallowing difficulties, CG2 had implemented a strategy to facilitate swallowing as the individual with AD reported that it felt as if her medication was stuck in her throat and reported the attempted strategy to be effective. The implementation of swallowing strategies without appropriate guidance may increase the risk of aspiration and, therefore, indicates an indirectly stated need for information about dysphagia management.

All three CGs directly stated a need for information about feeding and swallowing difficulties which may occur in the future. CG2 and CG3 reported specific concerns regarding aspects such as managing feeding and swallowing difficulties, as well as choking. This highlights the need for information about swallowing changes associated with the various stages. Although CG1 did not report any current signs of dysphagia, there was a directly stated need for information regarding addressing feeding and swallowing difficulties when the individual with AD does start to experience difficulties.

A need for information was also indirectly stated through perceptions CGs had about dysphagia. CG1 and CG2 appeared to understand that feeding and swallowing difficulties only occurred in the late stages of AD, which again highlights the need for information about swallowing changes associated with the various stages of AD. CG1 had the perception that an individual with AD can die of hunger. This CG also had the perception that individuals with AD are fed with feeding tubes. CG1 furthermore directly stated a need for information about the long-term care related to dysphagia, such as placement at care homes for individuals with feeding tubes, which again indicates a need for information in this regard as the use of tube feeding is not recommended in this population. Their perceptions specifically related to feeding and swallowing reflected indirect information needs.

3.1.4. Emotional impact of speech and language therapy services-related difficulties

Table 10 outlines the emotional impact that SLTS-related difficulties had on the CGs in the current study and provides supporting quotes translated from English to Afrikaans by the researcher.

Table 10

Sub-themes, codes, and quotes: Emotional impact of Alzheimer's disease-related difficulties

Sub-themes	Codes & Quotes
Receptive language	Emotional impact of receptive language difficulties *CG1:90 …because it can be very frustrating to you to speak to someone and it just looks like there is nothing.*
Cognitive functioning	Emotional impact of memory difficulties *CG1:47: I am almost too scared to want to know.* *CG2:60: Sometimes we argue..., because... I just told [refers to person with Alzheimer's disease] what it is and now she asks me again.* Emotional impact of orientation difficulties *CG1:71: You don't relax.* *CG3:154: Sometimes I am very frustrated and sometimes I am sad to think what he is now and what he was and so on [Refers to observed orientation difficulties].*
Feeding and swallowing	Emotional impact of feeding and swallowing difficulties *CG1:83: If a person can't eat anymore then I don't know if I can handle it.*

The CGs highlighted the emotional impact of AD-related difficulties on them as CGs. CG1 noted the frustration experienced because of receptive language difficulties and the fear of obtaining information about which type of memory symptoms to expect in the future. Arguments with the individual with AD due to short-term memory difficulties were reported by CG2. Orientation difficulties resulted in constant stress, as well as frustration and sadness as reported by CG1 and CG3, respectively.

CG1 reported that she did not discuss aspects of AD such as dysphagia, which she considered to be a specifically distressing symptom, with the individual with AD. She reported that she uses this as a coping strategy. CG1 further expressed concern about her ability to cope with managing dysphagia.

3.1.5. Preferred support group structure

The support group structure preferences of CGs, as well as the reasons for these preferences are outlined in Table 11. Supporting quotes translated from English to Afrikaans are provided.

Table 11

Sub-themes, codes, and quotes: Preferred support group structure

Sub-theme	Codes & Quotes
Location	Preference *CG1:19: …anything that is close.* Reason for preference *CG3:217: …because I don't have transport.* *CG2:213: …the information, if you don't know it you can quickly find out from a doctor [reference made to the hospital].*
Time of day	Preference *CG1:16: …after hours.* *CGP2:172: Mornings…From about 11 o'clock…* *CG3:222: … early afternoon.* Reason for preference *CG1:17: …because I have the child there.* *CG2:178: As soon as it is in the afternoon, your brain is sometimes made in a way that it switches off a bit.* *CG3:224: …then I have done my tasks…. and he has been cared for…*
Duration	Preference *CG1:10: … an hour to two hours.* Reason for preference *CG1:12: Less might be too little time because if it is a group with a few people, everyone might have some questions, and every question is discussed …* *CG1:14: … if I go for two hours I would need to drop him off somewhere or get someone to sit with him.* *CG2:185: I don't think longer, because then your ideas will have an effect on those you haven't implemented yet.*
Frequency	Preference *CG3:235: About once a month.* *CG2:189: Twice a week is good.* Reason for preference *CG1:8: …at this stage I don't get anything in that line, so anything is probably welcome.* *CG2:189: Not once a week, because … that period that you will get together again is too long.*
Group size	Preference *CG1:22: …one can probably go up until ten.* *CG2:196: Ten to fifteen?* Reason for preference

	CG1:24: Otherwise it can become too long if there are too many questions and things. *CG3:239… then you work on more people's what they are going through…* *CG2:198: That fifteen thoughts can maybe give you a different solution.*
Presence or absence of individual with Alzheimer's disease	Preference *CG1:29: I would prefer that he is not present…* *CG2:201: … once a week or so it would be nice to bring them…* Reason for preference *CG1:29: … because things might come out which are upsetting to the patient…* *CG2:201: …that other people might perhaps see … we work this way with that person, this person with Alzheimer's looks like this, that person with Alzheimer's looks like that.*

3.1.5.1. Location

The location preferred by all three CGs were locations close to their home. CG3 specified that this was due to lack of transport. Although hospitals and clinics were also identified as appropriate locations by CG2 and CG3, they noted that these locations were close to their home, which contributed to this preference. This again highlights the importance of proximity. CG2 also reported that support groups held at a hospital would allow access to a doctor for information, if needed.

3.1.5.2. Time of day

The preference for the time of day at which the support group should be held differed between CGs and ranged from the morning to early evening. Their preferences were influenced by home circumstances, such as familial tasks, the time in which they need to provide care to the individual with AD, and the time of day when they would be able to focus best.

3.1.5.3. Duration

The preferred duration of a support group session ranged from one to two hours. There were multiple reasons for this preference. CG1 reported that less time would not allow for all group members' questions to be raised and discussed. This was reiterated by CG2 who stated that shorter sessions would not allow time to obtain solutions to problems. CG1 also stated that longer sessions would result in the need for supervision for the individual with AD. Additionally, CG2 reported that session should not be longer than two hours, as strategies discussed in the group should be attempted before additional strategies are discussed.

3.1.5.4. Frequency

CG1 and CG3 indicated a preference for monthly support groups, whilst CG2 preferred support groups to be held twice a week. CG1 indicated that since she currently had no support, any support would be welcomed. CG2 reported that the time between sessions would be too long if groups are held less frequently than twice a week.

3.1.5.5. Group size

CG1 and CG3 preferred a group size of 10 attendees, while CG2 reported that the group could have between 10 and 15 attendees. The time needed for the session was noted as the reason for this preference by CG1, as more attendees could result in more questions being asked, thus creating the need for longer sessions. This CG also noted that the focus of the group would influence the size of the groups. Groups that mainly entail asking and answering questions, will require more time and thus influence how many attendees could be present to adhere to the time frame of the support group. There was also a need for a smaller group to ensure that all attendees' problems would be dealt with, as noted by CG3. CG2 preferred a larger group and reported that it would allow for multiple solutions to problems to be obtained from various attendees.

3.1.5.6. Presence of individual with Alzheimer's disease

CG1 and CG3 preferred the individual with AD not to be present in the support group. CG1 reported that the information discussed in the group could upset the individual with AD, while CG3 reported that the individual with AD would not be able to remain seated for the duration of the session. CG2, who preferred the individual with AD to be present, noted that it would allow the attendees to see the difficulties they experience and inform the discussion of ways in which difficulties could be addressed.

3.2. Quantitative data

The survey investigated questions received within support groups about communication, cognitive functioning and feeding and swallowing, and thus the SLTS-related aspects that are common points of discussion at the support groups. Information about the current structure of support groups in the Western Cape was also investigated. The raw data is outlined in Appendix O.

3.2.1. Participant information – support group facilitators

The first section of the survey collected demographic information of the SGFs. This data is summarized in Table 12.

Table 12

Demographic information: Support group facilitators

Participant number	Age	Highest level of education	Sex	Training received for support group facilitator role
1	60+	College	Female	Other (not specified)
2	60+	University	Female	Other (not specified)
3	50-60	University	Female	Other (not specified)
4	60+	University	Female	Other (not specified)
5	20-30	University	Female	Other (not specified)
6	60+	High school not completed	Female	No formal training
7	50-60	College	Female	A short course through the institution worked for
8	50-60	University	Female	Other (not specified)
9	60+	High school	Female	No formal training
10	60+	University	Female	Other (not specified)
11	40-50	University	Female	A short course through the institution worked for
12	50-60	University	Male	No formal training
13	60+	College	Female	A short course through the institution worked for
14	40-50	High school	Female	Other (not specified)
15	60+	High school	Male	A short course through the institution worked for

Demographically, there was a wide range in terms of age, level of education and training received amongst the SGFs. Their ages ranged from 20-30 years to over the age of 60, with 53% of the SGFs (n=8) older than 60. SGFs were predominantly female (n=13). Twenty seven percent of the SGFs (n=4) had secondary education and 73% (n=11) had tertiary education. Interestingly, 20% of the SGFs (n=3) had no formal training to prepare them for their facilitator role, while 27% (n=4) had attended a short course.

3.2.2. Questions asked at support groups

SGFs were asked about SLTS-related questions received in the support group, as well as their perceived ability to adequately answer these questions. These questions were divided into three subsections, namely communication, cognitive functioning, and feeding and swallowing information.

3.2.2.1. Communication

In the survey, SGFs were asked whether they had received questions in the support group pertaining to difficulty with various aspects of communication. The survey investigated questions received from attendees specifically about word finding difficulties, receptive language difficulties, and changes to pragmatic skills. Figure 3 outlines the number of SGFs who had been asked about these difficulties, as well as their perceived ability to adequately answer these questions.

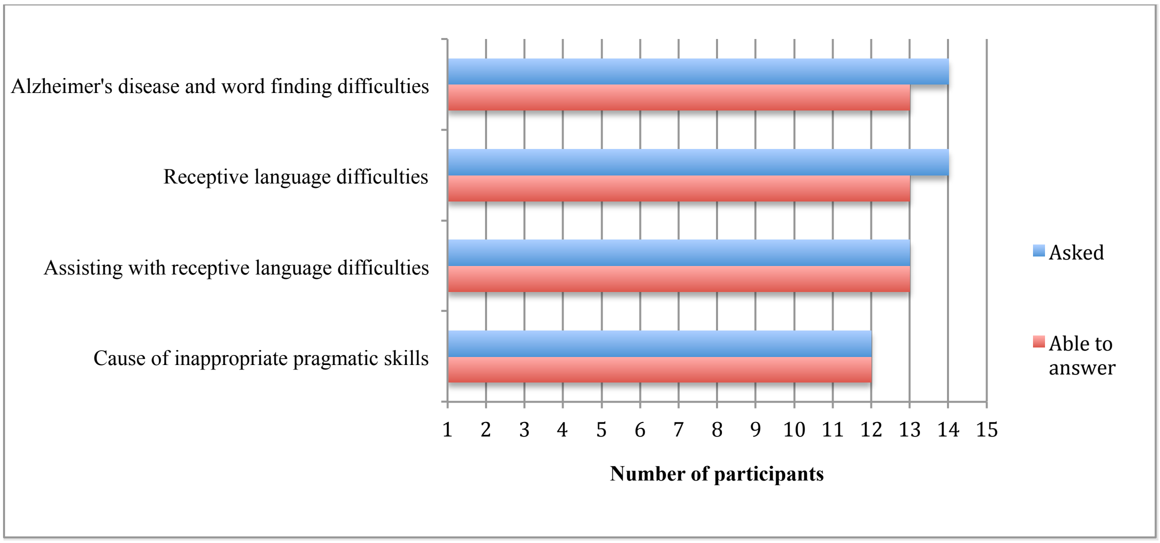

Figure 3

Communication-related questions received at support groups and support group facilitators' perceived ability to adequately answer these questions

Most of the SGFs (n=14) had received questions pertaining to individuals with AD experiencing word finding difficulties, and 93% of those who had been asked, (n=13) reported that they were able to answer. Ninety three percent of SGFs (n=14) had been asked about individuals with AD experiencing receptive language difficulties, while the majority of those (n=13) reported being able to answer. Furthermore, 87% of the SGFs (n=13) had been asked how to assist an individual with AD who experiences receptive language difficulties. All the SGFs who had been asked this question (n=13) reported that they were able to answer. Eighty percent of the SGFs (n=12) had been asked about the cause of changes in pragmatic skills of individuals with AD. All SGFs who had been asked this question (n=12) indicated they were able to answer.

3.2.2.2. Cognitive functioning

In this section of the survey, SGFs were asked whether they had received questions in the support group pertaining to specific aspects of memory as well as cognitive stimulation. Figure 4 outlines the number of SGFs who had been asked about these topics, as well as their perceived ability to adequately answer these questions.

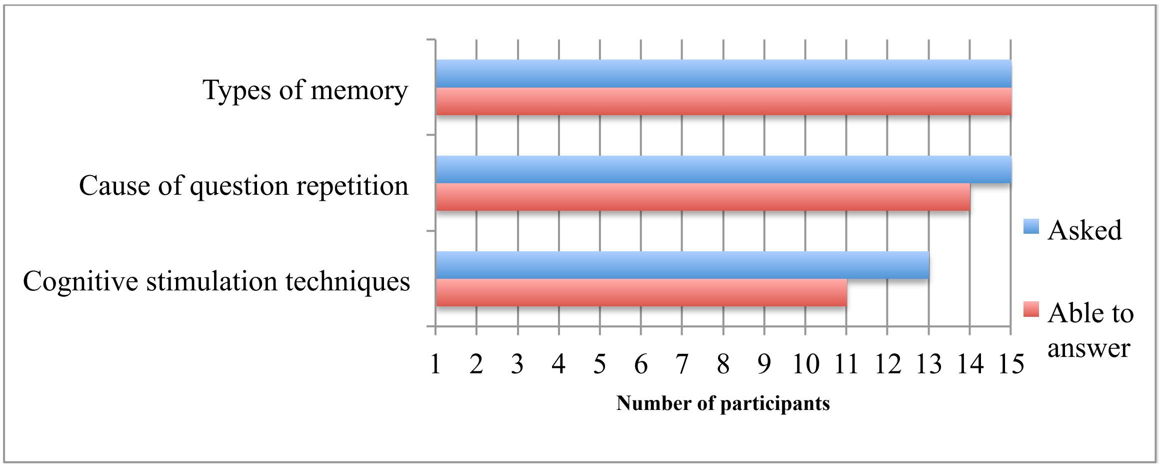

Figure 4

Cognitive functioning-related questions received at support groups and support group facilitators' perceived ability to adequately answer these questions

Within the support group setting, all SGFs (n=15) had been asked about the various types of memory and all the SGFs reported being able to answer this question. All the SGFs (n=15) had been asked about the cause of question repetition, while 93% of those who had been asked (n=14) indicated that they were able to answer. Eighty seven percent of SGFs (n=13) had received questions about ways in which to stimulate cognition in individuals with AD, while 85% of SGFs who had received this question (n=11) reported they were able to answer.

3.2.2.3. Feeding and swallowing

This section of the survey investigated the feeding and swallowing-related questions which had been received from attendees in the support group, as well as the SGFs' perceived ability to adequately answer these questions. It is noteworthy that only 33% of the SGFs (n=5) had been asked about signs of dysphagia in individuals with AD. Eighty percent (n=4) of those who had been asked reported they were able to answer.

3.2.3. Support group structure

The SGFs were asked about the current support group structure at the respective support groups. This information is outlined in Table 13.

Table 13

Support group structure

Support group structure	**Options provided**	**Facilitator selection (n=)**
Location	• At the facility I work for	6
	• At a hospital	2
	• In a religious building	1
	• At an academic facility, e.g., university	0
	• Other	6
Time of day	• Morning	7
	• Afternoon	6
	• Evening	2
Time of the week	• During the week	12
	• Over the weekend	3
Employment status of attendees	• Employed	1
	• Unemployed or retired	1
	• Both	13
Support group duration	• Half hour-hour	1
	• Hour-two hours	13
	• > Two hours	1
Support group frequency	• < Once a month	1
	• Once a month	14
Number of attendees	• 0-5	1
	• 6-10	4
	• 11-15	3
	• 16-20	5
	• 21-25	1
	• 26-30	1
Presence of individual with Alzheimer's disease	• Present	0
	• Not present	9
	• Sometimes present	6
Focus of the group	• Information provision	1
	• Emotional support and information provision	14

Forty percent of support groups (n=6) were held at the location of the support group organization and 40% (n=6) at locations other than those specified, namely at the support group facility, at a hospital, in a religious building or at an academic facility. Seven percent (n=1) of support groups were held in a religious building. Only 13% (n=2) of support groups were held at a hospital. It is also noteworthy that most of the support groups (n=13) were held during the day, although 87% of the groups (n=13) hosted both attendees who were employed and unemployed or retired and 7% (n=1) hosted only employed attendees. Only 20% of support groups (n=3) are held over the weekend.

Eighty seven percent of support groups (n=13) lasted for an hour to two hours. Ninety three percent of support groups (n=14) were hosted once a month, with 7% (n=1) being held less than once a month. The individuals with AD were not present at 60% of the support groups (n=9) and sometimes present at 40% of the groups (n=6). At none of the support groups were the individuals with AD always present. The number of attendees for 47% of support groups (n=7) was more than 15 per session. Most support groups (n=14) focused on both emotional support as well as information provision.

3.2.4. Perceived value of the speech-language therapist and referral to a speech-language therapist

To obtain insight into the need for input from a SLT, SGFs were asked whether they have received questions about the role of the SLT, their opinions about the value of the SLT in the support group and previous referral to SLTs. Interestingly, only 33% of SGFs (n=5) had been asked about the role of the SLT in the management of AD. All SGFs who had been asked this question (n=5) indicated that were able to answer. SGFs were also asked whether they had referred support group attendees to a SLT. Only 40% of the SGFs (n=6) reported that they had.

The SGFs were asked to rate the value of having a SLT at their support group. Using a Likert scale, a value of one indicated somewhat valuable, and a value of 5 indicated very valuable. Sixty percent (n=9) of SGFs rated the value of having a SLT at the support group as either a four, or five (i.e., very valuable). The value of having a SLT at the support group as reported by SGFs is represented in Figure 5.

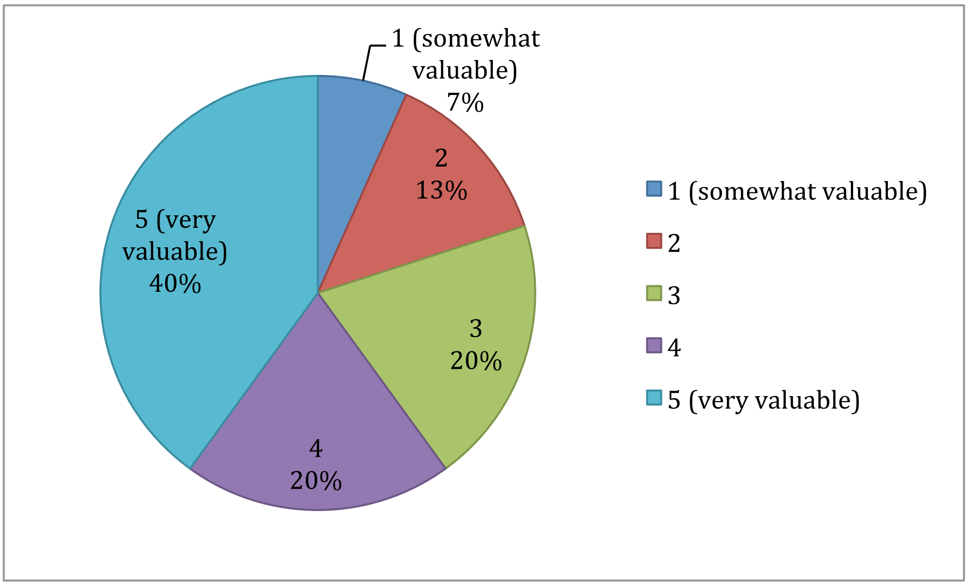

Figure 5

Support group facilitators' perception of the value of a speech-language therapist at the support group

3.3. Summary

The results of the current study indicated that CGs had several SLTS-related information and support needs. It was evident that these needs were not always directly stated, but rather indirectly stated, which may influence questions asked in the support groups and, therefore, influence the information CGs receive. The current study also identified that SGFs were able to answer most of the SLTS-related questions they had received. Feeding and swallowing was an aspect that the SGFs were not often asked about. Information about CGs' preferences regarding support group structure, as well as information about the current structure of support groups in the Western Cape was obtained. It was evident that the CGs' preferences are influenced by several factors and that these preferences could impact accessibility to and possible attendance of a support group. Furthermore, the findings indicate that the majority of SGFs perceived the presence of a SLT as valuable at their support group. Even though SGFs acknowledged the value of the SLT most SGFs had not referred attendees to a SLT. The study findings as well as their implications for clinical practice will be discussed in the next chapter.

CHAPTER 4: DISCUSSION

The discussion will focus on the integrated qualitative and quantitative results as they relate to the directly and indirectly stated information and support needs, as reported by the CGs in this study, as well as the results from the surveys completed by SGFs. Factors that influenced CGs' information and support needs were also identified and will be discussed. Another aspect of discussion is the difficulties CGs observed and experienced regarding SLTS-related aspects, namely communication, cognitive functioning, and feeding and swallowing. This could contribute to the CGs' emotional burden, which was identified as a theme in the qualitative analysis. A support group structure that will promote the accessibility and attendance of CGs will also be recommended. Accessibility is crucial to ensure that CGs have access to the information and support they require, as will be discussed below.

CGs in the current study had more directly stated information and support needs related to cognitive functioning difficulties than either communication or feeding and swallowing. It was evident that information and support needs were influenced by the current level of functioning of the individual with AD, CGs' perceptions about the features of AD and their management, and the acceptance of difficulties. Although past research found that the severity of the disease and the status of the individual as being either the individual with AD or the CG were the only two variables which influence information needs (Soong et al., 2020), the current study identified additional variables.

The first factor identified which influenced CGs' information and support needs was the current level of functioning of the individual with AD. The current level of functioning in this study was an estimation on the part of the researcher based on the time since diagnosis as well as CGs' descriptions during the interview of the difficulties experienced by the individual with AD. There were more directly stated information and support needs related to cognitive functioning difficulties in the current study than either communication or feeding and swallowing. Cognitive functioning is more severely affected in the early stages than language ability (Brookshire, 2015). Similarly, feeding and swallowing difficulties are less pronounced in the early stages. As feeding and swallowing difficulties are subtle in the early stage, symptoms may also go unrecognized. Seçil et al. (2016) found that 75% of the individuals with AD in their study had dysphagia despite having reported no swallowing difficulty. Thus, communication and feeding and swallowing only become more salient in the later stages, which contributes to CGs' limited directly stated needs about these areas during the earlier stage of the disease. As cognitive functioning difficulties are more severely affected earlier in the disease, it is expected that CGs will report more information and support needs in this regard. However, as the disease progresses and communication and feeding and swallowing difficulties become more apparent, it is likely that it will prompt an increase in directly stated information and support needs. The progression of the disease and the resulting impact on the individual with AD and the CG may contribute to CGs' directly stated information and support needs. In this study, it was evident that cognitive functioning difficulties impacted CGs' responsibilities in a much more immediate and significant way than communication or feeding and swallowing difficulties. CGs reported, for example, having to change their daily activities and needing to assist the individual with AD with activities such as washing due to cognitive difficulties. In comparison, CGs' daily activities and responsibilities were not influenced in the same way by either communication or feeding and swallowing difficulties. It therefore appears that the effect of cognitive functioning difficulties on the daily life of the CGs resulted in more directly stated information and support needs about cognitive functioning than communication or feeding and swallowing.

It is, however, noteworthy that the vast majority of SGFs in this study reported that they had been asked about communication difficulties by CGs attending support groups. This finding aligns with existing research, which has indicated that CGs of individuals with dementia seek information about ways in which to improve communication (Edelman et al., 2006; Killen et al., 2016). This may be an indication that CGs become more concerned about communication difficulties as the disease progresses and these difficulties have a greater impact on the daily life and responsibilities of the CG in the later stages. Contrary to this, the majority of SGFs reported that they had not been asked about feeding and swallowing difficulties, such as signs of aspiration, despite the progressive nature of these difficulties in AD and the impact that these difficulties may have on the CG and their daily life and responsibilities. The perception that feeding and swallowing difficulties only occur in the late stage of AD was noted in the qualitative section of the current study. These types of perceptions as well as the fact that feeding and swallowing difficulties may be less pronounced in the earlier stages, could be a reason for the limited number of SGFs who have been asked about signs of aspiration.

CGs in the current study showed an awareness of feeding and swallowing difficulties as one of the symptoms of AD, but were only aware of these difficulties occurring in the late stages of AD. However, research has demonstrated the presence of swallowing changes already in the early stages of AD (Humbert et al., 2010). As CGs had a perception that feeding and swallowing would only be affected in the later stages, they did not express concern about the feeding and swallowing difficulties that they currently observed. This resulted in limited directly stated information needs about these observed feeding and swallowing difficulties. However, CGs' perceptions about the symptoms/features of AD revealed the presence of indirectly stated information needs about feeding and swallowing difficulties. CGs' perceptions also limited and influenced their support needs regarding communication difficulties, as there were instances in which they believed that no support strategies were available to facilitate observed difficulties. This demonstrated limited directly stated needs about support strategies. However, their perceptions that support strategies were not available was interpreted as indirectly stated support needs.

Acceptance of difficulties observed also contributed to CGs' directly stated information and support needs. CGs appeared to have accepted communication-related difficulties as part of AD and consequently expressed limited information needs about this aspect. This apparent acceptance of difficulties may, however, reflect an underlying sense of hopelessness on the part of the CG, resulting in less directly stated information needs. In comparison, CGs expressed their concerns about the cognitive functioning difficulties currently observed, as well as the progression of these difficulties. The CGs in the current study did not merely accept the changes to cognitive functioning observed and actively sought information in this regard. This was reflected in them having more directly stated information needs regarding cognitive functioning difficulties in comparison to the communication difficulties they observed in the individual with AD. CGs also made active attempts to support the cognitive difficulties they observed and expressed their need for support strategies. Their attempted strategies for cognitive functioning difficulties also show that they do not merely accept the difficulties they observe, but make active attempts to assist the individual with AD. Their attempts at supporting cognitive functioning difficulties did, however, demonstrate that CGs have indirect support needs about cognitive functioning difficulties as their attempted strategies were often reported to be unsuccessful, which indicated a need for alternative support strategies. Regarding communication and feeding and swallowing, CGs did not report attempting many support strategies. This may be attributed to CGs being more accepting of communication and feeding and swallowing difficulties and subsequently not attempting strategies to support the individual with AD with these difficulties.

As CGs in this study expressed more concerns regarding cognitive functioning difficulty than communication, it may explain why CGs directly stated the need for cognitive stimulation strategies, but not for communication stimulation strategies. It is recognized that cognitive stimulation strategies can be discussed and applied in a support group format as they are less specific (Kim et al., 2017), while the possible involvement of the SLT is required to assess the communication and cognitive difficulties of the individual with AD to provide appropriate support strategies in relation to their specific difficulties and current level of functioning. The identification of support needs are crucial as information about dementia treatment is one of the three most common information needs identified in previous studies about dementia (Soong et al., 2020). The need for cognitive stimulation strategies was expressed by CGs and was reiterated by the SGFs in the current study. Most of the SGFs reported having received questions about cognitive stimulation strategies within the support group. This highlights the importance that CGs place on maintaining cognitive functioning abilities and delaying impairment. CGs in the current study did not express the same need for strategies to stimulate communication abilities. Cognitive stimulation strategies have, however, been shown to have a positive impact on communication (Swan et al., 2018). The discrepancy between the need for cognitive stimulation strategies compared to communication stimulation strategies likely stem from the factors discussed above, such as the current level of functioning and, therefore, the severity of communication difficulties and impact on the CG, CGs' perceptions and acceptance of difficulties.

The presence of CGs' indirectly stated information and support needs and the limited research available on SLTS-related information needs have implications for support groups. As a result of the limited research about CGs' SLTS-related information needs, support groups would be required to use PBE, as the lack of research demonstrates that EBP cannot be used in this instance. This demonstrates the importance of SGFs sharing information gleaned from PBE with each other in order to optimize the content and conversations about SLTS-related aspects at support groups. Furthermore, as several information and support needs in the current study were stated indirectly rather than directly by CGs, SGFs may not be aware of these needs within a PBE context. This finding is also supported by past research, as McCabe et al. (2016) reported that CGs of individuals with dementia's information needs are often indirectly stated. Subsequently, only directly stated information needs may be points of discussion at support groups. The current study demonstrates that although PBE may be informed by directly stated information needs, indirectly stated SLTS-related information needs should be driven by EBP. SGFs may also have difficulty answering indirectly stated needs as these information and support needs are less frequently received in the support group. SGFs may be able to answer questions that are routinely and directly stated, as they have had the chance to evaluate the outcomes of their answers based on PBE.

The concepts of EBP and PBE as described above yields the question of whether SGFs in the current study were able to adequately answer SLTS-related questions received at the support group. The majority of SGFs reported that they were able to answer SLTS-related questions. However, due to the limited scope of SGF training as approximately half of them either only attended a short course or had no formal training, their ability to answer these questions adequately may be impacted. Furthermore, the accuracy of the information included may be influenced by having to rely on PBE rather than EBP to inform the scope of the discussion in the group. Both EBP and PBE provide valuable information and, therefore, these two aspects should be used in conjunction to improve the success of interventions (The Royal Children's Hospital Melbourne, 2011).

Although the focus of the research was to gain insight into CGs' information needs, another clear theme that emerged was the emotional impact that the various difficulties had on the CGs. Egan et al. (2010) reported that the emotional impact on CGs ranges from conflict experienced due to communication difficulties, to the resultant feelings of isolation or depression. CG burden is associated with the individual with AD's cognitive functioning difficulty (Germain et al., 2009), while orientation difficulties (Berry, 2014) and executive functioning difficulties also increase CG burden (Davis, 2007). Feeding and swallowing difficulties impact CGs as it affects social connections, limits shared mealtimes and results in stress and isolation (Namasivayam-MacDonald & Shune, 2018). In the current study, emotional responses such as frustration were reported in instances where CGs did not understand the cause of communication-related symptoms and fear was reported about obtaining information about symptoms to expect in a subsequent stage(s) regarding cognitive functioning. Furthermore, limited information about cognitive support strategies resulted in arguments with the person with AD, as CGs did not have the information or strategies to manage specific difficulties. Information about support strategies could therefore prevent or lessen such consequences and reduce the emotional burden. It was also evident that CGs' perceptions had a negative emotional impact on them. This is supported by research as it has been shown that improved knowledge reduces CG burden (Schindler et al., 2012). The impact that CG perceptions had on their information needs, is therefore concerning as their perceptions resulted in less directly stated information needs. Subsequently, the information CGs have will not improve and their emotional burden will not be reduced. Attempts to increase access to the information and support CGs require to decrease the emotional impact and CG burden is warranted.

Interventions focused on peer support, skills training, and education of CGs showed the most likely potential to improve outcomes of CGs (Donath et al., 2019). This highlights the importance of providing peer support for the emotional impact of SLTS-related difficulties, providing skills training through appropriate guidance in response to support and stimulation needs, and understanding and responding to CGs' information needs as a means of improving education. An important aspect within the scope of the SLT (Bourgeois, 2019) is to educate family members and provide guidance, and therefore improve CG knowledge and ability to provide support strategies the individual with AD, but these one-on-one speech therapy sessions cannot provide peer support.

This demonstrates the value of support groups, as peer support is a crucial aspect of these groups. Attending a support group has been shown to reduce depression in CGs of individuals with dementia, as CGs are able to observe that the emotional impact on them as the CG is also experienced by others (Morrow-Odom & Robbins, 2012). Additionally, the ratio of SLTs to the South African population clearly demonstrates that relying solely on individual service provision from SLTS to the general population is not a feasible option. There are currently 39 SLTs per one million South Africans (Pillay et al., 2020). This significantly impacts on the availability of SLTs to serve the population of CGs of individuals with AD. It is also concerning that the AD population is expected to grow exponentially in the coming years (Cheng, 2017). Considering the large number of South Africans at increased risk of developing AD, the number of South Africans requiring SLTS will also grow exponentially, placing additional strain on an already resource constrained system. Therefore, on-going support through information provision and guidance on stimulation strategies can be provided at the support group level, while specialized input by a SLT can be provided individually when needed. This would reduce the strain on, and the need for, one-on-one SLTS. It is, therefore, evident that support groups are a more optimal way of serving the needs of CGs of individuals with AD in the South African context.

Due to the crucial role of support groups and the importance of optimizing accessibility, support groups should be structured in a manner which is aligned with CG preferences. Currently, support groups are held across a large geographical area in the Western Cape. This is important as CGs in the current study reported proximity as the primary factor influencing their location preference. Consequently, the likelihood of locating a support group close to the CGs is increased. This could positively affect attendance and, therefore, increase the number of CGs who can access SLTS-related information through support groups. The CGs in the current study also noted that support groups held at a hospital would be a preferred location as it would afford them access to doctors for information. This highlighted that the CGs have a need for information from other relevant healthcare professionals. This finding is supported in the literature as information about the use of services and the availability of help from healthcare professionals were identified as the most frequently reported information needs within the theme of healthcare service-related information needs (Soong et al., 2020).

The time of the day at which the support group is held, was another aspect that may influence attendance in the current study. It is concerning that most support groups in the Western Cape were held during the daytime, either in the morning or afternoon. Factors that motivated the preferences of CGs in the current study were home circumstances as well as personal factors. These factors may negatively influence attendance as some CGs reported only being able to attend the group after working hours. Evening groups also allow other family or community members to tend to the individual with AD as it is after hours, which in turn allows the primary CG to attend the support group (LaMore, 2011). Although employment was not a determining factor for the CGs in the current study, Morow-Odom and Robbins (2012) suggested that the employment status of attendees is a determining factor regarding the time of day most suitable for attendees. It is noteworthy that most SGFs indicated that the support group they facilitate consists of both individuals who are employed, as well as those who are unemployed or retired. Since most support groups are held during the day, accessibility for CGs who are employed would be hindered. A few support groups are held over the weekend, which may accommodate CGs who cannot attend daytime groups during the week due to work obligations. Considering all the factors which could influence the preference for the time of day the support group is held in the current study, accessibility may be promoted by providing sessions at various times of the day, including the evening.

Morrow-Odom and Robbins (2012) report that support groups do not typically last more than an hour and a half. CGs in the current study preferred sessions to be an hour to two hours. There was agreement among CG preferences in the current study and support groups included as most support group sessions currently last an hour to two hours.

Another important consideration is how frequently the support group sessions are held. The CGs in the current study's preference varied from twice a week to monthly groups. Notably, none of the support groups in the Western Cape offer sessions more frequently than once a month. One SGF reported that their sessions were held less than once a month. Due to the limited frequency of current support groups, CGs who miss the group will be required to wait a month for the next group, which could result in infrequent attendance. This will in turn affect their access to information and skills training as well as their perceived level of peer support. As knowledge and support affect burden levels (Diel et al., 2010), it is concerning that CGs may not be able to obtain at least monthly support. This could be resolved by hosting more frequent sessions as this increases the likelihood of the CG being able to attend one of the sessions. The literature does, however, recommend that support groups should be held at least twice a month for familial live-in CGs. This also improves the chance of CGs being able to attend a minimum of one session a month (Steffen & Magnum, 2012).

Another factor to consider is the number of attendees of the support group. CGs in the current study preferred a group of 10-15 attendees. The proposed size of support groups are approximately 10 members as reported by Morrow-Odom and Robbins (2012), while LaMore (2011) reports that six to 12 members is ideal. It is, therefore, concerning that close to half of support groups included in the current study had more than 15 attendees per session. Large groups may negatively impact on the time available to answer questions, and for CGs to share experiences and receive emotional support.

When hosting a support group for CGs, the presence or absence of the individual with AD should also be considered. Currently, the individuals with AD are not present at most support groups offered in the Western Cape. The CGs in the current study, who preferred that the individual with AD not attend the group stated that discussions may upset them and the inability of the individual with AD to remain seated for an extended amount of time. In contrast, it was also reported that it would be beneficial for the individual with AD to be present for other attendees to observe their difficulties and to allow discussion of ways of managing these difficulties. This discrepancy demonstrates that it may be beneficial to have a session in which the individual with AD can attend the group, although the focus will still be on the CG. The impact of their presence on the group should, however, be carefully evaluated by the SGF.

In the current study, the majority of SGFs deemed the presence of a SLT at the support group as valuable. Although the responsibility of providing information at the support group mainly falls on the SGF, the SLT can still fulfil an important role. This could include training SGFs regarding SLTS-related topics or addressing the SLTS-related information and support needs of the group on a consultative basis. This, once again, highlights the importance of understanding the information and support needs of the attendees. The needs of SGFs in terms of possible support from a SLT should also be identified. The SGFs in the current study indicated that they are not frequently asked about the role of the SLT in the management of AD. This may indicate limited awareness of the SLT role in the AD population on the part of support group attendees. CGs would benefit from information in the support group about the role of the SLT as well as a list of available SLTS in the surrounding areas. This would enable them to seek assistance, when required, if their concerns cannot be dealt with by the SGF. As a limited number of SGFs reported having been asked about the role of the SLT, the responsibility falls on the SGF to empower CGs with this information, as research has shown that CGs often obtain information through passive attention behaviour, in which information is obtained from the environment (Soong et al., 2020). This reiterates the importance of including information about the SLT role in AD management in the support group as CGs may not actively seek this information but may benefit from obtaining this information through passive attention behaviour. It is noteworthy that less than half of SGFs participating in this study reported having referred attendees to a SLT. Although the need for direct SLT input is reduced by the discussion of many SLTS-related aspects in the support group, certain SLTS-related difficulties cannot be managed in a support group, as is the case with feeding and swallowing. SGFs can provide information about symptoms of feeding and swallowing difficulties to aid attendees in identifying these difficulties. Feeding and swallowing difficulties experienced by the individual with AD should, however, be managed by a SLT, as an assessment and diagnosis, identification of aspiration, and a management plan is typically required (Egan et al., 2020).

4.1. Clinical implications

The results of the current study had implications for clinical practice regarding content and structure of support groups. The research on CGs' information and support needs may be used to inform the SLTS-related information provided at support groups. It is crucial for SGFs to have adequate information about how the current level of functioning and stage of progression of the individual with AD may impact CGs' information and support needs, to provide input in the areas of specific concern at the various stages. SGFs should also be aware of areas of difficulty in which CGs' perceptions may influence their directly stated information and support needs, i.e., communication and feeding and swallowing, as the provision of information about these difficulties is especially important. Additionally, SGFs should be encouraged to focus on the emotional impact of AD-related difficulties as this study highlighted a range of directly and indirectly stated information and support needs. SGFs should be aware that information about specific topics may evoke an emotional response and concerns from CGs, which may limit their directly stated information and support needs.

SGFs should also be aware of general recommendations regarding SLTS-related difficulties which can be provided within a support group setting and support strategies which should be determined by the SLT. The SGF can provide guidance on stimulation strategies, however, the SLT could fulfil a consultative role to recommend support strategies to CGs based on the current level of functioning and stage of progression of the individual with AD. As CGs may have already attempted support strategies to address observed difficulties, as was evident from the interviews with CGs in the current study, SGFs should acknowledge these strategies as well as the effectiveness thereof and additional strategies may be demonstrated through practical activities.

Findings from the current study revealed that many SGFs received limited training in preparation for the SGF role, which demonstrates the importance of the involvement of the SLT in support groups and in on-going SGF training. This may include in-service training, as well as scheduled visits from a SLT to the support group, to ensure that SLTS-related questions are adequately answered and for guidance on support strategies to be provided. It is recommended that a SGF have a SLT who they can contact to answer any questions they may have difficulty answering or for explaining SLTS-related concerns. In the current study, a limited number of SGFs have referred attendees to a SLT. Therefore, referral pathways can be agreed upon and established between the SGF and their nearest SLT.

Clinical implications were also identified in terms of support group structure to promote attendance and accessibility. It was evident that the current level of functioning and stage of progression of the individual with AD and, therefore, the severity of symptoms influenced CGs' information and support needs in the current study. Edelman et al. (2006) also found that 90% of CGs sought information about the stages and symptoms of AD. Therefore, grouping CGs according to the stage of progression of the individual with AD might allow SGFs to provide information which is specific and relevant to attendees. Additionally, CGs may benefit from sessions held more frequently than once monthly and with two sessions held at different times of the day. This increases the opportunity for, and likelihood of, CGs being able to attend at least one of the sessions, which may result in more regular attendance. As there was a discrepancy between CGs' preferences regarding the presence or absence of the individual with AD during the support group session, CGs may be encouraged to bring a video of the concerning behaviour. In this way, the SGF and attendees can observe the difficulty experienced by the individual with AD and respond appropriately, without the need for the individual with AD to attend the session. It is, therefore, evident that this study can be used to inform certain aspects of the content and structure of support groups.

4.2. Limitations and future research

Although the current study yielded valuable results about the information and support needs and preferred support group structure of CGs of individuals with AD, there were limitations to the study. One limitation was the small sample size of the qualitative phase, which meant that data saturation could not be reached. A larger sample size would have provided greater insight into the information and support needs of CGs, as well as their preferred support group structure. Furthermore, as a limited number of CGs participated in this study, purposive sampling could not be done. This limited the ability to explore the influence of CG characteristics, e.g. relationship to the individual with AD, on information and support needs. A larger sample size could have been achieved through an increased number of recruitment sites. The researcher and the head of the psychogeriatric department at the government health facility discussed the reasons why the recruitment of CGs for the current study proved to be problematic. The head of the psychogeriatric department reported that individuals with AD are often managed by primary care workers, such as GPs, during the early stages (Prof. Niehaus, personal communication, May 31, 2021). It is therefore recommended that future researchers approach primary care workers in order to recruit more participants. The decision to use only the one recruitment site was because it was the only geriatric psychiatric unit recognized by the HPCSA (Zikale, 2018), and that the site serves one third of the Western Cape (Ras et al., 2011). The other government health facilities contacted also reported a limited AD caseload. This site was consequently deemed to be the most appropriate site from which to obtain the largest number of CGs.

There were also limitations with the use of the online survey. One limitation was that SGFs subjectively evaluated their ability to answer SLTS-related questions. Obtaining detail about the specific information they provide to the various SLTS-related questions would allow the researcher to analyse the accuracy of their responses. A recommendation for future research is that a semi-structured interview with SGFs be utilized to obtain this information. Alternatively, observation of support group sessions may also be considered as the researcher could evaluate the accuracy of SGFs' responses to SLTS-related questions within the real-life context. Researchers may also provide SGFs with scenarios and possible SLTS-related questions and analyse their responses to determine accuracy. This will allow the researcher to obtain in-depth information and will allow for deeper analysis of the accuracy of information they provide. In turn, this will provide insight into their ability to answer SLTS-related questions and would also allow identification of education needs for SGFs. Furthermore, the questions included in the survey were purely literature-based and were not informed by the interviews. The level of detail obtained from the interviews would have proved valuable when formulating the questions in the online survey. Thus, by first conducting the interviews and then developing the survey, more specific detail about information and support provided at support groups could have been obtained from SGFs.

The current study also shed light on additional research needed. Future research could investigate the information sources that CGs have access to and how these sources influence CGs' perceptions about SLTS-related difficulties and treatment. This may also provide researchers with insight into additional ways of providing CGs with SLTS-related information. This study demonstrated that the emotional impact of AD-related difficulties on the CG may influence information seeking behaviour. CGs' perceived acceptance of difficulties, which may be an indication of hopelessness, also warrants investigation into CGs' information seeking behaviour as they accept certain difficulties, yet actively seek information and support for other areas of difficulty.

In addition, future research could focus on the specific aspects of SGF training courses, the scope of the training course or programme, as well as the SLTS-related information provided during training. Future research could also investigate SGF knowledge about the role of the SLT in AD management, as well as current referral pathways. This is deemed necessary as less than half of SGFs participating in this study had referred attendees to SLTs, even though the individuals with AD may benefit from such a referral. The limited number of SGFs who had referred attendees to a SLT also indicates a need for an investigation into the perceptions and attitudes of SGFs of the role of the SLT and SLT input in this population. It is recommended that this be done using an online survey to avoid social desirability effects.

CONCLUSION

The current study investigated the communication, cognitive functioning, and feeding and swallowing information and support needs of CGs as well as the support group structure that CGs preferred, considering current AD support group practices in the Western Cape. The focus on investigating information needs stem from the far-reaching effects of AD on communication, cognitive functioning and feeding and swallowing and the impact of these difficulties on the CG. AD has physical, social, financial, and psychological effects on the CG which result in significant CG burden. Burden may, however, be reduced through the provision of educational interventions as well as support (Granbo et al., 2019). Interventions focused on peer support, skills training and education have the most likely potential to improve CG outcomes (Donath et al., 2019). Support groups have been identified as a possible solution to providing SLTS-related information, guidance on cognitive and communication stimulation strategies, as well as emotional support. Although peer support has been identified as a crucial aspect of intervention, this cannot be provided through one-on-one speech therapy sessions. This highlights the importance of utilizing support groups in this population. Additionally, the unfavourable ratio of SLTs to the South African population also highlighted the importance of support groups as an alternative, and possibly effective means of providing peer support, skills training, and education. However, to reduce the need for one-on-one speech therapy intervention, and reduce the strain on the limited number of SLTs in SA, the quality and accuracy of information provided on SLTS-related questions during support groups should be adequate. Despite the effect of AD on the communication, cognitive functioning and feeding and swallowing ability of the individual with AD, previous studies regarding SLTS-related information needs of CGs of individuals with AD are limited.

The current study identified that the factors which influenced CGs' information and support needs were the current level of functioning of the individual with AD, CGs' perceptions about the features of AD and their management, as well as acceptance of difficulties. An important finding was that information and support needs are not always directly stated by CGs, but rather, may often be indirectly stated. As a result, SGFs could be unaware of several information and support needs of CGs. In addition, the limited research about the information needs of CGs of individuals with AD, pertaining to SLTS-related difficulties, also likely limit SGFs' awareness of a number of these information and support needs. This highlights the importance of providing CGs with information about SLTS-related aspects about which there may be many indirectly stated information and support needs due to CG perceptions. The finding of the current study that information needs are often indirectly stated, as well as the limited available research on the topic indicate that SGFs likely utilize PBE rather than EBP to guide the content and discussions at their groups. However, the current study emphasized the importance of utilizing both EBP as well as PBE to guide the discussion about SLTS-related aspects in support groups. Consequently, CGs may not receive the information they require to fully understand and appropriately address SLTS-related difficulties. Although SGFs reported that they were able to answer most SLTS-related questions received in the support group, the accuracy of their responses was not determined. They also expressed that the involvement of a SLT at the group would be valuable. The need for in-service training provided by a SLT as well as scheduled visits from a SLT to support groups to answer SLTS-related questions is supported by SGFs' perceived value of a SLT at the support group, SGFs' reliance on PBE, as well as the role of the SLT in determining appropriate support strategies.

Discrepancies between CGs' support group structure preferences and the current structure of support groups in the Western Cape were identified. By increasing the alignment between CG preferences and the current support group structure, accessibility and attendance may be promoted. Specific attention needs to be given to the time of day, frequency of the support group, and group size to afford a support group structure which promotes accessibility to provide a space in which CGs can gain the information and support they require to reduce CG burden.

A significant finding of the study was that CGs directly stated more information and support needs about cognitive functioning difficulties, however, the survey indicated that support group attendees also frequently ask for information about communication difficulties. This may indicate that communication-related information needs increase as the disease progresses, which demonstrates the influence of current level of functioning and stage of progression of AD on CG needs. Another important finding is that CGs' perceptions and acceptance of SLTS-related difficulties plays a crucial role in directly stated information and support needs, especially regarding communication and feeding and swallowing.

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APPENDIX A: INTERVIEW GUIDE

Introductory question

I would like to begin by asking you to tell me more about yourself

Focus areas
Age

Information pertaining to the individual with AD

Tell me about the person that you care for

Focus areas
Relationship Age of the patient Date of diagnosis

Support group structure

How would you describe an ideal support group structure?

Focus areas
Time Place Duration of sessions Frequency of the support group Number of members Patient present or absent

Feeding information

Tell me about any questions you have about the patient's swallowing ability

Focus areas
Forgetting to eat Forgetting to swallow Signs of dysphagia (choking, coughing, eyes watering, changes in colour, weight loss)

Speech and language information

Tell me what information you require about the patient's communication

Focus areas
Word finding problems Problems with comprehension Echolalia Empty speech Dysfluency Use of incorrect words Pragmatic fallouts Changes in speech (slurring, decreased intensity)

Cognitive function information

Can you tell me what information you require regarding problems with the patient's completion of daily activities?

Focus areas
Planning Decision-making Initiation of behaviour

Memory Information

Tell me about questions you have about the patient's memory

Focus areas
Long-term memory e.g. recognition of faces, family names Working memory

APPENDIX B: SUPPORT GROUP FACILITATOR SCREENING FORM

Name & Surname:

1. I am 18 years or older? _________

2. I am the facilitator of a support group for caregivers of individuals with Dementia or Alzheimer's Disease? _________

3. I have facilitated at least five sessions for the group? ________

4. I am proficient in English, Afrikaans or isiXhosa? ________

APPENDIX C: SUPPORT GROUP FACILITATOR SURVEY

Facilitator Survey

Due to a lack of resources in South Africa, it is possible that caregivers of individuals with Alzheimer's Disease may not have easy access to the speech-therapy related information they require to adequately care for the patient. One of the aims of this study is to compare the current support group structure used, as well as the information provision at support groups, to the caregivers' perspective of an ideal support group structure and the information needs which caregivers in this study express.

* Required

Your email

1. Are you a facilitator for a support group for caregivers of individuals with Alzheimer's Disease or Dementia? *

○ Yes
○ No

Support group structure

2. My age is: *

○ 20-30 years
○ 30-40 years
○ 40-50 years
○ 50-60 years
○ Over the age of 60 years

3. My highest level of formal schooling is: *

○ Primary school not completed
○ Primary school
○ High school not completed
○ High school
○ College
○ University

4. My sex is: *

○ Male
○ Female
○ Other

5. Which ethnic group do you identify with? *

○ Black
○ Coloured
○ Indian
○ White
○ No information

6. What training have you received to prepare you for the role of the facilitator of this support group? *

○ A short course through the institution I work for
○ Previous employment in the medical field
○ No formal training
○ Other

7. The support group I facilitate typically consists of the following number of members per session: *

○ 0-5 members
○ 6-10 members
○ 11-15 members
○ 16-20 members
○ 21-25 members
○ 26-30 members
○ More than 30 members

8. Where is the support group held? *

○ At the facility I work for
○ At a hospital
○ In a religious building
○ At an academic facility e.g. university
○ Other

9. The support group is held: *

○ During the week
○ Over the weekend
○ Both options are available

10. The support group is run the following number of times per month: *

- ○ Less than once a month
- ○ Once a month
- ○ Twice a month
- ○ Three to four times per month
- ○ Five to eight times per month
- ○ More than eight times per month

11. The support group is held in: *

- ○ The morning (between 08:00 and 12:00)
- ○ The afternoon (between 12:00 and 17:00)
- ○ The evening (after 17:00)

12. The duration of each session is: *

- ○ Less than 30 minutes
- ○ 30 minutes to an hour
- ○ An hour to two hours
- ○ More than two hours

13. At the support group, the individual diagnosed with major neurocognitive disorder (Alzheimer's Disease) is: *

- ○ Present
- ○ Not present
- ○ Sometimes present

14. The support group is focused on: *

- ○ Emotional support
- ○ Information provision
- ○ Emotional support as well as information provision

15. The majority of attendees are: *

- ○ Employed
- ○ Unemployed or retired
- ○ The support group consists of attendees both employed and unemployed or retired

Information dissemination

16. In the support group, have you been asked about patients experiencing difficulties with finding words? *

○ Yes
○ No

17. In your opinion, were you able to answer this question adequately? *

○ Yes
○ No
○ Not applicable

18. In the support group, have you been asked about patients experiencing difficulty with understanding what others are saying? *

○ Yes
○ No

19. In your opinion, were you able to answer this question adequately? *

○ Yes
○ No
○ Not applicable

20. In the support group, have you been asked how one can help a patient who has difficulty understanding what other are saying? *

○ Yes
○ No

21. In your opinion, were you able to answer this question adequately? *

○ Yes
○ No
○ Not applicable

22. In the support group, have you been asked why patients may exhibit inappropriate behaviours in conversation, such as changing between topics frequently, not staying on topic or screaming? *

○ Yes
○ No

23. In your opinion, were you able to answer this question adequately? *

○ Yes
○ No
○ Not applicable

24. In the support group, have you been asked about patients frequently choking on food, coughing while eating or drinking or eyes watering during meals or whilst having a beverage? *

○ Yes
○ No

25. In your opinion, were you able to answer this question adequately? *

○ Yes
○ No
○ Not applicable

26. In the support group, have you been asked about the various types of memory one has (e.g. long term, short term etc.)? *

○ Yes
○ No

27. In your opinion, were you able to answer this question adequately? *

○ Yes
○ No
○ Not applicable

28. In the support group, have you been asked why patients repeat questions they have already asked? *

○ Yes
○ No

29. In your opinion, were you able to answer this question adequately? *

○ Yes
○ No
○ Not applicable

30. In the support group, have you been asked about ways of stimulating cognition in these patients? *

○ Yes
○ No

31. In your opinion, were you able to answer this question adequately? *

○ Yes
○ No
○ Not applicable

32. In your support group, have you been asked about the role of the speech therapist in the management of the patient? *

○ Yes
○ No

33. In your opinion, were you able to answer this question adequately? *

○ Yes
○ No
○ Not applicable

34. In your opinion, how valuable would a speech therapist be at your support group? *

○ 1 Somewhat valuable
○ 2
○ 3
○ 4
○ 5 Very valuable

35. Have you referred support group members to a speech therapist? *

○ Yes
○ No

APPENDIX D: HEALTH RESEARCH ETHICS COMMITTEE APPROVAL (2019)

UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

Health Research Ethics Committee (HREC)

Approval Notice

New Application

28/01/2019

Project ID :8718

HREC Reference #: S18/10/263

Title: Communication, Cognitive Functioning, and Feeding Information Needs Within a Support Group Setting of Caregivers of Individuals Diagnosed with Alzheimer's Disease

Dear Miss Carla Le Roux,

The **Response to Modifications** received on 22/01/2019 21:35 was reviewed by members of **Health Research Ethics Committee 2 (HREC2)** via **expedited** review procedures on 28/01/2019 and was approved.

Please note the following information about your approved research protocol:

Protocol Approval Period: This project has approval for 12 months from the date of this letter.

Please remember to use your **Project ID [8718]** on any documents or correspondence with the HREC concerning your research protocol.

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

After Ethical Review

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

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

Provincial and City of Cape Town Approval

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

We wish you the best as you conduct your research.

For standard HREC forms and instructions, please visit: Forms and Instructions on our HREC website https://applyethics.sun.ac.za/ProjectView/Index/8718

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

Yours sincerely,

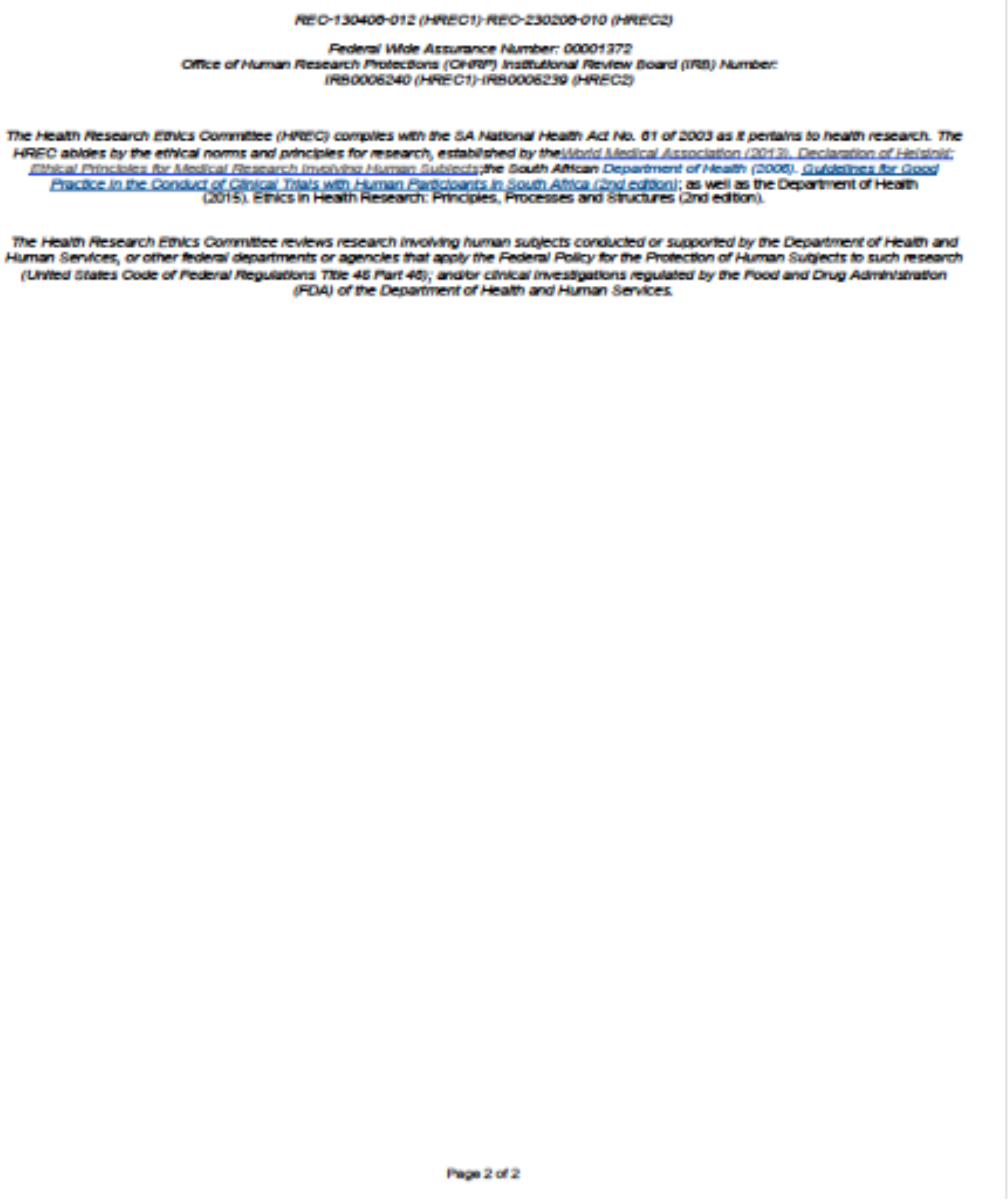
Francis Masiye,

HREC Coordinator,

Health Research Ethics Committee 2 (HREC2).

National Health Research Ethics Council (NHREC) Registration Number:

Page 1 of 2



REC-130408-012 (HREC1)·REC-230208-010 (HREC2)

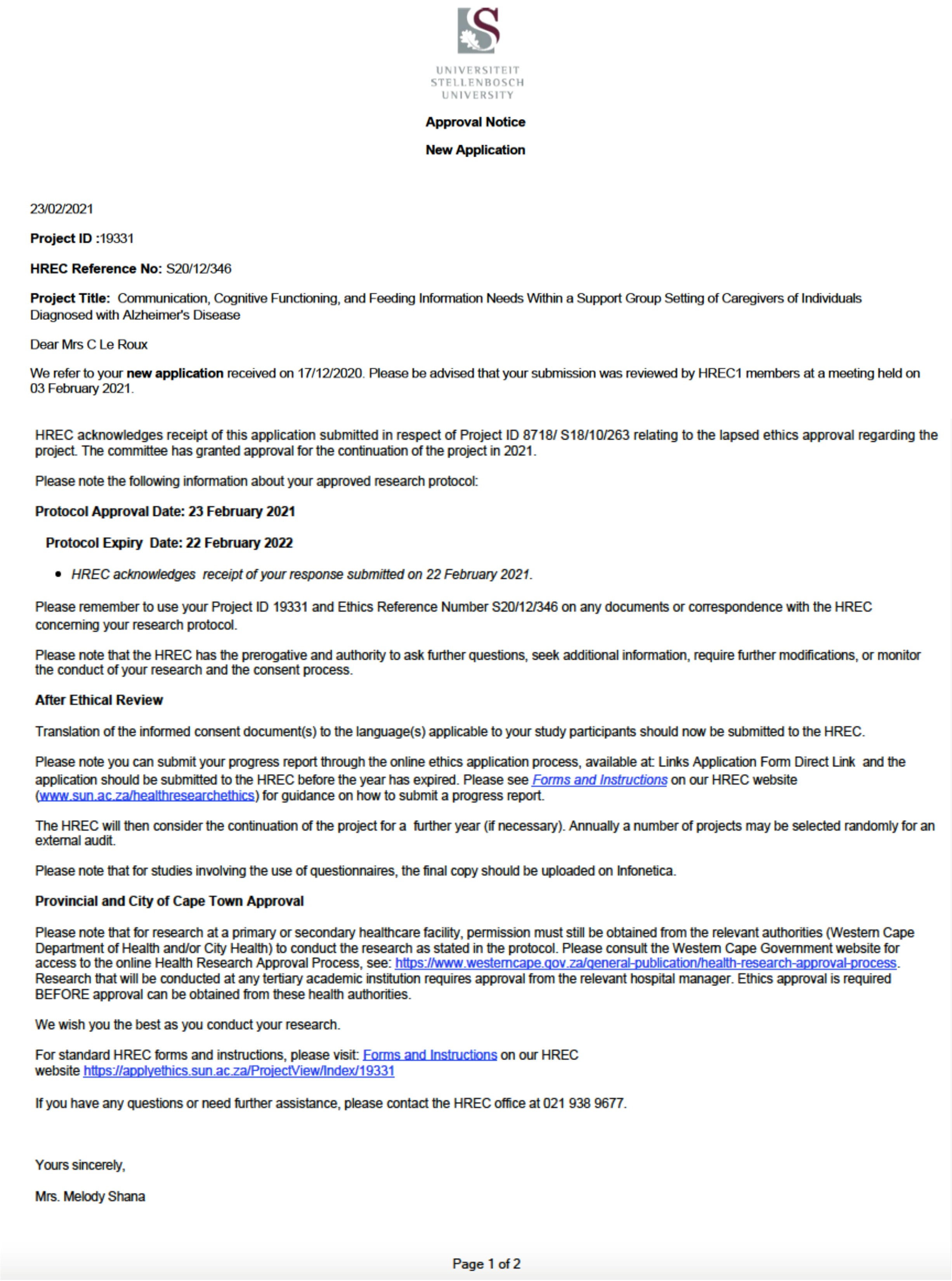
Federal Wide Assurance Number: 00001372
Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0005240 (HREC1)·IRB0005239 (HREC2)

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

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

Page 2 of 2

APPENDIX D: HEALTH RESEARCH ETHICS COMMITTEE APPROVAL (2021)



UNIVERSITEIT
STELLENBOSCH
UNIVERSITY

Approval Notice

New Application

23/02/2021

Project ID :19331

HREC Reference No: S20/12/346

Project Title: Communication, Cognitive Functioning, and Feeding Information Needs Within a Support Group Setting of Caregivers of Individuals Diagnosed with Alzheimer's Disease

Dear Mrs C Le Roux

We refer to your **new application** received on 17/12/2020. Please be advised that your submission was reviewed by HREC1 members at a meeting held on 03 February 2021.

HREC acknowledges receipt of this application submitted in respect of Project ID 8718/ S18/10/263 relating to the lapsed ethics approval regarding the project. The committee has granted approval for the continuation of the project in 2021.

Please note the following information about your approved research protocol:

Protocol Approval Date: 23 February 2021

Protocol Expiry Date: 22 February 2022

- *HREC acknowledges receipt of your response submitted on 22 February 2021.*

Please remember to use your Project ID 19331 and Ethics Reference Number S20/12/346 on any documents or correspondence with the HREC concerning your research protocol.

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

After Ethical Review

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

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

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

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

Provincial and City of Cape Town Approval

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

We wish you the best as you conduct your research.

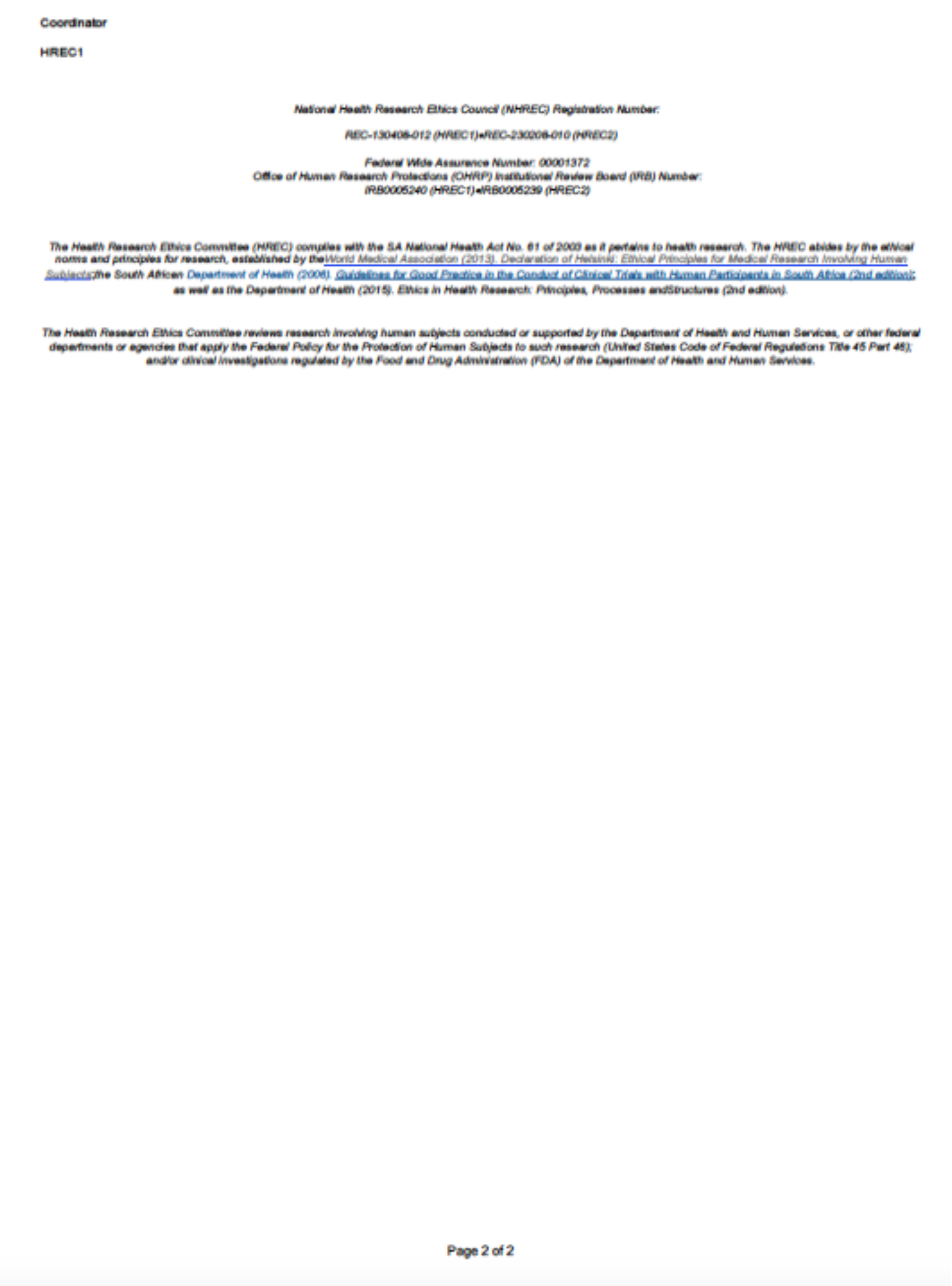
For standard HREC forms and instructions, please visit: Forms and Instructions on our HREC website https://applyethics.sun.ac.za/ProjectView/Index/19331

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

Yours sincerely,

Mrs. Melody Shana

Page 1 of 2



Coordinator

HREC1

National Health Research Ethics Council (NHREC) Registration Number:

REC-130408-012 (HREC1)•REC-230208-010 (HREC2)

Federal Wide Assurance Number: 00001372
Office of Human Research Protections (OHRP) Institutional Review Board (IRB) Number:
IRB0005240 (HREC1)•IRB0005239 (HREC2)

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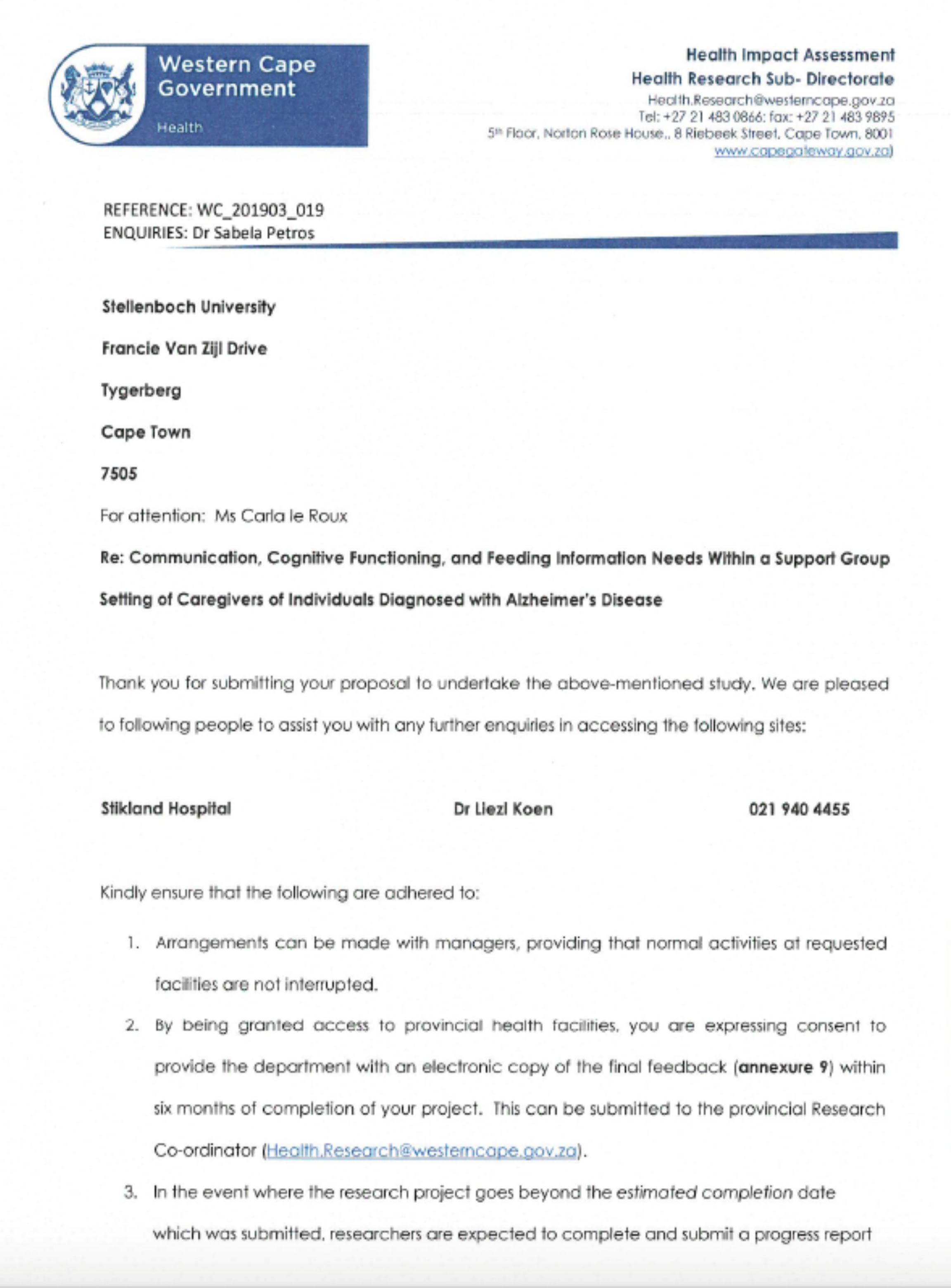
Page 2 of 2

APPENDIX E: WESTERN CAPE DEPARTMENT OF HEALTH APPROVAL (2019)



Western Cape Government
Health

Health Impact Assessment
Health Research Sub- Directorate
Health.Research@westerncape.gov.za
Tel: +27 21 483 0866: fax: +27 21 483 9895
5th Floor, Norton Rose House,, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za)

REFERENCE: WC_201903_019
ENQUIRIES: Dr Sabela Petros

Stellenbosch University

Francie Van Zijl Drive

Tygerberg

Cape Town

7505

For attention: Ms Carla le Roux

Re: Communication, Cognitive Functioning, and Feeding Information Needs Within a Support Group Setting of Caregivers of Individuals Diagnosed with Alzheimer's Disease

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to following people to assist you with any further enquiries in accessing the following sites:

Stikland Hospital	**Dr Liezl Koen**	**021 940 4455**

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. By being granted access to provincial health facilities, you are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of your project. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
3. In the event where the research project goes beyond the *estimated completion* date which was submitted, researchers are expected to complete and submit a progress report

(**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

4. The reference number above should be quoted in all future correspondence.

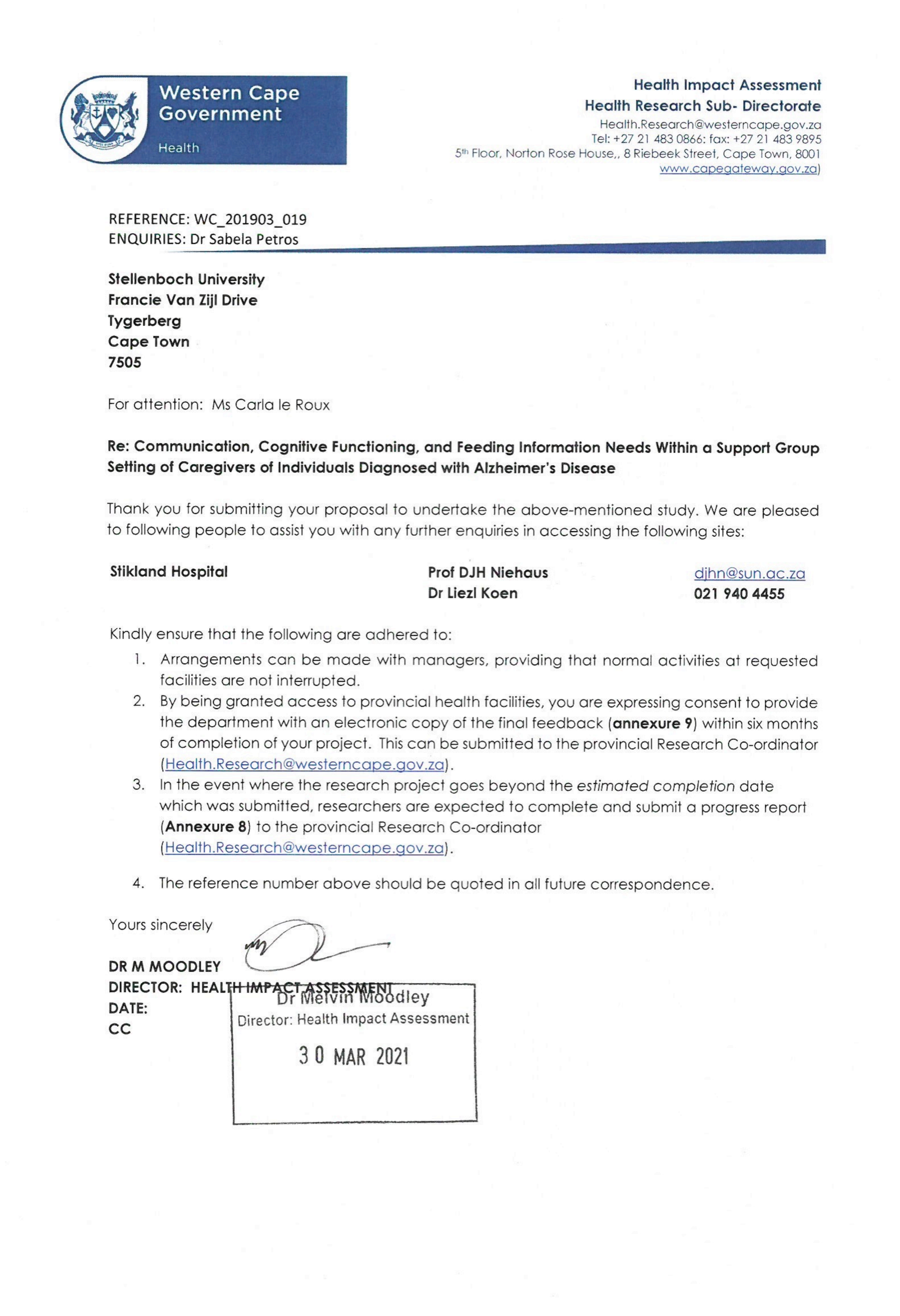
Yours sincerely

DR M MOODLEY

DIRECTOR: HEALTH IMPACT ASSESSMENT

DATE: 03-06-2019

APPENDIX F: WESTERN CAPE DEPARTMENT OF HEALTH APPROVAL (2021)



Western Cape Government
Health

Health Impact Assessment
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5th Floor, Norton Rose House,, 8 Riebeek Street, Cape Town, 8001
www.capegateway.gov.za)

REFERENCE: WC_201903_019
ENQUIRIES: Dr Sabela Petros

Stellenboch University
Francie Van Zijl Drive
Tygerberg
Cape Town
7505

For attention: Ms Carla le Roux

Re: Communication, Cognitive Functioning, and Feeding Information Needs Within a Support Group Setting of Caregivers of Individuals Diagnosed with Alzheimer's Disease

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to following people to assist you with any further enquiries in accessing the following sites:

Stikland Hospital	**Prof DJH Niehaus** **Dr Liezl Koen**	djhn@sun.ac.za **021 940 4455**

Kindly ensure that the following are adhered to:

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

Yours sincerely

DR M MOODLEY
DIRECTOR: HEALTH IMPACT ASSESSMENT
DATE:
CC

Dr Melvin Moodley
Director: Health Impact Assessment
30 MAR 2021

APPENDIX G: INFORMED CONSENT FORM – CEO OF THE HEALTH CARE FACILITY

TITLE OF THE RESEARCH PROJECT: Communication, Cognitive Functioning and Feeding Information Needs Within a Support Group Setting of Caregivers of Individuals Diagnosed with Alzheimer's Disease

PROJECT I.D: 8718

PRINCIPAL INVESTIGATOR: Carla le Roux

ADDRESS: Speech-, Language- and Hearing Therapy Department, Tygerberg Medical Campus, Francie Van Zyl Drive, Parow, 7500.

What is this research study all about?

A lack of resources in South Africa, may cause caregivers of individuals with Alzheimer's Disease to not have access to the information they require to fully understand the disease. The aim of the study is to obtain insight into the information needs relating to communication, cognitive functioning and feeding that caregivers of individuals diagnosed with Alzheimer's Disease wish to receive at a support group. A further aim of this study is to obtain information on the support group structure that caregivers prefer. Participants will be included until no new data is emerging.

Inclusion and exclusion criteria

A primary caregiver for the purpose of the current study will be considered an individual who spends 7+ hours per day with the individual with AD. In a study conducted in 2011, it was reported that primary family caregivers of individuals with MND spent an average of 9+ hours per day providing care to the individual (Fisher et al., 2011). The time frame of 7+ hours per day will account for individual differences in caregiving time.

Caregivers 18 years or older will be included into the study in order to obtain informed consent.

Caregivers who have previously cared for an individual with AD will be excluded from the research as they may have gained information and experience during this caregiving experience which may influence the information they require.

Caregivers who are allied health workers, nurses and medical doctors will be excluded from the study due to background knowledge of the illness which may influence their information needs.

Caregivers who are currently seeing or who have seen a speech therapist or other allied healthcare professional or are already attending a support group regarding the individual with AD will be excluded from the study as they may already have received information, which may have affected their information needs and may affect the results of the study.

Individuals not proficient in English, Afrikaans or isiXhosa will be excluded from the study. English, Afrikaans and isiXhosa are the three official provincial languages of the Western Cape.

Study procedure

The head psychiatrist at your facility will be informed of the research telephonically. Thereafter, a meeting will be arranged to discuss the research with all the psychiatrists at your facility. The psychiatrist at your facility will initially be required to identify possible participants for this study. The psychiatrists will be required to obtain informed consent from possible participants to provide the researcher with their details for interview scheduling purposes. The caregiver will be required to sign an informed consent form for the dissemination of this information. The psychiatrist will further be required to determine whether the patient of possible participants is able to provide informed consent at their current stage of progression. Possible participants will be contacted telephonically by the researcher. For individuals who qualify to take part in the research based on the inclusion and exclusion criteria, a convenient time and location for conducting the interview will be discussed. The researcher and participant will meet to conduct the interview. Interviews will be conducted in the language which the caregiver is most comfortable. An audio recording will be made of the interview for transcription purposes. All information will be kept anonymous. The audio-recordings will be kept in a locked drawer to which only the researcher has access and transcriptions of the interview will be kept on a password protected computer. After the interview has been transcribed, the audio-recording will be deleted. The interview will take approximately 45 minutes.

A copy of the research synopsis will be made available for further information.

Will the caregivers benefit from taking part in this research?

They will not benefit directly from participation in this study. However, they may indirectly benefit from being provided with contact to speech therapists and support groups, which may improve their understanding of the patient's condition. Future caregivers of individuals with Alzheimer's Disease may also benefit from their participation through improving support group information provision and support group structure to fit the needs of the caregivers.

Are there risks involved in taking part in this research?

There are no physical risks associated with taking part in this research study. There is minimal risk of emotional turmoil which may arise from the interview, however, the participant will be referred to psychiatric and psychological services after the interview as the interviews may elicit emotional responses, which should be dealt with by these professionals.

If they do not agree to take part, what alternatives do they have?

Participation is completely voluntary. If they do not agree to take part in the study, they may withdraw from the study.

Who will have access to the patient's medical records?

No one will have access to the patient's medical records.

Should you have further questions, please contact Carla le Roux at 021 938 9494.

I, ______________________________ approve this study to be conducted at the health facility.

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Signature of CEO **Date**

APPENDIX H: INFORMED CONSENT FORM – INFORMATION DISSEMINATION

TITLE OF THE RESEARCH PROJECT: Communication, Cognitive Functioning and Feeding Information Needs Within a Support Group Setting of Caregivers of Individuals Diagnosed with Alzheimer's Disease

PROJECT I.D: 8718

PRINCIPAL INVESTIGATOR: Carla le Roux

ADDRESS: Speech-, Language- and Hearing Therapy Department, Tygerberg Medical Campus, Francie Van Zyl Drive, Parow, 7500.

CONTACT NUMBER: 021 938 9494

What is this research study about?

Due to a lack of resources in South Africa, it is possible that caregivers of individuals with Alzheimer's Disease may not have access to the information they require to fully understand the disease. The aim of the study is to get insight into the information needs relating to communication, cognitive functioning and feeding that caregivers of individuals diagnosed with Alzheimer's Disease want to receive at a support group. A further aim of the study is to get information on the support group structure that caregivers want.

Declaration by participant

I *(name)* …………………………………..…………. provide permission to the psychiatrist *(name)* …………………………………..…………. to provide my contact details, the patient's stage of progression and biographical information to the principal investigator of this study for the purpose of possible inclusion into this study and for interview scheduling purposes.

Signed at (*place*) ....…........……………….. on (*date*) …………....……….. 2019.

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Signature of participant **Signature of witness**

Declaration by psychiatrist

I *(name)* ……………………………………………..……… declare that:

- I explained the information in this document to *(name of participant)* …………………………………..
- I encouraged him/her to ask questions and took adequate time to answer them.
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below).*

Signed at (*place*) ....……......…………….. on (*date*) …………....……….. 2019.

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Signature of psychiatrist **Signature of witness**

Declaration by interpreter

I *(name)* ……………………………………………..……… declare that:

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

Signed at (*place*) ....……......…………….. on (*date*) …………....………………..2019.

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Signature of interpreter **Signature of witness**

APPENDIX I: INFORMED CONSENT FORM – CAREGIVER

TITLE OF THE RESEARCH PROJECT: Communication, Cognitive Functioning and Feeding Information Needs Within a Support Group Setting of Caregivers of Individuals Diagnosed with Alzheimer's Disease

REFERENCE NUMBER: 8718

PRINCIPAL INVESTIGATOR: Carla le Roux

ADDRESS: Speech-, Language- and Hearing Therapy Department, Tygerberg Medical Campus, Francie Van Zyl Drive, Parow, 7500.

CONTACT NUMBER: 021 938 9494

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

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University (HREC)** and will be conducted according to the ethical guidelines and principles of the International Declaration of Helsinki, and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study about?

Due to a lack of resources in South Africa, it is possible that caregivers of individuals with Alzheimer's Disease may not have access to the information they require to fully understand the disease. The aim of the study is to get insight into the information needs relating to communication, cognitive functioning and feeding that caregivers of individuals diagnosed with Alzheimer's Disease experience and want to receive at a support group. A further aim of the study is to get information on the support group structure that caregivers prefer. This study will be done at a public health facility in the Western Cape. Participants will be included until no new data is emerging.

Before the start of the interview, you will be asked which languages you are proficient in. Should you not be proficient in English or Afrikaans, the researcher will get written consent from you to include a translator into the interview. The researcher will ask open-ended questions. Each interview will be audio-recorded for transcription purposes. All information you provide will be kept anonymous. The audio-recordings will be kept in a locked drawer to which only the researcher has access. Transcripts of the interview will be kept on a password-protected computer. After the interview has been transcribed, the audio-recording will be deleted. The interview will take approximately 45 minutes.

Why have you been invited to participate?

You have been invited to participate in this study as you are a caregiver to an individual diagnosed with Alzheimer's Disease, you are 18 years or older, proficient in English, Afrikaans or isiXhosa, you spend at least seven hours per day with the patient, you are not trained in the medical field and the patient you care for has not seen a speech therapist or other allied health care professional about Alzheimer's Disease. Furthermore, you have been invited to participate as you have not attended a support group before and you are not currently attending one. You have been invited to provide your insight on the communication, cognitive functioning and feeding information you, as a caregiver to an individual diagnosed with Alzheimer's Disease, wish to receive in a support group, as well as how you would prefer the support group to be structured.

What will your responsibilities be?

You will be requested to take part in an individual interview with the researcher. You are responsible for providing honest opinions during the interview and providing your informed consent.

Will you benefit from taking part in this research?

You will not benefit directly from your participation in this study. However, you may indirectly benefit from being provided with contact to speech therapists and psychological- and psychiatric services, which may improve your understanding of the patient's condition. Future caregivers of individuals with Alzheimer's Disease may also benefit from your participation through improved support group information provision and the use of support group structures that fit the needs of caregivers.

Are there any risks involved in your taking part in this research?

There are no risks involved in your participation in this research, although some emotional responses may arise upon reflection on your caregiver experience. You will be provided with the contact information of psychological- and psychiatric services after the interview.

If you do not agree to take part, what alternatives do you have?

Participation is voluntary. You may not agree to take part in the study or you can withdraw at any time, should you so wish.

Who will have access to the patient's medical records?

No one will have access to the patient's medical records.

What will happen in the unlikely event of some form of injury occurring as a result of your taking part in this research study?

There are no physical risks associated with you taking part in this research study.

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

No, you will not be paid to take part in the study. You will be reimbursed for your travelling costs if the interview is not held on the same day as your appointment with the psychiatrist. Snacks will be provided during the interview.

Is there anything else that you should know or do?

- You can contact Carla le Roux at tel 021 938 9494 if you have any further queries or encounter any problems with the research.
- You can contact the **Health Research Ethics Committee** at 021 938 9207 if you have any concerns or complaints that have not been adequately addressed by your researcher.
- You will receive a copy of this information and consent form for your own records.

Declaration by participant

I *(name)* …………………………………..………… agree to take part in a research study entitled Communication, Cognitive Functioning and Feeding Information Needs Within a Support Group Setting of Caregivers of Individuals Diagnosed with Alzheimer's Disease

I declare that:

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

☐ **I give permission for an audio-recording to be made of my interview, as required for the methods used in the study.**

Signed at (*place*) ....…........…………….. on (*date*) …………...……….. 2019.

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Signature of participant **Signature of witness**

Declaration by investigator

I *(name)* ………………………………………………..……… declare that:

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

Signed at (*place*) ....…......……………….. on (*date*) …………...……….. 2019.

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Signature of investigator **Signature of witness**

Declaration by interpreter

I *(name)* ………………………………………………..……… declare that:

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

Signed at (*place*) ....…......……………….. on (*date*) …………...………………..2019.

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Signature of interpreter **Signature of witness**

APPENDIX J: INFORMED CONSENT FORM – INDIVIDUAL WITH AD

TITLE OF THE RESEARCH PROJECT: Communication, Cognitive Functioning and Feeding Information Needs Within a Support Group Setting of Caregivers of Individuals Diagnosed with Alzheimer's Disease

PROJECT I.D: 8718

PRINCIPAL INVESTIGATOR: Carla le Roux

ADDRESS: Speech-, Language- and Hearing Therapy Department, Tygerberg Medical Campus, Francie Van Zyl Drive, Parow, 7500.

What is this research study about?

Due to a lack of resources in South Africa, it is possible that caregivers of individuals with Alzheimer's Disease may not have access to the information they require to fully understand the disease. The aim of the study is to get insight into the information needs relating to communication, cognitive functioning and feeding that caregivers of individuals diagnosed with Alzheimer's Disease want to receive at a support group. A further aim of the study is to get information on the support group structure that caregivers prefer. This study will be done at a public health facility in the Western Cape. Participants will be included until no new data is emerging.

Before the start of the interview, your caregiver will be asked which languages they are proficient in. Should he/she not be proficient in English or Afrikaans, the researcher will get written consent to include a translator into the interview. The researcher will ask open-ended questions to which your caregiver may respond. Each interview will be audio-recorded for transcription purposes. All information your caregiver provides will be kept anonymous. The audio-recordings will be kept in a locked drawer to which only the researcher has access. Transcripts of the interview will be kept on a password-protected computer. After the interview has been transcribed, the audio-recording will be deleted. The interview will take approximately 45 minutes.

Why has your caregiver been invited to participate?

Your caregiver has been invited to participate in this study as they are a caregiver to an individual diagnosed with Alzheimer's Disease, they are 18 years or older, proficient in English, Afrikaans or isiXhosa, they spend at least seven hours per day with you, are not trained in the medical field, and you have not seen a speech therapist or other allied health care professional about your condition. Furthermore, your caregivers has been invited to take part in the study as they have not attended a support group before and is not currently attending one. Your caregiver has been invited to provide their insight on the communication, cognitive functioning and feeding information he/she, as a caregiver to an individual diagnosed with Alzheimer's Disease, wish to receive in a support group, as well as how they would prefer the support group to be structured.

What will their responsibilities be?

They will be requested to take part in an individual interview with the researcher, where they must provide their honest opinions and provide informed consent.

Will they benefit from taking part in this research?

They will not benefit directly from their participation in this study. However, they may indirectly benefit from being provided with contact to speech therapists and psychological- and psychiatric services, which may improve their understanding of your condition. Future caregivers of individuals with Alzheimer's Disease may also benefit from your caregiver's participation through improved support group information provision and support group structure to fit the needs of the caregivers.

Are there in risks involved in your caregiver taking part in this research?

There are no risks involved in your caregiver's participation in this research, although some emotional responses may arise upon reflection on the caregiver experience, but they will be provided with the contact information of psychological and psychiatric services after the interview.

If they do not agree to take part, what alternatives do they have?

Participation is completely voluntary. They may choose to not take part in the study or they can withdraw at any time.

Who will have access to your medical records?

No one will have access to your medical records.

What will happen in the unlikely event of some form of injury occurring as a result of your caregiver taking part in this research study?

There are no physical risks associated with taking part in this research study.

Will the caregiver be paid to take part in this study and are there any costs involved?

No, they will not be paid to take part in the study. They will be reimbursed for their travelling cost if the interview is not held on the same day as your appointment with the psychiatrist. Snacks will be provided during the interview.

Is there any thing else that you should know or do?

- You can contact Carla le Roux at tel 021 938 9494 if you have any further queries or encounter any problems.
- You can contact the **Health Research Ethics Committee** at 021 938 9207 if you have any concerns or complaints that have not been adequately addressed by your researcher.
- You will receive a copy of this information and consent form for your own records.

Declaration by Patient

I *(name)* …………………………………..………… provide consent for my caregiver to take part in the research study entitled Communication, Cognitive Functioning and Feeding Information Needs Within a Support Group Setting of Caregivers of Individuals Diagnosed with Alzheimer's disease

I declare that:

- I have read, or had read to me, this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to provide consent.

☐ **I give permission for an audio recording to be made of my caregiver's interview, as required for the methods used in the study.**

Signed at (*place*) ....…........…………….. on (*date*) …………....……….. 2019.

Signature of patient

Signature of witness

Declaration by investigator

I *(name)* ……………………………………………..……… declare that:

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

Signed at (*place*) ....…........……………….. on (*date*) …………....……….. 2019.

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Signature of investigator   **Signature of witness**

Declaration by interpreter

I *(name)* ……………………………………………..……… declare that:

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

Signed at (*place*) ....…........……………….. on (*date*) …………....……………….. 2019.

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Signature of interpreter   **Signature of witness**

APPENDIX K: CAPACITY FOR INFORMED CONSENT FORM

TITLE OF THE RESEARCH PROJECT: Communication, Cognitive Functioning and Feeding Information Needs Within a Support Group Setting of Caregivers of Individuals Diagnosed with Alzheimer's Disease

PROJECT I.D: 8718

PRINCIPAL INVESTIGATOR: Carla le Roux

ADDRESS: Speech, Language and Hearing Therapy Department, Tygerberg Medical Campus, Francie Van Zyl Drive, Parow, 7500.

CONTACT NUMBER: 021 938 9494

I *(name)* …………………………………..…………., the attending psychiatrist, declare that the patient for whom participant *(name)* ………………………..…………. is responsible, is unable to provide informed consent due to the progression of Alzheimer's Disease. I further declare that this has been explained to the participant of the patient.

Signed at (*place*) ....…........…………….. on (*date*) …………...……….. 2019.

....

Signature of Psychiatrist

Signed at (*place*) ....…........…………….. on (*date*) …………...……….. 2019.

....

Signature of participant

APPENDIX L: INFORMED CONSENT FORM – NEXT OF KIN

TITLE OF THE RESEARCH PROJECT: Communication, Cognitive Functioning and Feeding Information Needs Within a Support Group Setting of Caregivers of Individuals Diagnosed with Alzheimer's Disease

PROJECT I.D: 8718

PRINCIPAL INVESTIGATOR: Carla le Roux

ADDRESS: Speech-, Language- and Hearing Therapy Department, Tygerberg Medical Campus, Francie Van Zyl Drive, Parow, 7500.

What is this research study all about?

Due to a lack of resources in South Africa, it is possible that caregivers of individuals with Alzheimer's Disease may not have access to the information they require to fully understand the disease. The aim of the study is to get insight into the information needs relating to communication, cognitive functioning and feeding that caregivers of individuals diagnosed with Alzheimer's Disease want to receive at a support group. A further aim of the study is to get information on the support group structure that caregivers want. This study will be done at a government health facility in the Western Cape. Participants will be included until no new data is emerging.

Before the start of the interview, the caregiver will be asked which languages they are proficient in. Should he/she not be proficient in English or Afrikaans, the researcher will get written consent to include a translator into the interview. The researcher will ask open-ended questions to which the caregiver may respond. Each interview will be audio-recorded for transcription purposes. All information the caregiver provides will be kept anonymous. The audio-recordings will be kept in a locked drawer to which only the researcher has access and transcripts of the interview will be kept on a password-protected computer. After the interview has been transcribed, the audio-recording will be deleted. The interview will take approximately 45 minutes.

Why has the caregiver been invited to participate?

The caregiver has been invited to participate in this study as they are a caregiver to an individual diagnosed with Alzheimer's Disease, they are 18 years or older, proficient in English, Afrikaans or isiXhosa, they spend at least seven hours per day with the patient, they are not trained in the medical field and the individual with Alzheimer's Disease has not seen a speech therapist or other allied health care professional. The caregiver is further invited to take part as they have not attended a support group and is not currently attending a support group. The caregiver has been invited to provide their insight on the communication, cognitive functioning and feeding information they, as a caregiver to an individual diagnosed with Alzheimer's Disease, wish to receive in a support group, as well as how they would prefer the support group to be structured.

What will the caregiver's responsibilities be?

The caregiver will be requested to take part in an individual interview with the researcher. They are responsible for providing honest reflections during the interview and providing their informed consent.

Will the caregiver benefit from taking part in this research?

They will not benefit directly from their participation in this study. However, the caregiver may indirectly benefit from being provided with contact to speech therapists and psychological- and psychiatric services, which may improve their understanding of the patient's condition. Future caregivers of individuals with Alzheimer's Disease may also benefit from the caregiver's participation through improved support group information provision and the use of support group structures that fit the needs of caregivers.

Are there any risks involved in the caregiver taking part in this research?

There are no risks involved in the caregiver's participation in this research, although some emotional responses may arise upon reflection on the caregiver experience. The caregiver will be provided with the contact information of psychological- and psychiatric services after the interview.

If the caregiver does not agree to take part, what alternatives do they have?

Participation is completely voluntary. The caregiver may not agree to take part in the study or they can withdraw at any time, should they wish.

Who will have access to the patient's medical records?

No one will have access to the patient's medical records.

Will the caregiver be paid to take part in this study and are there any costs involved?

No, they will not be paid to take part in the study. The caregiver will be reimbursed for their travelling costs if the interview is not held on the same day as the appointment with the psychiatrist. Snacks will be provided during the interview.

Is there any thing else that you should know or do?

- You can contact Carla le Roux at tel 021 938 9494 if you have any further queries or encounter any problems.
- You can contact the **Health Research Ethics Committee** at 021 938 9207 if you have any concerns or complaints that have not been adequately addressed by your researcher.
- You will receive a copy of this information and consent form for your own records.

Declaration by next of kin

I *(name)*………………………………….………. agree that the caregiver may take part in a research study entitled Communication, Cognitive Functioning, and Feeding Information Needs Within a Support Group Setting of Caregivers of Individuals Diagnosed with Alzheimer's Disease

I declare that:

- I have read, or had read to me, this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurized to provide consent.

☐ **I give permission for an audio recording to be made of the caregiver's interview, as required for the methods used in the study.**

Signed at (*place*) ....…........…………….. on (*date*) …………...……….. 2019.

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Signature of next of kin   **Signature of witness**

Declaration by investigator

I *(name)* ……………………………………………..……… declare that:

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

Signed at (*place*) ....…........…………….. on (*date*) …………...……….. 2019.

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Signature of investigator **Signature of witness**

Declaration by interpreter

I *(name)* ……………………………………………..……… declare that:

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

Signed at (*place*) ....…........…………….. on (*date*) …………...……………….. 2019.

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Signature of interpreter **Signature of witness**

APPENDIX M: INFORMED CONSENT FORM – SUPPORT GROUP FACILITATORS

TITLE OF THE RESEARCH PROJECT: Communication, Cognitive Functioning and Feeding Information Needs Within a Support Group Setting of Caregivers of Individuals Diagnosed with Alzheimer’s Disease

REFERENCE NUMBER: 8718

PRINCIPAL INVESTIGATOR: Carla le Roux

ADDRESS: Speech-, Language- and Hearing Therapy Department, Tygerberg Medical Campus, Francie Van Zyl Drive, Parow, 7500.

CONTACT NUMBER: 021 938 9494

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

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

What is this research study about?

This study will be conducted across various major neurocognitive disorder (dementia) support groups in the Western Cape, South Africa. The aim of the study is to obtain information on the information needs relating to communication, cognitive functioning and feeding that caregivers of individuals diagnosed with Alzheimer’s Disease wish to receive at a support group. A further aim of this study is to compare the communication, cognitive functioning and feeding information that is currently being given at these support groups to the information that caregivers wish to receive, as well as to compare the support group structure currently used to how caregivers would prefer the support groups to be structured.

Why have you been invited to participate?

You have been invited to provide your experience regarding the communication, cognitive functioning and feeding information currently being incorporated into the support group sessions at your institution, as well as the structure of the support group currently being used.

What will your responsibilities be?

You will be requested be to take part in a survey sent via e-mail. You are required to provide honest reflections and information in the survey and provide your informed consent.

Will you benefit from taking part in this research?

You will not benefit directly from your participation in this study. However, you may indirectly benefit from guidance on communication, cognitive functioning and feeding related information caregivers of individuals diagnosed with Alzheimer's Disease require, as well as how caregivers would prefer support group(s) to be structured.

Are there in risks involved in your taking part in this research?

There are no risks involved in your participation in this research.

What will happen in the unlikely event of some form of injury occurring as a direct result of your taking part in this research study?

There are no physical risks associated with participating in this research study.

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

No, you will not be paid to take part in the study. There will be no costs involved for you.

Is there any thing else that you should know or do?

- You can contact Carla le Roux at tel 021 938 9494 if you have any further queries or encounter any problems.
- You can contact the **Health Research Ethics Committee** at 021 938 9207 if you have any concerns or complaints that have not been adequately addressed by your researcher.

- ➢ You will receive a copy of this information and consent form for your own records.

Declaration by participant

I *(name)* …………………………………..………… agree to take part in a research study entitled Communication, Cognitive Functioning and Feeding Information Needs Within a Support Group Setting of Caregivers of Individuals Diagnosed with Alzheimer's Disease

I declare that:

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

Signed at (*place*) ....…........…………….. on (*date*) …………...……….. 2019.

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Signature of participant	**Signature of witness**

Declaration by investigator

I *(name)* ……………………………………………..……… declare that:

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

Signed at (*place*) ....…......……………….. on (*date*) …………....……….. 2019.

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Signature of investigator **Signature of witness**

Declaration by interpreter

I *(name)* ……………………………………………..……… declare that:

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

Signed at (*place*) ....…......……………….. on (*date*) …………...………………..2019.

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Signature of interpreter **Signature of witness**

APPENDIX N: REFERRAL NUMBERS FOR CAREGIVERS

Resource Guide

Speech therapy services

Tygerberg Hospital Speech Therapy Department
021 938 4825

Groote Schuur Hospital Speech Therapy Department
021 404 6458

Khayelitsha District Hospital
021 360 4544

Psychological and Psychiatric services

Tygerberg Hospital Psychiatry and Psychology Department
021 938 5120

Groote Schuur Department of Psychiatry and Mental Health
021 404 2174

Khayelitsha Mental Health Services
021 360 4201

APPENDIX O: RAW DATA – ONLINE SURVEY FOR SUPPORT GROUP FACILITATORS

Question	Options provided	Support group facilitator selection (n=)
Are you a facilitator for a support group for caregivers of individuals with Alzheimer's Disease or Dementia	Yes	15
	No	0
My age is:	20-30 years	1
	30-40 years	0
	40-50 years	2
	50-60 years	4
	Over the age of 60 years	8
My highest level of formal schooling is:	Primary school not completed	0
	Primary school	0
	High school not completed	1
	High school	3
	College	3
	University	8
My sex is:	Male	2
	Female	13
	Other	0
What training have you received to prepare you for the role of the facilitator of this support group?	A short course through the institution I work for	4
	Previous employment in the medical field	0
	No formal training	3
	Other	8
The support group I facilitate typically consists of the following number of members per session:	0-5 members	1
	6-10 members	4
	11-15 members	3
	16-20 members	5
	21-25 members	1
	26-30 members	1
	More than 30 members	0

Where is the support group held?	At the facility I work for	6
	At a hospital	2
	In a religious building	1
	At an academic facility e.g. university	0
	Other	6
The support group is held:	During the week	12
	Over the weekend	3
	Both options are available	0
The support group is run the following number of times per month:	Less than once a month	1
	Once a month	14
	Twice a month	0
	Three to four times per month	0
	Five to eight times per month	0
	More than eight times per month	0
The support group is held in:	The morning (between 08:00 and 12:00)	7
	The afternoon (between 12:00 and 17:00)	6
	The evening (after 17:00)	2
The duration of each session is:	Less than 30 minutes	0
	30 minutes to an hour	1
	An hour to two hours	13
	More than two hours	1
At the support group, the individual diagnosed with major neurocognitive disorder (Alzheimer's Disease) is:	Present	0
	Not present	9
	Sometimes present	6
The support group is focused on:	Emotional support	0
	Information provision	1
	Emotional support as well as information provision	14
The majority of attendees are:	Employed	1
	Unemployed or retired	1
	The support group consists of attendees both employed and unemployed or retired	13

In the support group, have you been asked about patients experiencing difficulties with findings words?	Yes	14
	No	1
In your opinion, were you able to answer this question adequately	Yes	13
	No	1
	Not applicable	1
In the support group, have you been asked about patients experiencing difficulty with understanding what others are saying	Yes	14
	No	1
In your opinion, were you able to answer this question adequately?	Yes	13
	No	1
	Not applicable	1
In the support group, have you been asked how one can help a patient who has difficulty understanding what others are saying?	Yes	13
	No	2
In your opinion, where you able to answer this question adequately?	Yes	13
	No	0
	Not applicable	2
In the support group, have you been asked why patients may exhibit inappropriate behaviours in conversation, such as changing between topics frequently, not staying on topic or screaming?	Yes	12
	No	3
In you opinion, were you able to answer this question adequately?	Yes	12
	No	0
	Not applicable	3
In the support group, have you been asked about patients frequently choking on food, coughing while eating or drinking or eyes watering during meals or whilst having a bevereage?	Yes	5
	No	10
In your opinion, were you able to answer this question adequately?	Yes	4
	No	1
	Not applicable	10

In the support group, have you been asked about the various types of memory one has (e.g. long term, short term, etc.)	Yes	15
	No	0
In your opinion, were you able to answer this question adequately?	Yes	15
	No	0
	Not applicable	0
In the support group, have you been asked why patients repeat questions they have already asked?	Yes	15
	No	0
In your opinion, were you able to answer this question adequately?	Yes	14
	No	1
	Not applicable	0
In the support group, have you been asked about ways of stimulating cognition in these patients?	Yes	13
	No	2
In your opinion, were you able to answer this question adequately?	Yes	11
	No	2
	Not applicable	2
In your support group, have you been asked about the role of the speech therapist in the management of the patient?	Yes	5
	No	10
In your opinion, were you able to answer this question adequately?	Yes	5
	No	0
	Not applicable	10
In your opinion, how valuable would a speech therapist be at your group?	1 (somewhat valuable)	1
	2	2
	3	3
	4	3
	5 (very valuable)	6
Have you referred a support group member to a speech therapist?	Yes	6
	No	9