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Complex decisions about tube feeding in advanced dementia: Insights from a sample of South African speech-language therapists

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Dissertation submitted in fulfilment of the requirements for the degree MA (Speech-Language Pathology) in the Department of Speech-Language Pathology and Audiology

Faculty of Humanities

University of Pretoria

Supervisor: Mrs Bhavani Pillay

Co-supervisor: Dr Esedra Krüger

Date: March 2023

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DEPARTMENT OF SPEECH-LANGUAGE PATHOLOGY AND AUDIOLOGY

Declaration of originality

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1. I understand what plagiarism is and am aware of the University's policy in this regard.
2. I declare that this dissertation is my own original work. Where other people's work has been used (either from a printed source, Internet or any other source), this has been properly acknowledged and referenced in accordance with departmental requirements.
3. I have not used work previously produced by another student or any other person to hand in as my own.
4. I have not allowed and will not allow anyone to copy my work with the intention of passing it off as his or her own work.

SIGNATURE

27 March 2023

DATE

Acknowledgements

Dear God, I give You all the glory for the completion of this study. Without Your unfailing grace, it would not have been possible (1 Corinthians 10:31; Philippians 4:13).

Thank You for using me as an instrument to contribute towards a topic and a population that I am deeply passionate about (1 Corinthians 12:4-6; Isaiah 6:8). Your creation includes both life and death, and yet You fill everything in between with hope (Isaiah 45:7; 1 Peter 1:3). My hope is that this study will bring glory to You wherever it may be used and highlight that the essence and beauty of life can be found not just at the beginning, but also at the end of our footsteps (2 Corinthians 12:9-10).

I am grateful for my wonderful husband, family, friends, and two knowledgeable supervisors that You have placed in my life. Despite my shortcomings, they provided words of encouragement, positive affirmations, dark humour, and bad dad jokes that kept me going (Ecclesiastes 4:9-10; Proverbs 17:17).

List of Tables

List of abbreviations

ASHA	American Speech-Language-Hearing Association
ESPEN	European Society of Parenteral and Enteral Nutrition
HPCSA	Health Professions Council of South Africa
FEES	Fiberoptic Endoscopic Evaluation of Swallowing
NGT	Nasogastric tube
NICE	National Institute of Health and Care Excellence
OPD	Oropharyngeal dysphagia
PEG	Percutaneous endoscopic gastrostomy
PWD	Person with dementia
SASLHA	South African Speech-Language-Hearing Association
SLTs	Speech-language therapists
UMIC	Upper middle-income country
VFSS	Videofluoroscopic Swallow Study

Abstract

UNIVERSITY OF PRETORIA

DEPARTMENT OF SPEECH-LANGUAGE PATHOLOGY AND AUDIOLOGY

Initials and surname	D. Pullen
Supervisors	Mrs Bhavani Pillay & Dr Esedra Krüger
Date	March 2023
Title	Complex decisions about tube feeding in advanced dementia: Insights from a sample of South African speech-language therapists

Abstract:

Background: As advanced dementia progresses, individuals become increasingly dependent on health, social, and community care services, and feeding difficulties become common. Oropharyngeal dysphagia is prevalent in people with advanced dementia, and speech-language therapists (SLTs) may recommend tube feeding. However, a deeper understanding of SLTs' practices, focused on dysphagia in advanced dementia, are needed.

Objective: To qualitatively describe insights and practices of a sample of South African SLTs, regarding feeding tube placement in people with advanced dementia.

Method: Semi-structured interviews were conducted using an interview schedule containing nineteen open-ended questions. The study employed a qualitative design based on phenomenological principles. Eight SLTs, with a particular interest in working with advanced dementia, were recruited using purposive sampling. The data collected were analysed using inductive reflexive thematic analysis.

Results: Three main themes were identified: a) Factors influencing SLTs' decisions for feeding tube placement in people with advanced dementia, b) Nature of clinical setting and SLTs' decision making and c) SLTs' considerations to improve the management of people with advanced dementia. Findings indicated that existing local palliative care guidelines were not employed by SLTs in decisions about tube feeding. Most participants did not recommend tube feeding during the end-of-life phase of advanced dementia. The perceived burden of care, experienced by

healthcare professionals and families, influenced decisions about tube feeding.

Conclusion: Decisions about feeding tube placement in advanced dementia is complex and require specialised teams. Caregiver involvement and promotion of patient autonomy is crucial. SLTs require support from local governing bodies for continued professional development and mentoring to improve ethical and evidence-based decision-making.

Keywords: Advanced dementia, feeding tube, speech-language therapists, qualitative, online interview

Chapter 1: Introduction

Chapter aim:

The aim of this chapter is to provide an overview of literature exploring the role of SLTs in feeding tube placement in people with advanced dementia. Chapter 1 concludes with the rationale, research question, clarification of terminology and outline of the chapters.

1.1. Introduction

Advanced dementia could be defined as an irreversible progressive disease that involves but is not limited to, impaired cognitive function, physical dysfunction, psychological and social issues (de Jager et al., 2017; Hýden et al., 2022). The complex challenges are reflected across multiple life domains and lead to the loss of independence requiring increased health, social and community care services (de Jager et al., 2017; Hýden et al., 2022). Impaired cognitive function in advanced dementia is evident in the accelerating decline of short- and long-term memory; motor planning difficulties of apraxia of speech, and challenges recognising objects (agnosia) may often emerge. These difficulties affect the person with dementia's (PWD) ability to make use of utensils correctly during a meal and to recognise food during feeding (Ijiaopo & Ijiaopo, 2019). In people with advanced dementia, both oral- and pharyngeal dysphagia can occur as the disease progresses, often resulting in malnutrition (Schwartz, 2018). Mastication during the oral phase could be affected; leading to pocketing of food and increased risk of aspiration (Espinosa-Val et al., 2020; Schwartz, 2018). Furthermore, affected sensory aspects in people with dementia lead to delayed oral transit times, resulting in oropharyngeal dysphagia [OPD] (Espinosa-Val et al., 2020). These implications correlate with the 90% prevalence rate of feeding deficits and the 53% to 60% prevalence rate of OPD among individuals with advanced dementia (Alagiakrishnan et al., 2013; Ijiaopo & Ijiaopo, 2019; Park et al., 2013).

During the management of patients with OPD, speech-language therapists (SLTs), who are experts in treating swallowing and feeding difficulties, make use of direct and indirect therapy methods such as making use of environmental modifications,

adapting diets and considering enteral feeding (American Speech-Language-Hearing Association [ASHA], 2016; Beckley, 2017). A team approach, following a patient-centred care approach, is used to manage people with advanced dementia, and alternative supplemental methods such as tube feeding are also considered. However, the effectiveness of tube feeding and SLTs' practices during the management of people with advanced dementia is controversial (American Geriatrics Society, 2014; Baijens et al., 2016; Cloete et al., 2022; Druml et al., 2016; Ijaopo & Ijaopo, 2019; Payne & Morley, 2018). The European Society for Clinical Nutrition and Metabolism (ESPEN) recommends tube feeding only when oral intake is insufficient or impossible, and in patients with a good chance of recovery or prolonged survival (Volkert et al., 2019). In advanced dementia, tube feeding has not been found to improve nutritional status, prevent aspiration pneumonia, or extend survival. In fact, prolonged tube feeding in advanced dementia may lead to increased discomfort, agitation, and risk of infection in patients (Volkert et al., 2019). Therefore, a team approach, involving the patient, family members, healthcare providers, and SLTs, should be used to make the decision to initiate tube feeding in patients with advanced dementia. The team should consider the patient's wishes, values, and potential risks and benefits, and alternative supplemental methods such as modified diets or environmental modifications should also be explored (American Geriatrics Society, 2014; Volkert et al., 2019). Nasogastric feeding tube (NGT) placement has not been shown to prevent malnutrition, pneumonia, or mortality in people with advanced dementia (Newman et al., 2020; Ijaopo & Ijaopo, 2019). The placement of percutaneous endoscopic gastrostomy (PEG) feeding tubes has been associated with earlier mortality when compared to patients who were fed orally (American Geriatric Society, 2014; Lynch, 2016).

Despite the global controversy and limited evidence supporting the claims that tube feeding is beneficial for PWD, it was found that South African SLTs perceived tube feeding as a standard treatment approach in PWD (Chen et al., 2019; Cloete et al., 2022). This perceived standard of treatment was found to be guided by clinical experience rather than research-based guidelines (Cloete et al., 2022). However, it is important to note that the Healthcare Professions Council of South Africa (HPCSA) has published guidelines on end-of-life care for healthcare professionals, including SLTs (HPCSA, 2019). The guidelines emphasise the importance of providing

palliative care to individuals with advanced dementia and avoiding unnecessary and burdensome treatments, such as feeding tubes, when the person is at the end-of-life stage (HPCSA, 2019). The guidelines encourage healthcare professionals to engage in advanced care planning and decision-making with the person, their family, and other members of the healthcare team (HPCSA, 2019). Therefore, it is important for SLTs in South Africa to be aware of the HPCSA guidelines and incorporate them into their practices when managing individuals with advanced dementia. The apparent mismatch between what guides decision-making is possibly a result of a lack of local guidelines by governing bodies for specific use by SLTs that reflect the unique or extraneous factors present in the South African context (Andrews & Pillay; 2017; Jacobs et al., 2020; Cloete et al., 2022; Kochovska et al., 2020; Tsao et al., 2019; Varindani Desai & Namasivayam-Macdonald, 2020). Probing local SLTs' practices regarding tube feeding in advanced dementia could serve as an advocating baseline for developing guidelines for future practice. This could be beneficial in low-income settings such as South Africa, where limited guidelines are currently available (Jacobs et al., 2020; Cloete et al., 2022; Varindani Desai & Namasivayam-MacDonald, 2020).

The European Association of Palliative Care (EAPC) defines advance care planning as a formal process where voluntary communication takes place between the patient, significant others and healthcare professionals, to dictate the future treatment of a patient whilst the patient still has the cognitive capacity to do so (van der Steen et al., 2014). ESPEN recommends that in the event where an advance directive is absent, the patient's representative is obligated to make the decisions; if the decisions are delayed, the healthcare professionals should start alternative nutrition (de Jager et al., 2017). However, the American Geriatrics Society suggests that when requests for eating and drinking are made by a PWD, the voluntary requests should ethically override the wishes mentioned in the advance directive (American Geriatrics Society, 2014). Insufficient experience and guidance in end-of-life care planning could also have an impact on SLTs practices as an international study identified a need for healthcare professionals to receive training in end-of-life care management (Volicer et al., 2019). End-of-life care could further be influenced by the SLTs culture or religious beliefs and the patient or family members' preferences (Volicer et al., 2019). Both, SLTs and family members, might feel

obligated to prolong life or relieve suffering in the PWD resulting from dehydration or malnutrition by recommending feeding tube placement, unaware that this controversially increases the risk for mortality (Cloete et al., 2022; Varindani Desai & Namasivayam-MacDonald, 2020; Newman et al., 2020; Malek et al., 2018). The implications of these influencing factors should be questioned in the local context where dementia care is viewed as a low priority and palliative care is poorly defined and under-resourced (Jacobs et al., 2020; Cloete et al., 2022; Lloyd-Sherlock, 2019; Newman et al., 2020; Volicer et al., 2019).

Due to dementia being a low priority in South Africa, PWD who require services mainly rely on non-governmental organisations such as Alzheimer's South Africa and Dementia South Africa (Lloyd-Sherlock, 2019). Public services are only rendered to a small portion of the older population and mainly in urban areas (Cloete et al., 2022; Jacobs et al., 2020). Most PWD, living in long-term care facilities, are cared for by caregivers (Jacobs et al., 2020; South African Human Rights Commission, 2017). The lack of service provision raises cause for concern when reviewing the American Geriatric Society's position statement on feeding tube placement in people with advanced dementia where careful hand feeding is suggested as an alternative treatment approach (American Geriatrics Society, 2014; Chou et al., 2020; Luk et al., 2017). An indirect therapy method like feeding PWD intermittently or completely during mealtimes might become necessary during the management of people with advanced dementia where direct therapy methods, such as spaced retrieval training, are no longer beneficial (American geriatric society, 2014; Batchelor-Murphy et al., 2019; Varindani Desai & Namasivayam-MacDonald, 2020). Despite acknowledged benefits such as positively affected oral intake and cultural considerations being adhered to, careful hand feeding was not reported by South African SLTs as an option to enhance the quality of eating and swallowing or reduce feeding difficulties in PWD even though it is considered best practice (Cloete et al., 2022; Fong, 2019; Luk et al., 2017). It is important to consider and investigate both the potential burdens and benefits of tube feeding to determine the appropriateness of implementation. This is important, especially in an upper-middle-income country (UMIC), with low-income settings like South Africa, where the recommended treatment for people with advanced dementia being careful hand feeding would likely be administered by unqualified caregivers, possibly motivating a preference towards

tube feeding to maintain patient well-being (Cloete et al., 2022; Druml et al., 2016; Ijaopo & Ijaopo, 2019; Lynch, 2016).

South Africa presents with a unique profile, exacerbated by limited resources, that does not, in a clinical context, adhere to global recommended evidence-based practice (Jacobs et al., 2020; Cloete et al., 2022). This warrants further local research to be conducted to reflect the unique factors of the South African setting that may dictate decisions. No studies to date have been conducted where the practices of local SLTs in advanced dementia management have been explored (Cloete et al., 2022). A recent South African study could be viewed as a first step to understand the current perspectives and beliefs of South African SLTs related to PWD (Cloete et al., 2022). The study included 83 participants that were surveyed using an online questionnaire about feeding tube placement in PWD, rendering mostly quantitative data. Thus, the current study aimed to qualitatively build upon these findings by narrowing the study population to advanced dementia and obtaining comprehensive data by probing perspectives of SLTs, with a particular interest in this field on their practices, through individual interviews. Probing participants with open-ended questions allows room for exploration and interpretation on identified areas, that are not yet understood, relating to the population with advanced dementia (Brink et al., 2018). The following research question was posed: “What are the insights and practices of a sample of South African SLTs regarding feeding tube placement in people with advanced dementia when probed using in-depth interviews?”.

1.2. Clarification of terminology

Palliative care: Palliative care is a specialised medical care approach focused on providing relief from the symptoms and stress of a serious illness, with the goal of improving the quality of life for patients and their families (World Health Organisation, 2021).

End-of-life care: End-of-life care refers to the care provided to people with a terminal illness or those approaching the end of their life. It involves addressing physical, emotional, and spiritual needs and providing comfort and support to the patient and their family (HPCSA, 2019).

Enteral feeding: Enteral feeding is a medical procedure that involves delivering nutrition directly to the stomach or small intestine through a feeding tube (ASHA, 2016):

- ***Nasogastric Tube (NGT) placement:*** It is a medical device that is inserted through the nose and passed down into the stomach. It is used to deliver nutrition, medication and hydration or to remove stomach contents for diagnostic purposes. NGTs are temporary and are typically used for short-term feeding in patients who are unable to eat or swallow food normally (ASHA, 2016).

- ***Percutaneous Endoscopic Gastrostomy (PEG) tube placement:*** PEG tube placement is a type of enteral feeding procedure that involves inserting a feeding tube directly into the stomach through the abdomen (ASHA, 2016).

Oropharyngeal Dysphagia (OPD): Oropharyngeal dysphagia is a medical condition characterised by difficulty swallowing food or liquid due to problems in the oral and/or pharyngeal phases of swallowing (ASHA, 2016).

1.3. Outline of chapters

An outline of the chapters contained in the dissertation is shown below.

- **Chapter 1:** Provides a comprehensive summary of the research topic by examining the related and supportive literature. It concludes in establishing the justification and research question, along with providing clarification of terminology.

- **Chapter 2:** A detailed discussion of the method used in the study.

- **Chapter 3:** Research article submitted to South African Journal of Communication Disorders (SAJCD) on 9 March 2023 (Appendix G).

- **Chapter 4:** The study's clinical and theoretical implications, its strengths and weaknesses, and suggestions for future research.

Chapter 2: Method

Chapter aim:

The aim of this chapter is to provide a detailed outline and description of the research design, study setting, study population and sampling, data collection and analyses.

2.1. Research aim

To qualitatively describe insights and practices of a sample of South African SLTs, regarding feeding tube placement in people with advanced dementia.

2.2. Research design

A qualitative study design with phenomenology, as a study framework, was used to cultivate concepts and themes related to SLTs' perspectives regarding feeding tube placement in people with advanced dementia. Phenomenological studies investigate the personal experiences and perspectives of participants (Braun & Clarke, 2022; Brink et al., 2018). Online interviews were conducted with SLTs who have specialised experience in the field of dementia. The interviews explored the SLTs' personal experiences and perspectives related to the feeding tube placement considerations in the advanced dementia population (Braun & Clarke, 2022; Brink et al., 2018).

2.3. Study setting

Online interviews were conducted with SLTs who work in the private and public health sectors in South Africa, including hospitals and care facilities, and have a special interest in working with people with advanced dementia. The interviews were conducted on the online videoconferencing platform, Microsoft Teams, allowing for accessibility to various participants across South Africa.

2.4. Study population and sampling

2.4.1. Study population

South African SLTs who have experience- and a special interest in the field of dementia and have worked with people with dementia in either the private or public health sector in South Africa within the last year.

2.4.2. Sample

Phenomenology makes use of criterion sampling, in which participants, who meet specific requirements relating to the study, are selected (Braun & Clarke; 2022; Brink et al., 2018; Moser & Korstjens, 2018). Criterion sampling, a type of non-probability, purposive sampling, was used to select participants (Braun & Clarke; 2022; Brink et al., 2018; Moser & Korstjens, 2018). It allowed the researcher to sample participants that met predetermined criteria relating to the study (Moser & Korstjens, 2018). Phenomenological studies require less than ten participants to be selected (Braun & Clarke, 2022; Brink et al., 2018). For this study, eight participants were recruited.

2.5. Participants

2.5.1. Inclusion criteria

To participate in the current study, participants had to meet the following criteria:

A. South African SLTs who completed one of the following degrees:
- Bachelors of Speech-Language Pathology degree;
- Bachelors of Speech-Language Pathology and Audiology or;
- Bachelor of Science in Speech-Language Pathology, or a tertiary equivalent.

B. SLTs who are classified as having a particular interest in the management of people with dementia. In South Africa, SLTs are specialists when they render services to a designated client or disorder group (South African Speech-Language-Hearing Association [SASLHA], 2010). Further, they had to meet the following requirements:
- Have completed post-graduate courses and training related to dementia related care and/or:
- Have at least three years of continuous work experience in dementia management, excluding the community service year.

C. Members who are registered with the HPCSA, were included in the study.
D. SLTs who had access to online platforms such as Microsoft Teams, and who had internet access.

Recruited participants were asked to confirm whether they met the criteria before they were allowed to participate in the study.

2.5.2. Participant description

The sample consisted of eight SLTs, practicing in South Africa, who met the inclusion criteria through purposive sampling. These SLTs had at least three years of experience and recent experience working with people with dementia in either the private or public health sector in South Africa. Four of the participants in the current study are considered specialists in working with people with dementia. In South Africa, SLTs are specialists when they provide services to designated client groups, as outlined by the South African Speech-Language-Hearing Association (SASLHA, 2010). These participants have either completed post-graduate courses and training related to dementia care and have a minimum of three years of continuous experience in working with people with dementia. Six of the participants were actively rendering services in the private sector. Most of the participants resided in the Gauteng province. The participants ranged in age from 26 to 48 years old. They had all completed an undergraduate degree in speech-language therapy or an equivalent and were registered with the HPCSA. The participants represented a variety of healthcare settings, including acute care hospitals, long-term care facilities, and community-based clinics. All participants were fluent in English, the language of the study, and had given their consent to participate in the research.

2.6. Data collection

2.6.1. Materials and apparatus

A self-compiled semi-structured interview schedule (Appendix A) comprising nineteen open-ended questions with probing questions was used during the online interviews to obtain in-depth information. The researcher made use of an Acer laptop, 2013 model to conduct the interviews. The interviews took place on a videoconferencing online platform, Microsoft Teams. Online interviews created room for accessibility to various participants better representing the diverse population of

South Africa (Moser & Korstjens, 2018). The need for a study making use of interviews to obtain in depth information was identified after a quantitative study was done through making use of an online survey and yielded further studies to explore SLTs' practices qualitatively (Cloete et al., 2022). The questions in the self-compiled interview schedule (Appendix A) were based on a quantitative study conducted in South Africa, that probed SLTs' practices and beliefs regarding feeding tube placement in PWD (Cloete et al., 2022). Other studies were also reviewed for the refinement of the questions (American Geriatrics Society, 2014; Jacobs et al., 2020; Baijens et al., 2016; Beckly, 2017; Campbell et al., 2011; Car et al., 2017; Cloete et al., 2022; Hickey & Bourgeois, 2017; Kuven, 2018; Luk et al., 2017; Malek et al., 2018; Newman et al., 2020; Schwartz et al., 2014; Varindani Desai & Namasivavam-Macdonald, 2020; Volicer et al., 2019; Volkert et al., 2015; Vose et al., 2018). The questions in the interview schedule (Appendix A) were specifically tailored to cultivate more in-depth descriptive information from participants; thus, only open-ended questions were included (Brink et al., 2018). Appendix B provides an overview as well as justification for the questions included in the interview schedule.

2.7. Pilot study

Participation was voluntary and written informed consent was obtained from all participants. A pilot study was conducted by requesting a qualified SLT to review the self-compiled interview schedule (Appendix A). The SLT provided feedback (Appendix C) on the questionnaire relating to the sequencing of the questions and the clarity thereof. The content and phrasing of the questions, as well as the probe questions, were scrutinised by the researcher thereafter to avoid ambiguity or leading questions. Asking leading questions could result in certain answers being favoured over another and thus the data obtained could be flawed (Brink et al.,2018). Feedback from the pilot study participant (Appendix C) was taken into consideration to rule out and adapt any factors within the schedule and the interview process that might have influenced the reliability and trustworthiness of the data to be obtained.

2.8. Procedure for data collection

The study received institutional ethical clearance (Appendix D) from the Faculty of Humanities' Research Ethics Committee at the University of Pretoria on 9 December 2021 (protocol number: HUM022/1021). Data collection commenced after ethical

clearance (Appendix D) was obtained. Informed consent (Appendix E) was requested from the participants prior to the interviews. An advert (Appendix F) was placed on social media platforms such as Facebook and was also sent to selected individuals via Whatsapp, from the researcher and supervisors' current network base, who met the identified criteria. Once participants responded to the advert, informed consent (Appendix E) was distributed via email. Upon receipt of the signed informed consent document, the researcher contacted the participants to schedule dates and times for the interviews to take place.

The semi-structured interview was conducted where eight participants' opinions and experiences regarding feeding tube placement in people with advanced dementia was explored one-on-one (Brink et al., 2018). A self-compiled interview schedule (Appendix A) was followed where a series of structured questions guided the researcher during the online interview. The sequence of the questions posed depended on the participants' responses and how the interview progressed (Moser & Kortsjens, 2018). This allowed for a dialogue to take place between the researcher and the participants and prevented a rigid question-answer interview (Moser & Kortsjens, 2018). Probe follow-up questions ("Tell me more about…", "What do you mean by?" and "Could you please describe?" or "Please elaborate…") created opportunities for detailed descriptions where needed. This allowed for clarification and expansion of responses whilst also establishing rapport between the researcher and the participants (Brink et al., 2018). Data obtained was recorded on the online platform, Microsoft Teams, along with field notes to allow for transcription and further interpretation afterwards (Brink et al., 2018).

2.9. Data management and analysis

To ensure confidentiality, each participant's recordings received an alphanumeric code or pseudonym (Braun & Clarke, 2022). Verbatim transcriptions of audio recordings of the eight participants were conducted to obtain written documents that was useful for inductive reflexive thematic analysis to take place (Braun & Clarke, 2022; Swain, 2018). Transcripts were uploaded for inductive coding and reflexive thematic analysis using qualitative data analysis and research software ATLAS.ti (Braun & Clarke, 2022; Brink et al., 2018; Terry et al., 2017). Data were coded after transcripts were reviewed numerous times to organise data under suitable codes.

Codes were subsequently grouped where themes then emerged. Findings of the transcriptions were discussed with the supervisors of the study to increase the reliability and validity of the collected data (Braun & Clarke, 2022; Brink et al., 2018; Terry et al., 2017). Data obtained were recorded and stored alongside the transcripts on a password protected computer. Inductive reflexive thematic analysis, outlined by Braun and Clarke (2022) comprises six phases. An overview of the phases followed by the researcher can be seen in Table 1 (Brink et al., 2018; Terry et al., 2017).

TABLE 1: Overview of reflexive thematic analysis

Phases	**Description**
1. Familiarisation	The researcher became immersed in the data; critically (re-listening to recordings or (re-)reading textual data (transcripts) to identify patterns or questions that guided the analysis process further. The researcher navigated through all the data obtained whilst also making notes of valuable clauses to be remembered later in the process (Brink et al., 2018; Terry et al., 2017).
2. Coding	Once an overview of the data was achieved, codes were generated. Coding involved creating labels for specific sections of the data obtained that has a high level of relevance to the research question. For example, all phrases relating to the role SLTs play in tube-feeding in people with advanced dementia was labelled with “SLTs role regarding TF”. Codes were continuously reviewed and adapted. Coding played a vital role in reducing and synthesising data and categorically organising the data. This played a vital role later when the researcher identified themes (Brink et al., 2018; Terry et al., 2017).
3. Theme development	Information was further processed to identify and construct themes that related back to the research question, which functioned as a filter to sort through relevant versus irrelevant information. Theme development involved examining codes and associated data: combining, clustering or collapsing data to further synthesise the data obtained. (Brink et al., 2018; Terry et al., 2017). Findings were discussed with the study’s supervisors and themes were identified collaboratively.

4. Reviewing and 5. Defining themes	Once the thematic map was constructed; the researcher started refining the themes. Themes were further shaped, clarified or rejected along with the study's supervisors. Thereafter, the researcher named and defined themes by providing short descriptions of each theme. This helped provide clarity while also bringing the data together and reflecting a coherent picture of what the data meant. (Brink et al., 2018; Terry et al., 2017).
6. Producing the report	The final phase entailed answering the study's research question. The writing style moved from illustrative to more analytic where arguments are both answered and brought forth for future studies (Brink et al., 2018; Terry et al., 2017).

Analysis of data started immediately after the first interview was conducted. This was important when considering data saturation. To achieve data saturation, participants had to be interviewed until no new topics/ ideas or information emerged (Brink et al., 2018; Braun & Clarke, 2022; Terry et al., 2017).

2.10. Trustworthiness and reliability of variables

The analytic processes and adherence to criteria to enhance the reliability and trustworthiness of the qualitative data collected and interpreted are presented in Table 2 (Brink et al., 2018; Braun & Clarke, 2022).

TABLE 2: Criteria for reliability and trustworthiness

Criteria	**Processes**
a) Credibility	Member-checking: The study's supervisors collaboratively reviewed and verified the researcher's interpretations and conclusions (Brink et al., 2018). Participants were also re-assured that they could have access to the results should they wish to review the interpretations made by the researcher. Reviewing of themes occurred in conjunction with the study supervisors until consensus was reached.
b) Dependability	Detailed descriptions of the data were made; transcriptions and field notes were reviewed cautiously (Braun & Clarke, 2022).
c) Confirmability	Reviewing of themes occurred with the supervisors until consensus was reached. Data was analysed until data saturation was achieved, thus until no new themes or information emerged from the obtained data and when the data obtained matched published literature (Braun & Clarke, 2022).

d) Transferability	Data saturation was obtained, the data is considered transferable and rich in information, thus applicable to other settings and people (Braun & Clarke, 2022).
e) Authenticity	Authenticity was reflected in the inclusion of direct quotes of the answers from the participants involved to portray their experiences. Secondly, member-checking by the corresponding supervisors allowed for more accurate interpretation of the answers obtained (Braun & Calrke, 2022; Brink et al., 2018).

2.11. Ethical and legal considerations

Ethical considerations were categorised based on Leedy and Ormrod (2016), all of which were considered in this study:

2.11.1. Permission

The study received institutional ethical clearance (Appendix D) from the Faculty of Humanities at the University of Pretoria (protocol number: HUM022/1021).

2.11.2. Informed consent

Informed consent (Appendix E) was requested from participants by sending a detailed information leaflet (Appendix E) explaining the data collection process and what will be expected from the participants. An option was also made available to the participants to contact the researcher, Danette Pullen, if they required more information before providing consent. It was made clear in the information leaflet (Appendix E) that participants should only give consent when they fully understood what was expected from them and what the study entailed. Participation in this study was voluntary and participants could decide at any point in time to no longer participate without giving a reason.

2.11.3. Confidentiality and data storage

To ensure confidentiality, transcripts made from the recordings were coded by providing an alphanumeric code (Braun & Clarke, 2022). To adhere to ethical considerations, the obtained- and transcribed data was stored safely on a password-protected computer. The data was shared with those involved in the study. To adhere to the University of Pretoria's research data management policy, the

collected- and transcribed data will be electronically stored on the UP repository safely for at least 15 years to ensure accessibility for future studies (University of Pretoria, 2017). The University's research data repository is established in collaboration with Figshare; an international cloud-based repository (University of Pretoria, 2017). This allows the researcher to securely store obtained- and transcribed data once research has been finalised and simultaneously give access to the University of Pretoria to utilise the data for research purposes (University of Pretoria, 2017).

2.11.4. Protection from harm

The information participants provided was kept strictly confidential and was not used in any way to cause harm to them. Cultural differences were respected throughout the data collection procedure (Mash, 2016). Due to the online nature of the recordings, participants were allowed to select the environment where they were interviewed. The participants could request at any point to stop the recordings if they wished to do so. Participants were informed that they could view and listen to the recordings afterwards to ensure accurate portrayal, if they wished to do so (Plummer 2001).

2.11.5. Plagiarism

The American Psychological Association (APA) version seven guidelines were used to reference all sources used. Acknowledgement was given to other researchers' findings and cited accordingly throughout the research project (APA, 2019).

Chapter 3: Article

Chapter aim:

This chapter comprises an article derived from the research project, which was submitted to the "South African Journal of Communication Disorders" on 9 March 2023 (Appendix G). The format of this chapter differs to that of the rest of the dissertation as the journal specified guidelines for formatting of the article.

Complex decisions about tube feeding in advanced dementia: insights from a sample of South African speech-language therapists

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Abstract

Background: As advanced dementia progresses, individuals become increasingly dependent on health, social, and community care services, and feeding difficulties become common. Oropharyngeal dysphagia is prevalent in people with advanced dementia, and speech-language therapists (SLTs) may recommend tube feeding. However, a deeper understanding of SLTs' practices, focused on dysphagia in advanced dementia, is needed.

Objective: To qualitatively describe practices of a sample of South African SLTs, regarding feeding tube placement in people with advanced dementia.

Method: Semi-structured interviews were conducted using an interview schedule containing nineteen open-ended questions. The study employed a qualitative design based on phenomenological principles. Eight SLTs, with a particular interest in working with advanced dementia, were recruited using purposive sampling. The data collected were analysed using inductive reflexive thematic analysis.

Results: Three main themes were identified: a) Factors influencing SLTs' decisions for feeding tube placement in people with advanced dementia, b) Nature of clinical setting and SLTs' decision making and c) SLTs' considerations to improve the management of people with advanced dementia. Findings indicated that existing local palliative care guidelines were not employed by SLTs in decisions about tube feeding. Most participants did not recommend tube feeding during the end-of-life phase of advanced dementia. The perceived burden of care, experienced by healthcare professionals and families, influenced decisions about tube feeding.

Conclusion: Decisions about feeding tube placement in advanced dementia is complex and require specialised teams. Caregiver involvement and promotion of patient autonomy are crucial. SLTs require support from local governing bodies for continued professional development and mentoring to improve ethical and evidence-based decision-making.

Keywords: Advanced dementia, feeding tube, speech-language therapists, qualitative, online interview

Introduction

As advanced dementia progresses, individuals lose their agency and become increasingly reliant on health, social, and community care services (de Jager et al., 2017; Hýden et al., 2022). Feeding difficulties are common, including compromised mastication and increased risk of aspiration (Espinosa-Val et al., 2020; Schwartz, 2018). Oropharyngeal dysphagia (OPD) is prevalent in 53% to 60% of people with advanced dementia due to delayed oral transit times (Alagiakrishnan et al., 2013; Espinosa-Val et al., 2020; Ijiaopo & Ijiaopo, 2019). Speech-language therapists (SLTs), experts in OPD treatment, use direct and indirect therapy methods to manage patients with OPD and may recommend tube feeding (Beckley, 2017; Cloete et al., 2022).

Global controversy exists regarding the effectiveness of tube feeding and SLTs' practices when managing people with advanced dementia (American Geriatrics Society, 2014; Baijens et al., 2016; Cloete et al., 2022; Druml et al., 2016; Hýden et al., 2022; Ijaopo & Ijaopo, 2019; Payne & Morley, 2018). Despite limited evidence supporting the claims that tube feeding is beneficial for people with dementia (PWD), South African SLTs perceived tube feeding as a standard treatment approach in PWD (Chen et al., 2019; Cloete et al., 2022). This perceived standard of treatment was found to be guided by clinical experience rather than research-based guidelines (Cloete et al., 2022). The mismatch between what guides decision making may be due to a lack of local guidelines that reflect the unique or extraneous factors present in South Africa (Andrews & Pillay; 2017; Jacobs et al., 2020; Cloete et al., 2022; Kochovska et al., 2020; Tsao et al., 2019; Varindani Desai & Namasivayam-Macdonald, 2020). Probing local SLTs' practices regarding tube feeding in advanced dementia could serve as a starting point for SLT guideline development.

SLTs may face challenges managing people with advanced dementia due to their lack of experience in end-of-life care planning. Healthcare professionals require training in end-of-life care management (Volicer et al., 2019). The recommended approach is to follow a palliative care model that manages disease prognosis with support, advance care planning, and pain management (Durepos et al., 2017). However, SLTs and family members may unknowingly opt for feeding tube placement to relieve perceived suffering in people with advanced dementia, which

may increase the risk of mortality (Cloete et al., 2022; Malek et al., 2018; Newman et al., 2020; Varindani Desai & Namasivayam-MacDonald, 2020). The National Institute for Health and Care Excellence (NICE) suggests tube feeding should only be used for short periods during end-of-life care and supports prolonged tube feeding only when the decision is made by the patient or an advance directive (NICE, 2006; de Jager et al., 2017). The European Society for Clinical Nutrition and Metabolism (ESPEN) recommends the PWD's representative make decisions in the absence of an advance directive, and healthcare professionals start alternative nutrition if the decision is delayed (de Jager et al., 2017). The American Geriatrics Society suggests voluntary requests for eating and drinking by PWD should ethically override the advance directive (American Geriatrics Society, 2014). These factors must be considered in South Africa, where dementia care is perceived as a low priority, and palliative care is under-resourced (Jacobs et al., 2020; Cloete et al., 2022; Newman et al., 2020; Volicer et al., 2019)

South Africa has limited resources; public services are only accessible to a small percentage of older people, predominantly in urban areas (Jacobs et al., 2020; Cloete et al., 2022). Private practitioners make up the majority of SLTs, experienced in working with PWD, further limiting access to more specialised care (Jacobs et al., 2020; Cloete et al., 2022). The American Geriatrics Society recommends careful hand feeding as an alternative to feeding tube placement for people with advanced dementia (American Geriatrics Society, 2014; Chou et al., 2020; Luk et al., 2017). However, South African SLTs did not report that careful hand feeding enhances swallowing quality or reduces feeding difficulties in PWD (Cloete et al., 2022; Fong, 2019; Luk et al., 2017). It is crucial to investigate the potential burdens and benefits of tube feeding in low-income settings like South Africa, where unqualified caregivers administer careful hand feeding. This could encourage the preference for tube feeding to maintain patient well-being (Cloete et al., 2022; Druml et al., 2016; Ijaopo & Ijaopo, 2019; Lynch, 2016).

The survey study previously conducted in South Africa by Cloete et al. (2022) provides a foundation for understanding SLTs' current practices working with PWD. However, to gain a more comprehensive understanding of the topic, the current

study aimed to focus specifically on advanced dementia and involves individual interviews with SLTs who have a particular interest in working with PWD.

Methods

Study design

The study utilised a qualitative approach with a phenomenological framework (Brink et al., 2018; Moser & Korstjens, 2018) to investigate SLTs' practices regarding feeding tube placement in people with advanced dementia. Online interviews were conducted with SLTs who had a particular interest in working with people who have dementia. The interviews aimed to explore the participants' experiences and practices related to feeding tube placement considerations in the advanced dementia population.

Study population and sampling strategy

Purposive sampling (Brink et al., 2018; Moser & Korstjens, 2018) was used to select eight participants who met the inclusion criteria: qualified SLTs, with at least three years of experience, and who have had experience within the previous year, working with people with advanced dementia in either the private- and/or public- health sector in South Africa. Four of the participants are considered specialised in working with people with dementia. Six of the participants were actively rendering services in the private sector. Five participants resided in the Gauteng province (Table 1).

TABLE 1: Participant demographic information (n=8).

Participant	Age	SLT experience (years)	Dementia experience (years)	Dementia related qualifications and training	Province	Healthcare setting	Clinical setting
A1	37	17	6	Rendered dementia care, as part of a multidisciplinary team, at one of two dementia clinics in South Africa; Attended seminars, symposiums and short courses related to dementia	Kwazulu-Natal	Public	Acute
A2	48	26	25	Cognitive stimulation therapy; Alzheimer's South Africa Consultant; Member of South African Healthy Ageing Association; Member of Memorycare; Postgraduate research project related to dementia; FEES training	Gauteng	Private	Sub-acute, acute, frail-care
A3	33	10	7	Master's degree: AAC for adults with receptive difficulties; Various CPD events related to palliation and tube-feeding; FEES training	Eastern-Cape	Private	Acute
A4	42	18	4	LSVT Loud training; Vital-stim qualified; FEES training	Gauteng	Private	Sub-acute

A5	31	10	5	Completed multiple courses via The Wicking Dementia Centre; FEES training	Gauteng	Private	Rehabilitation centre
A6	27	4	4	LSVT Loud training; Attended South African geriatric society continuous professional development series – dysphagia in the geriatric population; Presented to various frail care facilities: dysphagia in the geriatric population	Gauteng	Private	Acute
A7	44	23	13	Attended multiple seminars and symposiums related to dementia care	Eastern-Cape	Private	Acute, Rehabilitation centre
A8	26	4	3	Adult dysphagia course; Adult neuro skills building – multidisciplinary team initiative	Gauteng	Public	Acute

FEES; Fiberoptic endoscopic evaluation of swallowing
LSVT; Lee Silverman voice treatment

Data collection

Data were collected over a period of six months via online interviews on a video-conferencing platform, Microsoft Teams. Once-off online interviews created an opportunity for accessibility to various participants better representing the diverse population of South Africa (Moser & Korstjens, 2018). The interviews were guided by a self-compiled semi-structured interview schedule. The questions were tailored according to relevant literature and a recent quantitative study in the same context (American Geriatrics Society, 2014; Jacobs et al., 2020; Baijens et al., 2016; Beckly, 2017; Campbell et al., 2011; Car et al., 2017; Cloete et al., 2022; Colette et al., 2022; Hickey & Bourgeois, 2017; Kuven, 2018; Luk et al., 2017; Malek et al., 2018; Newman et al., 2020; Schwartz et al., 2014; Varindani Desai & Namasivavam-Macdonald, 2020; Volicer et al., 2019; Volkert et al., 2015; Vose et al., 2018).

Data analysis

The study used verbatim transcription of data, which was uploaded for inductive coding and reflexive thematic analyses using ATLAS.ti, a qualitative data analysis and research software. The transcripts were reviewed multiple times to organise the data into appropriate codes, which were then grouped into themes. To increase the reliability and validity of the collected data, the plausible themes were discussed with the second and third author. The study followed the guidelines of Braun and Clarke (2022) and Terry et al. (2017).

Ethical considerations

The study received institutional ethical clearance from the Faculty of Humanities' Research Ethics Committee at the University of Pretoria on 9 December 2021 (protocol number: HUM022/1021). Participation was voluntary and written informed consent was obtained from all participants.

Results

The study identified three main themes and multiple sub-themes that were in line with its aim. Table 2 provides an overview of the themes and sub-themes related to participants' practices regarding feeding tube placement in people with advanced dementia.

TABLE 2: Themes and sub-themes identified in the study.

Themes	Sub-themes
1. Factors influencing SLTs' decisions for feeding tube placement in people with advanced dementia	*Intrinsic factors* a) SLTs level of experience b) SLTs morals and beliefs c) Awareness of guidelines *Extrinsic factors* a) Availability of local guidelines b) Advance directives c) Cultural and religious background of families d) Perceived family caregiver burden
2. Nature of clinical setting and SLTs' decision making	*Clinical setting* a) Acute setting b) Instrumental assessments c) Feeding tube consideration and duration d) SLTs role e) Compensatory strategies f) Perceived nursing caregiver burden *South African contextual challenges* a) Socioeconomic status b) Geographical location c) Limited healthcare resources
3. SLTs' considerations to improve the management of people with advanced dementia	Early involvement of SLTs Continuous mentorship and collaborative practice among healthcare professionals

Factors influencing SLTs' decisions for feeding tube placement in people with advanced dementia

The theme of decision-making highlights intrinsic and extrinsic factors that influence SLTs' decisions regarding feeding tube placement in people with advanced dementia. Participants believed that increased experience and exposure, coupled with evidence-based practice, resulted in improved decision making. Two participants expressed that their experience had served them best when dealing with OPD in people with advanced dementia:

> ‘I enjoy implementing whatever I read and try new things out, but for now it’s just kind of from experience and what has served me the best so far.’ (A4, Sub-acute – Private)

> ‘It is something that takes a couple of years and a couple of different patients and different families to start making sense and putting the picture together.’ (A5, Rehabilitation centre – Private)

To be deemed competent in providing services for individuals with dementia, SLTs must possess familiarity with appropriate protocols and guidelines (American Speech-Language-Hearing Association [ASHA], 2016; HPCSA, 2019). Five SLTs in this study referred to guidelines from organisations such as the American Speech-Language-Hearing Association, the European Society for Enteral Feeding (ESPEN), and the American Geriatric Society related to feeding difficulties in people with advanced dementia. However, one participant held the view that there is limited research on the benefits of feeding tubes, stating:

> ‘. . . in terms of the pros, that I've been reading up on a little bit as well …. own bias, really trying to get both sides and with the right guidelines, with the right intervention and follow up, it [feeding tube placement] can be a good thing.’ (A3, Acute – Private)

Seven participants appeared to be unaware of local guidelines including information related to feeding tube placement in people with advanced dementia, such as the Health Professions Council of South Africa’s (HPCSA) 2019 ethical guidelines on palliative care, the National Policy Framework and Strategy for Palliative Care (2017), and Standards for Palliative Care in South Africa (2017). Three participants believed that there are limited local guidelines related to feeding tube placement in the advanced dementia population. It is possible that SLTs may be using international guidelines due to a lack of awareness of local guidelines.

Participants' beliefs also appeared to influence decision-making. Specifically, participants expressed their opinion that feeding tube placement is associated with prolonging life and how this may be ethically and morally questionable:

> ‘You say, “Oh, don’t worry, there’ll be no stress for eating. You just put the food in this tube and it’s lovely. You never have to stress about it again”, and families who have been ‘sukkel-ing’ [slang for having difficulty with] and carrying on trying to get the food in think “oh, this is the answer to my prayers”, you know, but we are changing the course of people's lives and I

> think we don't take enough of a conscious calculated ethical or moral decision-making process around it.' (A2, Acute/Rehabilitation centre/Frail care – Private)

> '. . . it is kind of until they pass away and that's more where the ethical part of it comes in. Because now you are kind of keeping someone alive but sending them home to die.' (A3, Acute – Private)

Five participants expressed the belief that feeding tube placements do not improve quality of life for people with advanced dementia:

> 'They [SLTs] have good intentions, because they have realised that oral intake is not sufficient anymore, but they're causing harm, because the life is sustained artificially. There is just so many variables that in my perspective do not guarantee a great quality of life going forward.' (A5, Rehabilitation centre – Private)

Two participants held the belief that feeding tubes can increase quality of life by ensuring adequate nutritional intake:

> 'Now, they can feed better, they look healthier, they are less frequently sick. If they do not, they are back and forth every two months. With better feeding [Percutaneous Endocscopic Gastrostomy (PEG) feeding], there is definitely better health.' (A7, Acute/Rehabilitation centre – Private)

Participants' decision-making appeared to be influenced by their own cultural and religious backgrounds, which they may not have been fully aware of. Three participants claimed that their culture or religion did not affect their decisions regarding feeding tube placement in people with advanced dementia, and that they relied solely on clinical experience:

> 'I try to approach things clinically and with as much evidence to support decisions as much as possible.' (A5, Rehabilitation centre – Private)

> 'It's one of those things that might not be a popular opinion, but unfortunately within the medical realm, there is not really place for religion and culture to affect your decisions and it is right, because we are working with medicine and it is scientific and there is a right and there is a wrong.' (A6, Acute – Private)

Two participants shared views on how their religion influenced their decisions. Participant A4 felt that her religion was an important factor but as she gained clinical experience, her decisions were increasingly guided by her expertise:

> ‘Initially, when I just started working in this field, my religion, in a very youthful sense, played a big role. I felt we are not to decide whether a patient lives or dies. My view on feeding and my knowledge and experience has changed. Also, making peace with death and the process of death. So, I think it’s more experience that plays a role, than my religion.’ (A4, Sub-acute – Private)

Participant A8 expressed how her religious beliefs influence her recommendations to ensure nutritional health in people with advanced dementia:

> ‘In terms of religion, we believe that you need to look after your health, holistically. If it means you going to a doctor …you allow yourself medical care purely because your religion requires that you look after your health. I will put it in [feeding tube], purely because I feel it can help, but obviously only through God’s help, can it help.’ (A8, Acute – Public)

Two participants disclosed that cultural stereotyping could impact their interactions with patients and recommendations:

> ‘I also acknowledge the fact that I’m dealing with an Indian family, and this is my expectations … I’m dealing with an African family, so this is the likely thing that I would encounter and if I’m dealing with a typical Afrikaans family then this is the kind of situation I might encounter. Maybe it’s also my expectation on the details that affect how I see that.’ (A7, Acute/Rehabilitation centre – Private)

> ‘We always have cultural bias, and you are trying to be so aware of your own bias because it can slip in so much.’ (A3, Acute – Private)

Participants acknowledged that the final decision related to feeding tube placement lies with a patient's family. Seven participants emphasised the importance of providing informational counselling to families prior to making decisions. Participants also expressed the belief that families' cultural and religious backgrounds could influence their attitudes towards advanced dementia and tube feeding. Six participants noted that cultural factors such as the influence of traditional healers or belief that the person with advanced dementia is bewitched may lead to a decision against feeding tube placement. Overall, participants perceived that culture has a bigger influence than the family's religious orientation.

> ‘I remember there was one particular family that we had, and they were convinced that their father was bewitched. And that was why he was presenting in this manner.’ (A1, Acute – Public)

> ‘You have to let the patient sign to that – to say that “I want to take my loved one out of the hospital to go and do this (go to a traditional healer) and I am basically refusing care from the hospital.”’ (A8, Acute – Public)

The presence of an advance directive was found to facilitate collaboration with family members, as reported by six participants. They felt that advance directives eased decisions related to feeding tube placement. However, two participants mentioned that advance directives primarily relate to palliative considerations such as ventilation and resuscitation, rather than feeding tube placement.

Six participants felt feeding tube placement should not be recommended during palliative care for people with advanced dementia, citing reasons such as decreased energy levels, poor cognitive abilities, and increased risk of infection from dislodged feeding tubes. In contrast, some attempts to alleviate perceived caregiver burden may lead to PEG tube placement in this population:

> ‘…maybe there is not a good plan in place, or the family has not figured out a frail care setting or there is not consensus about who is going to take care of this member [the patient with advanced dementia]. Then I really see that PEG placements happen very quickly.’ (A3, Acute – Private)

Three participants reiterated that feeding tube placement can ease perceived caregiver burden, while two participants disagreed and expressed the view that PEG tube placement increases caregiver burden:

> ‘It is decreasing their mortality, because obviously they get longer nutrition, their bodies are healthy, …have a little bit more strength. It is just that their mind is not there. So, you are decreasing mortality, yes, but like I said – you do not know how long the family is going to continue doing it [feeding through PEG tube], because it is such a big responsibility on them.’ (A8, Acute – Public)

Nature of clinical setting and SLTs decision making

This theme highlights the role of the clinical setting and geographical location in South Africa in shaping SLTs practices regarding feeding tube placement in people with advanced dementia. The findings suggest that the acute care setting is the most prevalent setting where participants encounter people with advanced dementia, and six participants reported their likelihood to recommend feeding tubes if patients are admitted to acute care settings.

Five participants expressed their need for access to instrumental assessments, such as videofluoroscopic swallowing study (VFSS) and fiberoptic endoscopic evaluation of swallowing (FEES), to assess OPD and facilitate improved decision-making. Participant A5 emphasised that instrumental assessments, particularly FEES, could enhance the effectiveness of informational counselling by providing tangible evidence in addition to clinical opinion. This sentiment was echoed by two other participants:

> 'If objective assessments would be more accessible, then I would know I am making the right decisions and maybe I would have more evidence to educate the patients and families, because "look, you can see it on the screen, what's happening."' (A5, Rehabilitation centre – Private)

Two other participants felt that patients with advanced dementia often present with poor health and cognition affecting accessibility to, and the feasibility of, instrumental assessments. Five participants indicated that nasogastric tube (NGT) placements serve as a temporary solution, not exceeding six weeks. After six weeks, a permanent decision should be made: transitioning to oral feeds or PEG tube placement, especially for discharge to home. Participants felt that NGT feeding poses a greater risk for aspiration as it can dislodge easily, and it requires frequent follow-up appointments.

Some SLTs (n=3) considered PEG tubes as a safer option. Participants noted that certain rehabilitation and frail care facilities admitted patients under two conditions: feeding orally or feeding via PEG tubes, as an attempt to decrease the perceived burden of care on nursing staff. Discharge planning is believed to be further complicated by socio-economic factors. Four participants felt that PEG tube

placement, in people with advanced dementia, living in a rural setting with limited resources, is not feasible. Participants expressed that poor access to basic sanitary resources may increase the risk of aspiration. The person with advanced dementia's health was perceived to be further exacerbated by poverty, affecting optimal nutritional intake:

> '… it is often times that someone maybe lives very rurally. They do not have access to clean water, so they are not going to be able to clean the PEG tube nicely, or they do not have the equipment to actually blend the feeds to pass it through the PEG tube …' (A6, Acute – Private)

Alternatively, participant A7 considered socio-economic challenges and how it affects access to healthcare. Participants believed the progressive nature of advanced dementia leads to poor adherence of follow-up appointments. This is exacerbated by contextual factors such as poor access to healthcare due to increased travelling distance and decreased transport availability, further aggravated by financial constraints. For these patients, who also present with ongoing feeding difficulties, the participant would consider PEG tube placement:

> 'It also depends on whether the patient will be able to return for follow ups as often as they should. If they are from really far away then you have to consider (most probably pensioners) that they cannot afford to keep coming back for review, so my decision is also linked to that [the distance]. Then that has to be a quick decision and a more permanent one and most convenient.' (A7; Acute/Rehabilitation centre – Private)

Participant A1 reiterated this view as there are likely only two dementia clinics in South Africa. Despite these challenges, five participants verbalised that feeding tube placement is considered a team decision and should be a collaborative practice:

> 'I am very lucky to work in a multidisciplinary team. We discuss it with the geriatrician or the physician, the pulmonologist or the neurologist if need be. It is very much a team decision. It is never down to just my decision, and obviously consulting with the families as well.' (A2, Acute/Rehabilitation centre/Frail care – Private)

All participants (n=8) indicated that the SLT's role in the clinical team is to advocate for the family's and patient's rights and to provide informational counselling. Contrastingly, three participants mentioned that they would still make

recommendations related to feeding tube placement, despite the patient's wishes indicated in the advance directive:

> 'As from a clinical perspective, I'm still saying that that is my recommendation, but however, the family or the person with dementia has stipulated in whatever it may be [advance directive].' (A8, Acute – Public)

> 'My recommendations will kind of still stay the same in terms of these are the pros and cons of both.' (A3, Acute – Private)

To ensure safe oral feeding in people with advanced dementia, who also present with OPD, all participants revealed a preference towards compensatory strategies such as careful hand feeding, environmental modifications such as modifying diets by following international dysphagia diet standardisation initiative guidelines (IDDSI), and the use of the Frazier free water protocol (Cichero et al., 2017; Panther et al., 2005).

Two participants expressed that understaffed units may lead to poor adherence to compensatory feeding strategies and an increase in NGT placements within the acute setting, to relieve the perceived healthcare burden experienced by nurses. This was particularly emphasised when related to public acute health care settings:

> 'We are not an ideal gold standard where it is a nurse to a patient. It is sometimes one nurse to six patients … ten patients. She has to now feed all these patients and by the time she is done, it is already the next feed (for example). There are other responsibilities – medication, looking at their vitals… That is also our safety net – to know that the NGT is in, because sister is not going to feed that full bowl of food.' (A8, Acute – Public)

SLTs' considerations to improve the management of people with advanced dementia

Four participants highlighted early involvement of SLTs during management of people with advanced dementia. This may lead to timely informational counselling, allowing the SLT to guide families when making important decisions, especially during palliative care. Additionally, earlier initiation of treatment may delay the progression of the disease:

> ‘If we catch it [dementia] earlier, then we can delay the whole thing, obviously the advanced stages, it is going to come, but it is delayed for as long as possible.’ (A1, Acute – Public)

> ‘Whether it be me or someone else, but hopefully a speech therapist, to just say what we are expecting, what the prognosis is, so that it does not lead to a rash decision when they come into acute with late stage [advanced dementia], but that the family is already aware of the options from day one and that the actual person with dementia can have a say in how they would like their quality of life to be at the end stages.’ (A3, Acute – Private)

Two participants highlighted the importance of continuous mentorship and collaboration between healthcare professionals to render optimal services to people with advanced dementia:

> ‘I was initially challenged by a doctor that I worked with in a sub-acute unit, where I felt very strongly that this man should get an NGT and eventually a PEG tube and the doctor said “What for? What do you think you’re going to gain for this person?” After a lot of years of working together, you kind of came to a middle ground, but from my personal experience, it made me start thinking in another way.’ (A4, Sub-acute – Private)

> ‘I strongly feel the need for mentorship in this specific area of practice with speech.’ (A6, Acute – Private)

Discussion

The study revealed that SLTs decisions regarding feeding tube placement in people with advanced dementia were influenced by a number of factors. Participants relied heavily on their clinical experience rather than available literature. Participants’ work setting and geographical location may alter decisions on whether patients are recommended feeding tubes. Participants revealed that SLTs’ perspectives on culture and religion could change their decisions.

Figure 1 depicts the feeding tube placement decision-making process of SLTs in patients with advanced dementia who have OPD and the various factors that can influence their recommendations.

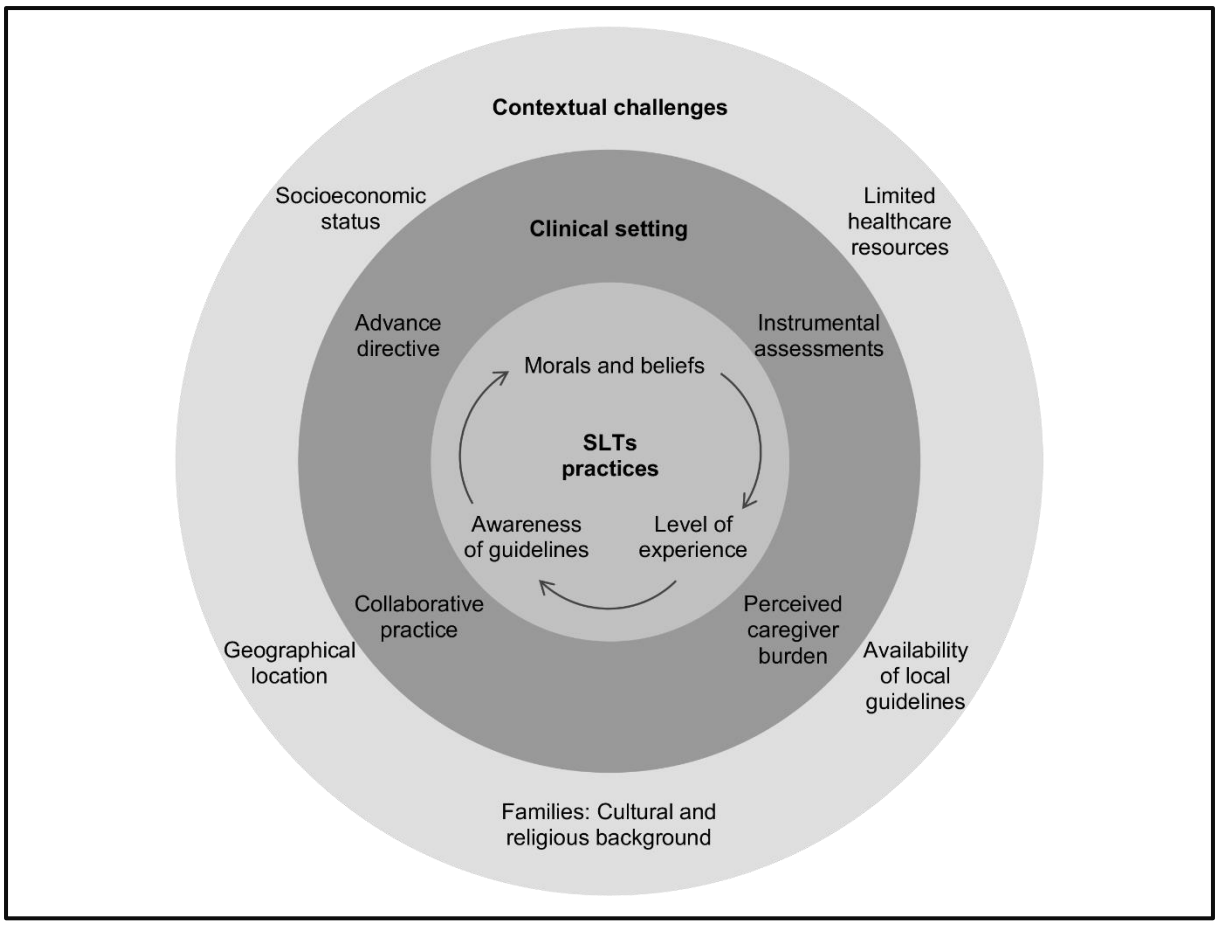

FIGURE 1: SLTs' practices and influencing factors related to decisions about tube feeding in the advanced dementia population.

An ecological approach (Bronfenbrenner, 1979) is followed (Figure 1) to illustrate the complex interplay between SLTs and various environmental factors that may impact their decision-making when treating individuals with advanced dementia. This approach acknowledges that SLTs are not solely responsible for their decisions, as external factors can also influence their choices. Intrinsic factors, such as SLTs' personal beliefs, extrinsic factors such as guidelines, and contextual challenges like socioeconomic status and geographical location, are included. The interplay between these factors and their impact on SLTs' approaches to treatment is depicted. Limited resources may lead to consideration of feeding tube placement, while personal beliefs and experiences may favour palliative care and careful hand feeding. Understanding these factors is vital for providing person-centred care to people with advanced dementia.

Existing local guidelines on palliative care were not mentioned by SLTs, which could contribute to a mismatch between decision-making and best practice. The lack of

awareness of guidelines, combined with the absence of SLT clinical practice guidelines that reflect the unique challenges present in South Africa (Andrews & Pillay, 2017; Jacobs et al., 2020; Cloete et al., 2022; Durepos et al., 2017; Kochovska et al., 2020; Tsao et al., 2019; Varindani Desai & Namasivayam-Macdonald, 2020), may mean that SLTs rely on clinical expertise rather than recent literature and research. A need for contextually relevant guidelines for SLTs developed by local governing bodies such as SASLHA, is highlighted. Clinical practice guidelines that define the palliative care approach and end-of-life care management would support less-experienced SLTs and address challenges specific to South Africa.

The SLTs in the study demonstrated partial alignment with the palliative care approach by acknowledging that tube feeding does not improve quality of life of people with advanced dementia, but some still believed it could support optimal nutrition (Drenth et al., 2018). This contradicts current evidence that neither quality of life nor nutrition are enhanced by tube feeding in such patients (American geriatrics society, 2014; Baijens et al., 2016; Hýden et al., 2022; Ijaopo & Ijaopo, 2019; Payne & Morley, 2018). Additionally, participants appeared to make decisions influenced by their lived-experiences, such as cultural stereotyping and imparting moral beliefs, which may have compromised the quality of life of their patients with advanced dementia. Healthcare professionals tend to make decisions based on emotions rather than evidence-based findings (Kozlowski, 2017). Although cultural sensitivity is important in a diverse context , it may introduce personal bias into recommendations that do not align with literature (Stellenberg & de Wet, 2016; Mash, 2016). To ensure that the care of individuals with advanced dementia prioritises quality of life over longevity, it is essential for SLTs to be cognisant of how their own cultural and religious beliefs, as well as those of the patient's family, may influence their decision-making (Drenth et al., 2018). SLTs should be educated about current evidence-based research and culturally-sensitive practices related to people with advanced dementia at university to prevent personal biases from influencing their decision-making.

In chronic illnesses such as advanced dementia, end-of-life care is inevitable, and continuum of care is crucial (Durepos et al., 2017). Participants preferred

compensatory strategies, i.e., careful hand feeding, to promote exclusive oral feeding and improve quality of life before considering enteral feeding, in line with current research (American Geriatrics Society, 2014; Chou et al., 2020; Luk et al., 2017). In South Africa, contextual challenges such as perceived caregiver burden, financial costs, and time constraints may complicate continuum of care, leading SLTs to recommend PEG tube placement as a solution. The deviation from evidence-based practice may compromise a patient's quality of life. Additionally, people in residential care homes for the elderly often require hospitalisation due to feeding tube complications, despite the perceived caregiver burden being lessened (Yuen et al., 2022). Contextual constraints place a clinical burden on SLTs that inevitably compromise the management of their patients with advanced dementia. To better support healthcare professionals in making evidence-based decisions, larger scale measures such as prioritising home-based visits should be considered to ensure optimal continuity of care. This may assist SLTs to prioritise the quality of life of patients, despite contextual challenges.

Participants mentioned that access to instrumental assessments could improve information-giving to families when considering tube feeding in people with advanced dementia who present with OPD. Frailty of patients was identified as a clinical obstacle affecting access to such assessments (Dziewas, 2017). Participants highlighted the applicability of FEES to the advanced dementia population, where cognitive decline may limit the feasibility of other assessments, citing benefits such as portability and continuity of care (Dziewas, 2017; Langmore et al., 2007; Warnicke et al., 2010, 2016; Wirth et al., 2016). However, limited access to instrumentation and training locally may hinder the practicality of implementing FEES. Further research could explore the effectiveness of alternative, accessible, and cost-effective approaches like telemedicine and mobile health technologies in facilitating remote access to instrumental assessments and providing training for healthcare professionals in resource-limited settings.

Participants believed their role was to advocate for patients' rights, but some made recommendations that contradicted patients' advance directives. This deviation from patient autonomy goes against the principles of palliative care, as noted in previous research (Durepos et al., 2017; Huang et al., 2020). While the study finds that the

SLTs were mostly aware of ethical considerations involved in palliative care, they sometimes disregarded the legal bindings and consequences thereof, which has ethical implications for service delivery. The study highlights the need for healthcare settings in South Africa to regularly review and enforce ethical guidelines. By adhering to the HPCSA ethical code of conduct, healthcare professionals, including SLTs, can promote patient autonomy and uphold ethical standards in palliative care (HPCSA, 2019).

The acute setting was identified as the context where SLTs often opted for tube feeding usually due to pneumonia, dehydration or dysphagia. In this study, participants stated that PEG tube insertion would be considered if the person with advanced dementia had not established oral feeds after six weeks or if the NGT needed to be removed upon discharge. The study highlighted a gap in practice as SLTs did not consider tube feeding placement during the palliative phase of dementia, despite dementia being considered a palliative illness from its onset (Drenth et al., 2018). This finding is troubling, given that ESPEN guidelines only recommend tube feeding for mild to moderate cases of dementia, and prolonged tube feeding in advanced dementia should only be considered if informed by the patient or an advance directive (de Jager et al., 2017; NICE, 2006). The importance of awareness and education of SLTs regarding the use of tube feeding in advanced dementia is highlighted. It is crucial that healthcare professionals, including SLTs, understand the palliative nature of dementia and the appropriate use of tube feeding in advanced cases. Healthcare settings should prioritise professional development for SLTs regarding end-of-life care management (Cloete et al., 2022; Huang et al., 2020), particularly the use of tube feeding in advanced dementia. Acquiring a strong foundation in ethical practice and end-of-life care management through undergraduate training may enable SLTs to make informed decisions based on patient needs, preferences, ethics, and evidence-based guidelines.

Decision-making about tube feeding placement for people with advanced dementia can be challenging and complex for SLTs in low-resourced settings. However, the study highlighted that such decisions should be a collaborative practice among a team of specialised healthcare professionals. This could be achieved through early MDT involvement, collaboration in end-of-life discussions, and establishing

discharge and care planning alongside family and caregivers (Anantapong, 2022; Cloete et al., 2022; Toles, 2018). To ensure best practice in management of advanced dementia, it is crucial to provide continued mentorship to SLTs and encourage collaborative discussions among allied healthcare professionals (Anantapong, 2022; Cloete et al., 2022). To explore partially understood topics, SLTs could use designated discussion forums or groups focused on special interests, highlighting the importance of continuing professional development and continued research efforts.

Further research is needed to improve decision-making for feeding tube placement in people with advanced dementia in South Africa. Large-scale studies to explore factors that impact decision-making among health care professionals, as well as assessing roles of other team members, and exploring ethical and legal dilemmas, are warranted. Such research can ensure ethical and enhanced quality of care to prioritise patient autonomy and involve caregivers in more optimal decision-making.

Conclusion

The study finds that SLTs in South Africa often rely on clinical expertise rather than research evidence and published guidelines when making decisions about feeding tube placement for people with advanced dementia. Updated local guidelines and continued professional development in the form of education and training for qualified SLTs will improve end-of-life care for people with advanced dementia. Interprofessional collaboration among healthcare professionals is important to ensure best practice and ethical decision making throughout the continuum of care for the advanced dementia population.

Strengths and limitations

The study included a small sample of SLTs with a particular interest in managing people with advanced dementia. Therefore, findings cannot be generalised, but provide useful insights into the decision-making of South African SLTs working with people with advanced dementia.

Competing interests

The authors of the study have no competing interests to declare. The study was conducted during the Master's degree of DP.

Author contributions

DP, BP and EK conceptualised the research and co-wrote the article. Data collection and analysis was conducted by DP with input from co-authors. All authors reviewed and approved the final version of the manuscript for submission.

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Data availability

The data used in this study will be made available on the University of Pretoria's repository for transparency and reproducibility purposes.

Disclaimer

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Chapter 4: Implications and conclusions

Chapter aim:

The purpose of this chapter is to discuss the implications of the study on feeding tube placement decisions for people with advanced dementia in South Africa.

4.1. Summary of main results

Three main themes emerged from the study: a) Factors influencing SLTs' decisions for feeding tube placement in people with advanced dementia, b) Nature of clinical setting, and SLTs' decision making and c) SLTs' considerations to improve the management of people with advanced dementia.

The first theme centred on the factors influencing SLTs' decision-making about feeding tube placement in individuals with advanced dementia. The participants considered clinical experience, exposure, and evidence-based practice as important factors in making sound decisions. Additionally, guidelines or protocols from relevant organisations and professional bodies were deemed crucial in SLTs' knowledge of working with individuals with dementia. However, beliefs and values of SLTs also played a role in decision-making, as participants often believed that feeding tube placement can prolong life. Participants' beliefs and values that may influence their decisions could result in ethical and moral dilemmas.

The second theme showed that the participants experience a high prevalence of advanced dementia in acute care settings, where there is a need for instrumental assessments, such as videofluoroscopic swallow studies (VFSS) and fiberoptic endoscopic evaluation of swallowing (FEES), and there are numerous socio-economic factors that impact discharge planning. The participants stressed that feeding tube placement should be a collaborative practice and a team decision. They emphasised the use of compensatory feeding strategies, such as careful hand feeding to improve feeding, environmental modifications, and adherence to the IDDSI and the Frazier free water protocol according to known literature (Cichero et al., 2017; Panther et al., 2005).

The third theme pointed out the importance of the early involvement of SLTs in the management of advanced dementia. Participants viewed continuous mentoring and collaboration in the management of advanced dementia as imperative. The participants highlighted their view that timely informational counselling by SLTs is critical to guide families in making important decisions especially during palliative care. Participants also believed that earlier initiation of treatment could delay disease progression. Additionally, participants emphasised the importance of continuous interprofessional collaboration between healthcare professionals and mentoring for less-experienced clinicians to deliver optimal services to individuals with advanced dementia, specifically to develop better decision-making skills and provide services aligned with evidence-based practice.

4.2. Clinical and theoretical implications

This study reflecting SLTs insights (practices and perspectives) related to feeding tube placement in people with advanced dementia in South Africa has important clinical and theoretical implications. SLTs' decision-making in South Africa is complex and influenced by various factors, highlighting the need for contextually relevant guidelines (Anantapong, 2022; Cloete et al., 2022; Toles, 2018).

Considering the following challenges faced by South African SLTs: (a) limited awareness and access to locally relevant guidelines, (b) perceived caregiver burden, financial costs, and time constraints affecting continuum of care for people with advanced dementia, and (c) limited access to instrumental assessments; it is important to develop contextually relevant guidelines. This process should involve collaboration with various stakeholders, including healthcare professionals, caregivers, and policymakers. Encouraging and supporting SLTs to stay up-to-date with evidence-based practice could be achieved through accessible databases, workshops, and online resources (Greenwell & Walsh, 2021). Enhancing undergraduate education through hands-on examples and research opportunities can equip students to address post-graduate clinical challenges more efficiently.

Aligned with current research, participants preferred compensatory strategies, such as careful hand feeding, to promote exclusive oral feeding and improve quality of life before considering enteral feeding (American Geriatrics Society, 2014; Chou et al.,

2020; Luk et al., 2017). However, contextual challenges like perceived caregiver burden, financial costs, and time constraints may lead to SLTs recommending PEG tube placement as a solution, deviating from evidence-based practice and compromising the patient's quality of life. This current study's findings imply that the palliative care approach should be prioritised in the management of advanced dementia (Drenth et al., 2018). Therefore, increased community-based measures such as prioritising home-based visits should be considered to ensure continuity of care and help SLTs prioritise the quality of life of their patients.

SLTs in this study alluded to the limited access that they have to conduct instrumental assessments with their patients. Access to instrumental assessments can improve the quality of information provided to families when considering tube feeding in people with advanced dementia who also present with OPD (Dziewas, 2017; Warnicke et al., 2010, 2016; Wirth et al., 2016). However, frailty was identified as a clinical obstacle affecting access to such assessments, highlighting the need for further exploration of the feasibility of instrumental assessment in this vulnerable population (Dziewas, 2017). Efforts must be made to address these obstacles and ensure comprehensive informational counselling, which are crucial for treating patients with advanced dementia and OPD. Considering the context of South Africa, it is essential to acknowledge the limited access to instrumental assessments such as VFSS and FEES for SLTs (Coutts & Pillay, 2021). Due to the lack of accessibility and the potential risks associated with these procedures in frail populations, alternative and creative solutions must be sought to address the challenges faced by SLTs in assessing and managing dysphagia in individuals with advanced dementia.

One approach could be the development and implementation of context-specific, non-instrumental assessment methods and tools that can be used by SLTs to evaluate swallowing difficulties in people with advanced dementia. These methods and tools should be designed to provide reliable and clinically relevant information while minimising the burden on patients and healthcare providers. A multidisciplinary team approach that includes quality-of-life assessments and comprehensive informational counselling could be beneficial in improving decision-making and providing valuable support to SLTs, patients, and their families. As suggested in the study by Lam et al. (2017), counselling as a collective can be an effective strategy to

address the challenges faced by healthcare professionals in managing patients with advanced dementia related OPD. Fostering collaboration among team members allows them to share their expertise and provide tailored recommendations based on the patient's specific needs and preferences.

Fostering patient autonomy and adhering to ethical standards in palliative care is underscored by this study. While participants felt their role was to advocate for patients' rights, some participants made recommendations that contradicted patients' advance directives. The recommendations conflict with the principles of palliative care (Durepos et al., 2017; Huang et al., 2020). Disregarding a patient's wishes and ethical guidelines set forth by professional bodies such as the HPCSA's (2019) ethical guidelines on palliative care, the National Policy Framework and Strategy for Palliative Care (2017), and Standards for Palliative Care in South Africa (2017), could be considered unethical conduct. To ensure ethical decision-making and adherence to ethical guidelines, continuous professional development and education is essential for healthcare professionals, including SLTs, in palliative care. It can be achieved through education on ethical principles, communication skills, and decision-making. Healthcare professionals can provide ethical and patient-centred care by gaining knowledge and tools to navigate complex situations and make informed, ethical decisions that respect patients' autonomy and preferences.

In light of this study's findings, it is evident that healthcare professionals need more than just knowledge of ethical guidelines. Healthcare professionals, such as SLTs, require ongoing support and education to ensure appropriate application and implementation of such principles in daily practice. Professional bodies such as SASLHA play a crucial role in addressing this issue. SASLHA may actively promote continuing professional development opportunities focused on ethical conduct, decision-making, and communication skills for healthcare professionals working in palliative care. This would provide SLTs with the knowledge and tools necessary to make informed, ethical decisions that respect patients' autonomy and preferences. Furthermore, implementing mentorship programs within healthcare settings can help professionals gain practical insights and guidance from experienced colleagues. Engaging in mentorship programs within healthcare settings would allow professionals to learn from practical examples, discuss ethical dilemmas, and gain

valuable feedback on their decision-making. Regular reviews of ethical guidelines within healthcare settings, along with strict enforcement of consequences for violations, would help maintain high ethical standards and accountability among healthcare professionals. Incorporating a multi-faceted approach that involves continued professional development, mentorship, and ongoing evaluation of guidelines would contribute to improved decision-making and an ethical, patient-centred approach to palliative care in South Africa.

Collaborative decision-making, related to feeding tube placement, among a team of specialised healthcare professionals is crucial to ensure best practices in the management of advanced dementia. Ongoing mentoring for less-experienced SLTs and collaborative dialogues among healthcare professionals are vital for improving care quality, prioritising patient autonomy, adhering to ethical standards, and engaging caregivers in decision-making (Anantapong, 2022; Cloete et al., 2022; Toles, 2018). SLTs possess specialised knowledge, but some decisions, related to feeding tube placement in people with advanced dementia, may extend beyond their scope, requiring the collective expertise of a multidisciplinary team. Incorporating various healthcare professionals, such as doctors, nurses, dietitians, and social workers, can facilitate a comprehensive and holistic approach to care. The collaborative framework acknowledges that there are no one-size-fits-all solutions, and decision-making, around feeding tube placement, should be tailored to each patient's unique needs and circumstances (Gilbar & Miola, 2015). Early involvement of the team is essential to ensure a cohesive and coordinated approach to care. Proactive collaboration in end-of-life discussions and discharge planning, involving family caregivers as active participants, can facilitate achieving this goal (Anantapong, 2022; Cloete et al., 2022).

Integrating motivational interviewing techniques can be an effective strategy for engaging families in the decision-making process of feeding tube placement for individuals with advanced dementia. The approach encourages families to explore and clarify their beliefs, values and preferences, considering their cultural and religious backgrounds (Miller & Rollnick, 2012). By incorporating motivational interviewing, healthcare professionals can gain a deeper understanding of each family's unique needs, enabling enhanced personalised and culturally sensitive care

and support (Miller & Rollnick, 2012). Through fostering a collaborative environment and placing emphasis on open dialogue, SLTs could effectively navigate the complexities of decision-making in feeding tube placement for individuals with advanced dementia.

4.3. Strengths and limitations

The choice of a qualitative approach with a phenomenological framework (Braun & Clarke, 2022; Brink et al., 2018) for this study allowed the researcher to delve into the participants' experiences and practices related to feeding tube placement considerations in the advanced dementia population. The approach provided valuable insights into the decision-making processes and the factors influencing SLTs, which might not have been captured through quantitative methods.

The study also utilised purposive sampling to select qualified SLTs with recent experience and a particular interest in working with people with advanced dementia in South Africa's private and public health sectors (Brink et al., 2018). Utilising purposive sampling to select qualified SLTs with recent experience and a particular interest in working with people with advanced dementia in South Africa's private and public health sectors (Brink et al., 2018) is valuable for several reasons. First, it ensured that the participants were knowledgeable and experienced in the topic under investigation, which increases the credibility and relevance of the findings. Second, including SLTs from private and public health sectors captured diverse perspectives and practices, enhancing the understanding of challenges and decision-making processes in this context. Finally, by targeting professionals with a specific interest in the field, the study benefited from participants' passion and commitment to improving care for individuals with advanced dementia, enhancing the depth and quality of insights gained. The interviews were conducted online via a video conferencing platform, which provided accessibility to various participants. The use of verbatim transcription and inductive coding with reflexive thematic analyses using ATLAS.ti allowed for a thorough and systematic analysis of the collected data.

The sample size of the study was relatively small, consisting of eight participants who met the inclusion criteria. Therefore, the study's findings may not be generalisable to all SLTs in South Africa. While the study's reliance on self-reported

data may introduce bias (Brink et al., 2018), as participants may not always provide accurate or complete information, it is essential to note that the chosen participants were knowledgeable and experienced in the topic under investigation. As a result, the data gathered from these participants is likely to be valuable and insightful, offering an in-depth and meaningful understanding of the challenges and decision-making processes in the context of advanced dementia care.

4.4. Future research recommendations

Based on the results of the study and the identified limitations, several recommendations for future research can be made. Firstly, the study was limited to a small sample of SLTs in South Africa who had recent experience working with people with advanced dementia. To gain a comprehensive understanding of the decision-making process regarding feeding tube placement in people with advanced dementia, it may be useful to explore the perspectives of other healthcare professionals involved, such as doctors, nurses, and caregivers (Durepos, 2017). Conducting focus group discussions or in-depth interviews with these stakeholders could provide valuable insights into their experiences, challenges, and opinions on the subject (Brink et al., 2018). This broader approach would contribute to a holistic understanding of the decision-making process, capturing diverse perspectives and facilitating the development of more effective, collaborative care strategies.

It may be valuable to investigate the impact of cultural and religious beliefs on feeding tube placement decisions in people with advanced dementia among healthcare professionals. This study is in line with a previous study, which revealed that participants' cultural and religious backgrounds influenced their decision-making (Cloete et al., 2022). However, due to the small sample size and the study's qualitative nature, further research is required to explore this issue in greater depth. Additionally, future research could explore the role of healthcare professionals in addressing cultural and religious factors related to families of people with advanced dementia when making decisions about feeding tube placement.

Finally, the study revealed that SLTs relied on international guidelines for feeding tube placement in the absence of local guidelines. Future research could focus on the development of local guidelines in South Africa specifically for SLTs, addressing

feeding tube placement in people with advanced dementia (Cloete et al., 2022). These guidelines would provide SLTs with a clear framework for assessment, management, and decision-making processes tailored to the unique context of South Africa. By incorporating context-specific information and considerations, such as available resources, cultural factors, and interdisciplinary collaboration, these guidelines can better support SLTs in providing effective, evidence-based care for individuals with advanced dementia and their families. The study also found that some participants were unaware of local guidelines related to feeding tube placement in advanced dementia, such as the HPCSA's (2019) ethical guidelines on palliative care, the National Policy Framework and Strategy for Palliative Care (2017), and the Standards for Palliative Care in South Africa (2017). Future research could explore ways to increase awareness and implementation of guidelines among healthcare professionals working with people with advanced dementia.

4.5. Conclusion

The findings of this study on feeding tube placement considerations in advanced dementia are valuable for SLTs, other healthcare professionals involved in advanced dementia care, families of individuals with advanced dementia, and policymakers in South Africa. To enhance SLTs decision-making capabilities related to people with advanced dementia, SLTs could benefit from ongoing education and support related to ethical principles and decision-making processes, as well as local guidelines tailored to the unique, local context. Further research is needed to improve decision-making for feeding tube placement in people with advanced dementia in South Africa. Large-scale studies to explore factors that impact decision-making among health care professionals, as well as assessing roles of other team members, and exploring ethical and legal dilemmas, are warranted. Such research can ensure ethical treatment and enhanced quality of care to prioritise patient autonomy and involve caregivers in optimal decision-making in the advanced dementia population.

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Appendices

Appendix A: Self-compiled semi-structured interview schedule

Section	Questions	Probe-questions
A. Tube feeding and the role of the SLT.	1. Advanced dementia presents with frequent challenges affecting multiple domains involved in daily living. How would you define advanced dementia? 2. Overall, what would you say is your assessment approach regarding individuals with advanced dementia who present with OPD? 3. Keeping Q1 in, what would you say is your overall intervention approach regarding individuals with advanced dementia who present with OPD? 4. In your opinion, what does the role of SLTs involve when working with people who have advanced dementia who present with OPD? 5. What is your opinion on tube feeding (such as NGT and PEG), in people with dementia, especially during the advanced stage of dementia? 6. Considering your answer in Q5, what do you believe is your specific role in feeding tube placement in people with advanced dementia?	
B. Current practices.	7. Please classify your clinical setting (public/private & acute/rehab) and tell me how you (in your clinical setting) make the decision to provide tube feeding to people with advanced dementia.	a) Please elaborate on what you base your decision.
	8. What type of tube placement do you recommend, more frequently, in people with advanced dementia?	a) When would you prefer recommending feeding tube placement as a treatment method? Elaborate. b) When would you not recommend tube feeding? c) What alternative intervention methods would you recommend if not selecting tube feeding?
	9. What guidelines do you use to guide your decision making relating to feeding tube placement in people with advanced dementia?	a) Elaborate upon local or international guidelines/principles? b) What guidelines relating to feeding and swallowing related to advanced dementia, are stipulated and recognised within your scope of practice by your professional regulatory body (i.e., the HPCSA or SASLHA)?
	10. What is the typical duration of tube feeding placement in people with advanced dementia and under what circumstances would you decide to possibly wean people with advanced dementia from tube feeding?	a) Elaborate on assessments you may use or protocols available to you.
	11. Have you ever heard of careful handfeeding among individuals with advanced dementia, if so, have you made use of this method?	a) Could you elaborate on careful hand feeding and those who are familiar with it? b) When would you make use of it? c) Why would you or wouldn't you make use of it?

	12. Between tube feeding and careful hand feeding, which one would you, in your experience, say is more beneficial relating to advanced dementia?	a) Why is that so, in your opinion?
	13. How is your answer in Q12 reflected in your clinical practice?	
	14. How do you think culture and religion influence SLTs clinical decision-making regarding feeding tube placement in people with advanced dementia?	a) If you feel comfortable enough to answer, how have your views related to your religion or culture influenced your clinical decision-making regarding feeding tube placement in people with advanced dementia?
	15. How does input from a patient, or family member, influence your decision making in the management of a person with advanced dementia?	a) How does the presence and/or absence of an advanced directive affect your decision making on whether or not to recommend tube feeding?
C. Training, skills and future practice for challenges perceived in UMIC, with low-income settings such as South Africa.	16. How do you feel about current practices of SLTs in South Africa associated with tube feeding in people with advanced dementia?	a) What challenges have you encountered in a South African healthcare setting that influenced your decision-making regarding tube feeding in people with advanced dementia?
	17. In terms of mortality and quality of life, what difference do you believe you are making for people with advanced dementia and their families when you provide feeding recommendations like tube-feeding?	
	18. What do you feel are your needs regarding OPD in people with advanced dementia?	a) Will you please mention a few ideas you may have about your needs regarding the management of OPD in people with advanced dementia? b) Can you perhaps tell me more about your needs, if you have any, in terms of resources in your setting?
	19. Is there anything we have missed that you want to tell me about your clinical practice with people with advanced dementia and feeding tube placements?	

Appendix B: Content and justification for use of questions in the interview schedule

Section and proposed questions	Justification for inclusion in the interview and supporting references
Section A: Tube feeding and the role of the SLT. 1. Advanced dementia presents with frequent challenges affecting multiple domains involved in daily living. How would you define advanced dementia? 2. Overall, what would you say is your assessment approach regarding individuals with advanced dementia who present with OPD? 3. Keeping Q1 in, what would you say is your overall intervention approach regarding individuals with advanced dementia who present with OPD? 4. In your opinion, what does the role of SLTs involve when working with people who have advanced dementia who present with OPD? 5. What is your opinion on tube feeding (such as NGT and PEG), in people with dementia, especially during the advanced stage of dementia? 6. Considering your answer in Q4, what do you believe is your specific role in feeding tube placement in people with advanced dementia?	To gain insight regarding SLTs perceived role regarding tube feeding in people with advanced dementia (Beckly, 2017; Hickey & Bourgeois, 2017).
Section B: Current practices. 7. Please classify your clinical setting (public/private and acute/rehab) and tell me how you (in your clinical setting) make the decision to provide tube feeding to people with advanced dementia. 8. What type of tube placement do you recommend, more frequently, in people with advanced dementia? 9. What guidelines do you use to guide your decision making relating to feeding tube placement in people with advanced dementia? 10. What is the typical duration of tube feeding placement in people with advanced dementia and under what circumstances would you decide to possibly wean people with advanced dementia from tube feeding? 11. Have you ever heard of careful handfeeding among individuals with advanced dementia, if so, have you made use of this method? 12. Between tube feeding and careful hand feeding, which one would you, in your experience, say is more beneficial relating to advanced dementia? 13. How is your answer in Q12 reflected in your clinical	Currently in South Africa, there are no regulatory guidelines to support SLTs clinical decision-making regarding feeding tube placements in people with dementia. This study aims to further explore challenges related to, as well as the possible influence of culture, religion and family of the PWD have on SLTs clinical decision making related to feeding and swallowing difficulties. Relative quantitative data have been reported on these challenges, consequently, this study aims to build upon this data obtained with the focus on the advanced dementia population (Cloete et al., 2022; Jacobs et al., 2020; Varindani Desai & Namasivavam-MacDonald, 2020). a) To investigate what treatment methods and guidelines influence SLTs current practices regarding tube feeding in people with advanced dementia. b) To determine if religious preferences and culture play a role in the beliefs and practices of SLTs in the management of people with advanced dementia. c) To gain insight regarding alternative

practice? 14. How do you think culture and religion influence SLTs clinical decision-making regarding feeding tube placement in people with advanced dementia? 15. How does input from a patient, or family member, influence your decision making in the management of a person with advanced dementia?	treatment methods: i.e., careful hand feeding. d) To consider the implications of contributing factors (i.e., level of experience, family members) on SLTs decision making regarding tube feeding. (American geriatrics society, 2014) (Baijens et al., 2016) (Beckly, 2017) (Campbell et al., 2011) (Car et al., 2017) (Hickey & Bourgeois, 2017) (Kuven, 2018) (Luk et al., 2017) (Malek et al., 2018) (Newman et al., 2020) (Schwartz et al., 2014) (Volicer et al., 2019) (Volkert et al., 2015) (Vose et al., 2018)
Section C: Training, skills and future practice for challenges perceived in a UMIC, with low-income settings, such as South Africa. 16. How do you feel about current practices of SLTs in South Africa associated with tube feeding in people with advanced dementia? 17. In terms of mortality and quality of life, what difference do you believe you are making for people with advanced dementia and their families when you provide feeding recommendations like tube-feeding? 18. What do you feel are your needs regarding OPD in people with advanced dementia? 19. Is there anything we have missed that you want to tell me about your clinical practice with people with advanced dementia and feeding tube placements?	A recent South African study revealed that SLTs who had more than six hours of weekly experience in managing people with dementia, felt more confident in decisions pertaining to feeding tube placements, however it also revealed that SLTs in South Africa rather make use of clinical experience than research-based experience to guide their decisions. a) To identify SLTs needs relating to training and support regarding tube feeding in people with advanced dementia in South Africa. b) To determine SLTs perspectives regarding future practice for tube feeding in advanced dementia in South Africa. (Jacobs et al., 2020) (Cloete et al., 2022)

Appendix C: Pilot study feedback

The aim of this semi-structured interview schedule is to gain in-depth information regarding SLTs practices regarding tube-feeding in people with advanced dementia. This interview schedule will be followed during interviews with recruited participants where a qualitative framework guides the open-ended questions posed to the participants. The semi-structured interview schedule was developed by adapting questions used in recent studies that were similar in nature (American Geriatrics Society, 2014; Ashwell et al., 2020; Baijens et al., 2016; Beckly, 2017; Campbell et al., 2011; Car et al., 2017; Ellison, 2016; Colette et al., in press; Desai & Namasivavam-Macdonald, 2020; Hickey et al., 2018; Kuven, 2018; Luk et al., 2017; Malek et al., 2018; Meier & Ong, 2015; Mount, 2019; Newman et al., 2019; Punchik et al., 2018; Schwartz et al., 2014; Volicer et al., 2019; Volkert et al., 2015; Vose et al., 2018; Wright et al., 2019).

Section	Questions	Probe-questions
A. Tube feeding and the role of the SLT.	1. Advanced dementia presents with frequent challenges affecting multiple domains involved in daily living. Overall, what would you say is your intervention approach regarding individuals with advanced dementia who present with either feeding difficulties or OPD? 2. In your opinion, what does the role of SLTs involve when working with people who have advanced dementia who present with OPD? 3. What is your opinion on tube feeding in people with dementia, especially during the advanced stage of dementia? 4. Considering your answer in Q3, what do you believe is your specific role in feeding tube placement in people with advanced dementia?	
2. Current practices.	5. Please classify your clinical setting (public/private) and tell me how you (in your clinical setting) make the decision to provide tube feeding to people with advanced dementia by elaborating on what you base your decision.	
	6. What are the most frequent treatment methods that you use relating to feeding tube placement in people with advanced dementia?	a) In what contexts do you prefer feeding tube placement as a treatment method? Elaborate. b) Describe contexts where you avoid tube feeding as an intervention method.

Commented [A1]: What are the current practices of SLTs regarding feeding tube placement in people with advanced dementia when probed using in-depth interviews rendering qualitative data?"

Commented [A2]: What are the current practices of SLTs regarding feeding tube placement in people with advanced dementia when probed using in-depth interviews rendering qualitative data?"

Commented [A3]: Not differentiated or are you clarifying the term for them here?

Commented [A4]: Start with intervention, not ax? Ax may be valuable because you can see if family is interviewed – ecological approach/ ICF is/ is not used

Commented [A5]: Must you differentiate?

Commented [A6]: Do you want to leave it open for them to clarify the kind of tube or speak about tube feeding in general e.g. NG to PEG?

Commented [A7]: What about asking about dysphagia treatment once the tube is in situ – do you want to ask if they still try achieve oral feeds, like missed feeding or do you hope that will come from their answers? i.e. indictive qualitative approach

Commented [A8]: Should tis not be before section A?

Commented [A9]: And acute vs rehab, may need to probe here

Commented [A10]: Maybe make this the probe if needed. Also, type of tube feeding will impact this decision making. Here do you want to see if the team approach comes through? Again inductive?

Commented [A12]: Do you mean context of client, family, condition/co morbidities, severity, or acute vs rehab vs home? Or low vs higher SES

Commented [A11]: I don't understand this Q – are you asking what type of tube placement or if I continue giving food orally along with rx or rx to manage secretions. Try make more specific

Commented [A13]: Make sure they know what you mean RE contexts

7. What principles/guidelines do you use to guide your decision making relating to feeding tube placement in people with advanced dementia?	a) Elaborate upon local or international guidelines/principles? b) What roles relating to feeding and swallowing, are stipulated and recognized within your scope of practice by your professional regulatory body (i.e. the HPCSA or SASLHA)?	
8. Under what circumstances do you decide to possibly wean people with advanced dementia from tube feeding?	a) Elaborate on assessments you may use or protocols available to you.	
9. What alternative intervention methods would you recommend if not selecting tube feeding?		
10. Have you ever heard of careful handfeeding among individuals with advanced dementia, if so, when do you make use of this method?	a) Could you elaborate on careful hand feeding and those who are familiar with it? b) When do you make use of it? c) Why do you or don't you make use of it?	
11. Between tube feeding and careful hand feeding, which one would you, in your experience, say is more beneficial relating to advanced dementia?	a) Why is that so, in your opinion?	
12. Keeping your answer of Q11 in mind, what treatment method would you recommend in your clinical setting of employment?		
13. If you feel comfortable enough to answer, how have your views related to your religion or culture influenced your clinical decision-making regarding feeding tube placement in people with advanced dementia?		
14. Can you think of an instance or situation where input from a patient, or family member, changed the way you engaged in management of a person with advanced dementia?	a) Could you, please expand on how it changed your work? b) How do the presence and/or absence of an advanced directive affect your decision making on whether to choose tube feeding as an appropriate intervention method?	

Commented [A14]: Different answer depending – guidelines makes me think you want me to name a policy but principles makes me want to name literature

Commented [A15]: Perhaps at the beginning you should first ask how they define advanced dementia – in terms of delineating the term and clinically providing that diagnosis so that you know you are comparing on apples

Commented [A16]: But roles was queried in previous section, section A.

Commented [A18]: And family input – hopefully in their ax protocol

Commented [A17]: Perhaps ask – typical duration and then say would you wean

Commented [A19]: What about asking, when would you not recommend tube feeding and then follow up probe may be, what would you then do

Commented [A20]: Can't say when, as hearing about it does not imply doing it, rephrase to get their opinion about it

Commented [A21]: Maybe ask which do you use more or how is your answer in Q11 reflected in your clinical prac

Commented [A22]: Maybe start by saying how do you think culture and religion influence… then ask for themselves – that way you at least will always get a half answer

Commented [A23]: Can you rather ask – how does input from…. Influence or what considerations influence your decision making (asked earlier) and from there follow on to say (probe) about family input

Commented [A24]: Not clear

3. Training, skills and future practice for challenges perceived in UMIC, with low-income settings such as South Africa.	15. How do you feel about current practices of SLTs in South Africa associated with tube feeding in people with advanced dementia?	a) What SLT based practices, relating to tube feeding in advanced dementia, are present in the healthcare setting in South Africa? b) What challenges have you encountered in a South African healthcare setting that influenced your decision-making regarding tube feeding in people with advanced dementia?	**Commented [A25]:** What are your perspectives of… maybe **Commented [A26]:** This would be so anecdotal though **Commented [A27]:** Should be its own Q not a probe
	16. In terms of mortality and quality of life, what difference do you believe you are making for people with advanced dementia and their families when recommending tube feeding when oral feeding is no longer a viable option?		**Commented [A28]:** But what if they said they mix feed or follow another approach. So maybe say when you provide feeding recommendations like tube feeding
	17. What do you feel are your needs regarding OPD in people with advanced dementia?	a) Will you please mention a few ideas you may have about your needs regarding the management of OPD in people with advanced dementia?	**Commented [A29]:** palliative oral feeding is done in SA – will that not be contrasted against oral tube feeding? **Commented [A30R29]:** Is this careful hand feeding spoken about in intro and above?
	18. Can you perhaps tell me more about your needs, if you have any, in terms of resources in your setting?		**Commented [A31]:** How is this not a probe to the above Q?
	19. Is there anything we have missed that you want to tell me about your clinical practice with people with advanced dementia and feeding tube placements?		

Appendix D: Ethical clearance letter from the Faculty of Humanities

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Fakulteit Geesteswetenskappe
Lefapha la Bomotho

Humanities 100. Since 1919

09 December 2021

Dear Miss D Bruwer

Project Title:	Speech-Language Therapists' practices regarding feeding tube placement in people with advanced dementia: A qualitative study
Researcher:	Miss D Bruwer
Supervisor(s):	Mrs SB Pillay
Department:	Speech Language Pathology and Audiology
Reference number:	15124755 (HUM022/1021)
Degree:	Masters

I have pleasure in informing you that the above application was **approved** by the Research Ethics Committee on 09 December 2021. Data collection may therefore commence.

Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should the actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

We wish you success with the project.

Sincerely,

Prof Karen Harris
Chair: Research Ethics Committee
Faculty of Humanities
UNIVERSITY OF PRETORIA
e-mail: tracey.andrew@up.ac.za

Research Ethics Committee Members: **Prof KL Harris (Chair)**; Mr A Bizos; Dr A-M de Beer; Dr A dos Santos; Dr P Gutura; Ms KT Govinder Andrew; Dr E Johnson; Dr D Krige; Prof D Maree; Mr A Mohamed; Dr I Noomé, Dr J Okeke; Dr C Puttergill; Prof D Reyburn; Prof M Soer; Prof E Taljard; Ms D Mokalapa

Appendix E: Participant information leaflet and informed consent

- Bachelors of Speech-Language Pathology and Audiology as well as Bachelor of Science in Speech-Language Pathology, or a tertiary equivalent.

B. SLTs who classify as specialists in the management of people with dementia. In South Africa SLTs are classified as specialists when they render services to a designated client or disorder group. Further, they must meet the following requirements according to SASLHA (2010):
    - Have completed post-graduate courses and training related to dementia and/or:
    - Have at least three years of continuous working experience in dementia management, excluding community service year.
C. Members who are registered with the HPCSA will be included in the study.
D. SLTs who are familiar with online platforms, and who have adequate internet access.

DATA COLLECTION PROCEDURE:

In order to adhere to COVID-19 protocols and to ensure your safety as a participant, you will be required to participate in a once-off online interview in the comfort of your own home or space of preference. The researcher, Danette Bruwer, will lead the interview and will guide you to gain further insight upon your answers provided. Whilst the interview will be taking place, the researcher will be recording the interview as well as taking notes. Follow-up questions will be asked to clarify answers and to refrain from making biased assumptions. The interviews will take place once ethical clearance has been granted and at a time convenient for the participants. The interviews will be no longer than an hour.

ETHICAL APPROVAL:

The research is approved by the Research and Ethics Committee of the Faculty of Humanities.

WHAT ARE YOUR RIGHTS IF YOU DECIDE TO PARTICIPATE?

Your participation is voluntary; you can decide at any point to no longer participate without giving a reason. The information you provide will be kept strictly confidential and will not be used in any way to cause harm to you. Data obtained may be reported in scientific journals, however no identifying information will be published; pseudonyms or codes will be used throughout the research study. The study has been guided by the Declaration of Helsinki (last

update 2013) which aims to protect human participants in research. A copy of the declaration can be obtained online or through request from the researcher at dbruwer1@gmail.com. The information provided by you will be kept strictly confidential and will not be used in any way to cause harm to you, cultural differences will be respected throughout the data collection procedure. Due to the online nature of the recordings, you will be allowed to select your environment where you will be interviewed. Furthermore, you can request at any point to stop the recordings if you wish to do so. The researcher is also obligated to inform you when the recordings have been stopped and resumed accordingly to protect you from disclosing private information. Participants will also be allowed to view and listen to the recordings afterwards to ensure accurate portrayal of interpreted data.

Sincerely,

Ms Danette Bruwer
MA Student

Mrs Bhavani S Pillay
Supervisor

Dr Esedra Krüger
Co-supervisor

Prof. Jeannie van der Linde
Head of department

Room 2-12, Communication Pathology Building
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Tel +27 (0)12 420 4910 | Fax +27 (0)12 420 3517
Email esedra.kruger@up.ac.za | www.up.ac.za/faculty-of-humanities

PARTICIPANT INFORMED CONSENT

I hereby confirm that I have been informed about the nature, conduct, risks and benefits of the research study titled: Speech-Language Therapists' practices regarding feeding-tube placement in people with advanced dementia: A qualitative study. I have also received, read and understood the information provided regarding the research study. I am aware that the results of the study, will be processed into a research report with no identifying information used (i.e., a code will be assigned to each participant and used for recording and reporting of results). To oblige to the University of Pretoria's research data management policy, the collected- and transcribed- data will be stored for at least ten years to ensure accessibility for future studies. I have had sufficient opportunity to ask questions and, of my own free will, declare that I am prepared to participate in this study.

I hereby confirm that:
I have a minimum of six months experience working with people with advanced dementia. ☐

I understand that if I decide at any time before the research data collection that I no longer wish to participate in this project, I can notify the researcher involved and withdraw immediately without giving any reason. I confirm my informed consent to participate in the current study. ☐

Herewith, I give consent that the data obtained in the current research study may be used for future research, if necessary:

Yes ☐ **No** ☐

Participant's name: _____ (please print)

_____ _____
Participant's signature Date

_____
Researcher's name (Please print)

_____ _____
Researcher's signature Date

Room 2-12, Communication Pathology Buildin
University of Pretoria, Private Bag X2
Hatfield 0028, South Afric
Tel +27 (0)12 420 4910 | Fax +27 (0)12 420 351
Email esedra.kruger@up.ac.za | www.up.ac.za/faculty-of-humanitie

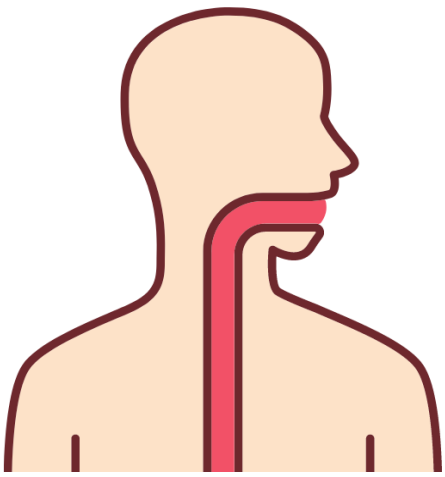
Appendix F: Advertisement used for recruitment purposes

ATTENTION FELLOW SLT

I kindly invite you to participate in my Master's study exploring the practices of Speech-Language therapists regarding feeding tube placement in people with advanced dementia.

All you have to do is meet the following criteira:

- Completed one of the following degrees:
  - Bachelors of Speech- Language Pathology degreee
  - Bachelors of Speech-Language Pathology and Audiology
  - Bachelors of science in Speech-Language Pathology OR a tertiary equivalent
- SLTs who classify as specialists in the management of people with dementia. In South Africa SLTs are classified as specialists when they render services to a designated client or disorder group. Further, they must meet the following requirements according to SASLHA(2010);
  ·Have completed post-graduate courses and training related to dementia and/or;
  ·Have at least three years of continuous working experience in dementia management, excluding community service year.
- Registered with the HPCSA.
- SLTs who are familiar with online platforms, and who have adequate internet access.



If you ticked all the boxes please contact me via Facebook Messenger or
send me an email at dbruwer1@gmail.com for more information.

I am looking forward to hearing from you!

Danette Bruwer

Appendix G: Confirmation of submission to the South African Journal of Communication Disorders

#970 SUMMARY

1. SUMMARY 2. REVIEW 3. EDITING

Submission

Authors	Danette Pullen, Bhavani Pillay, Esedra Krüger
Title	Complex decisions about tube feeding in advanced dementia: insights from a sample of South African speech-language therapists
Original file	970-9374-1-SM.DOCX 09-Mar-23
Supp. files	970-9375-1-SP.PDF 09-Mar-23 ADD A SUPPLEMENTARY FILE 970-9376-1-SP.PDF 09-Mar-23 970-9377-3-SP.DOCX 15-Mar-23 970-9378-1-SP.DOCX 09-Mar-23 970-9379-1-SP.DOCX 09-Mar-23 970-9380-1-SP.DOCX 09-Mar-23 970-9387-2-SP.DOCX 15-Mar-23
Submitter	Mrs Bhavani Pillay
Date submitted	09 March 2023 - 12:22
Section	Original Research
Editor	None assigned

Status

Status	Awaiting assignment
Initiated	09-Mar-23
Last modified	16-Mar-23

aosis@sajcd.org.za
to me, Bhavani, Esedra

****

Ref. No.: 970
Manuscript title: Complex decisions about tube feeding in advanced dementia: insights from a sample of South African speech-language therapists
Journal: South African Journal of Communication Disorders
****

Dear Danette Pullen, Bhavani Pillay, Esedra Krüger

The above manuscript, for which you are listed as a contributing author, has been received by the journal. Future communications regarding this manuscript will be sent to the corresponding author only, Mrs Pillay.

If you need to contact us or the publisher about your manuscript for any reason, please be sure to quote the journal name and manuscript reference number 970.

Kind regards,
Ms Botes
AOSIS