



Caregiver Checklist for Dysphagia Risk (CCDR) development and preliminary evaluation: a pilot study

By

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Declaration

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SENATE PLAGIARISM POLICY

Declaration by Students

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Abbreviations

ADLs – Activities of daily living
CCDR – Caregiver Checklist for Dysphagia Risk
CDOA – Community Dwelling Older Adults
DHI – Dysphagia Handicap Index
DOSS – Dysphagia Outcome Severity Scale
DRACE – Dysphagia Risk Assessment for the community-dwelling elderly
EAT-10 – Eating Assessment Tool
FEES - Fiberoptic endoscopic evaluation of swallowing
FOIS – Functional Oral Intake Scale
GUSS – Gugging Swallow Screen
LMICs – Lower-middle income countries
MEOF – Minimal Eating Observation Form
mMASA – Modified Mann Assessment of Swallowing Ability
MOCL – Mealtime Observation Checklist
NGO – Non-Government Organisation
NOMS – National Outcomes Measurement System
OD – Oropharyngeal Dysphagia
SDQ – Swallowing Disturbance Questionnaire
SSQ – Sydney Swallow Questionnaire
SWAL-QOL – Quality of Life in Swallowing Disorders
TOMASS – Test of Mastication of Solids
TWST – Timed Water Swallow Test
VFSS - Videofluoroscopic swallow study
V-VST – Volume-Viscosity Swallow Test
WHO – World Health Organisation

Note: For the purpose of this study the term ‘caregiver’ refers to individuals employed for the purpose of care provision in care facilities

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Abstract

Background: The potential risk for dysphagia may be a concern in the elderly population and can often lead to aspiration pneumonia. Due to a shortage of speech therapists in South Africa, nurses and caregivers within care facilities are typically the individuals who are responsible for monitoring eating and drinking of the residents at the care facilities. This makes them ideal for early identification of individuals at risk of dysphagia.

Method: The aim of this study was twofold 1) to document current tools used to identify dysphagia in the elderly in care facilities by way of a scoping review and 2) to establish the preliminary diagnostic accuracy, validity, and reliability of a researcher-developed tool, the Caregiver Checklist for Dysphagia Risk (CCDR) as informed by the scoping review. The study used the scoping review methodological framework and quantitative cross-sectional correlational design for its respective parts. The caregivers and residents from a care facility were recruited using convenient and purposive sampling, respectively. The CCDR was, completed by caregivers, thereafter the Eating Assessment Tool (EAT-10) was administered by the researcher to residents with and without suspected risk of dysphagia for a total sample of 32 residents ($n=32$). *Data Analysis:* Data was analysed using thematic analysis for the scoping review and, descriptive and inferential statistics for data pertaining to the CCDR. Content validity was established using a scoping review that assisted with the content of the CCDR. The reliability was measured using Cronbach's Alpha to determine internal consistency. Concurrent validity of the CCDR was established by correlating the results against the results of the EAT-10. Diagnostic accuracy in the form of sensitivity and specificity were assessed.

Results: The scoping review identified tools currently being used to identify dysphagia with the elderly and confirmed that no tool exists for this population in the South African residential care context. A lack of one appropriate tool led to the development of the CCDR. Preliminary results of the CCDR indicated a strong internal consistency (Cronbach's Alpha = 0,815), moderate positive correlation (Pearson's $r(30) = 0.499$, $p < 0,001$; Spearman's Rank Order $r(30) = 0.454$, $p < 0,001$), a high sensitivity (0,90) and specificity (0,82) indicating promise in its use.

Implications: Clinical implications reveal that the CCDR can identify dysphagia risk in elderly residents in care facilities. Theoretically, this tool adds to existing dysphagia resources in the scientific world by providing a tool, to identify dysphagia risk. Further research may include multiple research sites as well as explore caregiver feedback and investigate feasibility of the use of the CCDR with community-dwelling elderly.

Keywords: care facility, caregivers, dysphagia, elderly, risk-base, checklist

1. Introduction

The introduction provides insight on what the study explored. It provides a brief outline of themes further explored in the literature review.

Due to advances in education and medicine, as well as a reduction in mortality rates, people globally are living longer than they did before (Chalise, 2020; Chipps & Jarvis, 2015; Lee et al., 2020). Lower-middle income countries (LMICs) will have the majority of the elderly population over the age of 65 (Santosa et al., 2016). From 36,6 million, the elderly population in Sub-Saharan Africa is set to rise to 141 million by the year 2050 (Gerber et al., 2016). A longer life expectancy, however, does not indicate an improved quality of life in these individuals (Gerber et al., 2016; Santosa et al., 2016). Disability is common within the elderly, and access to adequate healthcare is often limited due to expense and overall strains that the healthcare system carries (Santosa et al., 2016).

The majority of the older population is likely to reside in care facilities as care provision by family members becomes difficult (Coimbra, 2018). Research indicates that as individuals age, the more common it is for them to be living in care facilities (Artmann et al., 2017). In Europe, people aged 85 and older had a 7% higher prevalence in care facilities as compared to the 65-84 age group (Artmann et al., 2017). Similar data is limited within the South African context (Artmann et al., 2017). Due to an increase in the need for medical and rehabilitation services with age, as co-morbidities increase, many elderly people are in need of more specialised care, and it is something that care facilities need to be aware of and make provision for (Roquete et al., 2017; Shi et al., 2018).

Globally, the occurrence of oropharyngeal dysphagia (OD) in the elderly is high. In people over the age of 65, there is a prevalence of between 30-40%, with an even higher prevalence in care facilities, with a rate of between 55 and 60% (Di Pede et al., 2016; Peladic et al., 2019). Oropharyngeal dysphagia is, however, often underdiagnosed in this population and gives rise to possible malnutrition, dehydration, aspiration pneumonia, and, even death in some cases (Peladic et al., 2019). Due to the above, it is important for signs and symptoms such as coughing, anterior spillage, gurgly voice, increased time needed to swallow, difficulty completing a meal, pocketing of food and difficulty to chew to be looked out for frequently for early identification (Campos et al., 2022; Ishak et al., 2021).

Speech therapists are essential in diagnosing and treating dysphagia; however, there is currently a shortage of these professionals, who consequently often have high caseloads (Pillay et al., 2020; Wilkinson et al., 2021). Speech therapists in the public sector are mainly found in hospitals due to limited funding available in care facilities (Lloyd-Sherlock, 2019; Pillay et al., 2020). As a result, the elderly population may only be referred by caregivers when symptoms have progressed too far. Regular monitoring and screening protocols are required so that OD can be identified early (Artiles et al., 2021).

Caregivers are most involved in care provision of residents in care facilities (Muller-Schoof et al., 2022). This includes assisting residents in their activities of daily living (ADLs), which comprises of assistance with meals (Backhaus et al., 2018). In South Africa, there is a lack of training, in general, for caregivers, apart from dysphagia training, which is specialised (Marais et al., 2023). The current study, therefore, explored whether caregivers who are employed at care facilities are able to fill this gap of early identification of residents they believe of being at risk for difficulty swallowing, to ensure timeous and appropriate referrals to speech therapists are made by using a newly developed tool. In order for the tool to be developed, a scoping review of existing literature was conducted for better insight of dysphagia-related tools being used globally with the elderly population.

1.1. Literature Review

The literature review further defines and explains aspects that the study explored. This includes the elderly and the potential risks they face and their entrance into care facilities. It further discusses dysphagia and its effects on the elderly population specifically. The process of dysphagia identification and the current role and prevalence of speech therapists is also discussed. Lastly, caregivers, who are the forefront of care in care facilities, their role, and why they could be critical in early identification of dysphagia is described.

1.1.1. Elderly

An elderly person is defined by the United Nations as someone who is over the age of 60 (Ahn et al., 2020). Many more people are living beyond this age due to advances in medicine and education, with this population set to increase further by the year 2050 (Chalise, 2020; Gerber et al., 2016). Chronic diseases such as heart disease, respiratory disease, musculoskeletal diseases as well as neurological disorders, cancer and mental disorders become common within this population and in turn affects their quality of life (Gerber et al., 2016). However, it should also be noted that not all elderly people present

with chronic disease, some just experience normal ageing, which can be due to the decline of the nervous system (Schott, 2017).

The elderly population may present as a burden towards their families, and this may be one of the reasons they are placed in residential care facilities (Coimbra et al., 2018). Similarly, many families may feel that they are unable to provide the care that their elderly loved one requires (Coimbra et al., 2018). Placing their aged family member in a care facility ensures that they receive professional care that they have come to require when they are unable to take care of themselves (Artmann et al., 2017; Coimbra et al., 2018). This may include assistance with ADLs, chronic condition management, and participation in social settings (World Health Organisation [WHO], 2020).

Globally, the demand for residential care facilities has increased (Lloyd-Sherlock, 2019). In South Africa, there are 400 registered residential care facilities, most of which are managed by non-government organisations (NGOs), while unregistered facilities also exist (Lloyd-Sherlock, 2019). Eight of these facilities are public run, while the remainder are privately run (Jacobs et al., 2020). A survey conducted in 2010 across 405 regulated homes found that only 25% of staff at these facilities knew about standards and norms (Lloyd-Sherlock, 2019). It was further mentioned that most of these facilities did not feel adequately prepared for residents that required complex care (Lloyd-Sherlock, 2019). Unregulated facilities often serve people from a poorer background by providing lower rates, alluding to very basic services provided (Lloyd-Sherlock, 2019). Living units at care facilities are usually arranged according to the level of care that is required (Artmann et al., 2017). Despite the growing need for care facilities and the increase of the aging population, data remains limited on this subject.

1.1.2. *Dysphagia in elderly*

Within care facilities, dysphagia is likely to occur in about 55-60% of residents (Di Pede et al., 2016; Shune & Linville, 2019). Dysphagia is the difficulty experienced when swallowing during consumption of food and/or liquids or the obstruction of movement of the bolus from the mouth to the stomach (Artiles et al., 2021). Dysphagia is often a symptom of underlying pathology, chronic disease, or neurological disorders, which all commonly occur in the elderly (Artiles et al., 2021). Healthy elderly individuals may experience alteration to their physiology used for swallowing and difficulty swallowing may occur due to the loss of muscle mass which is known as presbyphagia (Wirth et al., 2016; Rivelrud et al., 2023). An elderly individual may present with presbyphagia, which may or may not result in dysphagia (Wirth

et al., 2016). Thus, an individual may have presbyphagia but still be able to swallow safely. The region and structures that contribute to dysphagia, along with the consequent impact on function, determine the type of dysphagia that is present, which then informs the required treatment plan (Wirth et al., 2016). The most common type of dysphagia found in the elderly population is oropharyngeal dysphagia which specifically refers to difficulty moving the bolus from the oral cavity which is the mouth to the oesophagus (Wirth et al., 2016).

The observed clinical signs and patient-reported symptoms together with clinical examination, inform where the dysphagia is (Ishak et al., 2021). Some of the signs and symptoms observed can include coughing during and after meals, regurgitation through the nasopharynx, choking, drooling or anterior spillage of food from the mouth, wet sound during voice production, increased time needed to swallow, difficulty to finish a meal, residue of food in mouth after meal completion, difficulty to chew food, fever post-meal consumption, decrease of food consumed and pain during a swallow (Campos et al., 2022; Ishak et al., 2021).

The presence of OD may lead to aspiration, which in many cases leads to aspiration pneumonia (Wirth et al., 2022). Aspiration occurs when foreign material or contaminated bacteria enters or is inhaled into the lungs, which may result in a pneumonia and can have long-term effects on the individual consisting of lung inflammation or lung abscesses (Wirth et al., 2022). Initial signs and symptoms of aspiration pneumonia can include nausea, headaches, fever, breathing difficulties, and coughing while at other times it is silent and these symptoms cannot be seen making its diagnosis more difficult (Wirth et al., 2022). Aspiration pneumonia related-death accounted for 76% of adults aged 75 and older in the United States (Niederman & Cilloniz, 2022). It is therefore necessary that those at risk for oropharyngeal dysphagia are identified early to prevent aspiration pneumonia based on signs and symptoms observed or reported.

Speech therapists play the biggest role in the assessment of OD (Wilkinson et al., 2021). They conduct formal assessments, which include clinical swallow evaluations as well as gold standard instrumental assessments such as a video fluoroscopic swallow study (VFSS) or fiberoptic endoscopic evaluation of swallowing (FEES) (Wilkinson et al., 2021; Wirth et al., 2022). The current availability of speech therapists in South Africa is low (Pillay et al., 2020). Data available indicates the current medical model of care together with the global burden of illness and disease in South Africa, do not give priority to rehabilitation workers, which includes speech therapists (Morris et al., 2021, Pillay et al., 2020). It is, therefore, due to the extensive need for these services that there is a lack of therapists available. The shortage of

services that has been documented is said to occur mainly in healthcare facilities with no data available with regard to the prevalence of therapists in care facilities.

1.1.3. *Dysphagia Identification*

There are various ways in which dysphagia can be identified which includes screening, triage, risk-based checklists and diagnostic assessments. It is important to understand the differences between these methods and their use in the South African context.

Screening refers to the process of identifying individuals who may present with dysphagia and is conducted on all people in a particular place or presenting with a specific condition (Artiles et al., 2021; Garand et al., 2020). Screening results are determined by a pass/fail criteria (Garand et al., 2020). Despite being quicker to administer than a diagnostic assessment, screenings still require some form of training as well as use of food and liquid, which may not always be available (Kater & Seedat, 2023). A scoping review conducted by Artiles et al., (2021) looked at screening tools currently used in care facilities, as well as the validity of these tools. The Eating Assessment Tool (EAT-10) (Belafsky et al., 2008), the Gugging Swallow Screen (GUSS) (Trapl et al., 2007) and the Yale Swallow Protocol (Suiter et al., 2014) are considered to have the best clinical accuracy in this context (Artiles et al., 2021). The study, however, did not consider tool specifications, nor did it solely focus on the elderly. Furthermore, none of these tools consider the resource and contextual realities of care facilities in South Africa.

Dysphagia triage on the other hand, refers to the identification of dysphagia within emergency departments, where patients are ranked according to the level of care needed (Kater & Seedat, 2023). Since time is limited in these departments, dysphagia triage is meant to be quickly administered as well as require minimal resources (Kater & Seedat, 2023). Similarly, an at-risk checklist would aim to identify those identified as being at risk for dysphagia and comprises of a quickly administered checklist which can be used to determine the need for further referral. This, however, would not be limited to emergency departments in hospitals but rather be administered in places such as residential care facilities or long-term rehabilitation facilities by professionals involved in the care of its residents. The use of at-risk checklists can be particularly advantageous as they would not have to be used with all members in a population but rather only those that have signs that put them at risk for dysphagia, making it different from a screening tool. Only if an individual fails an at-risk tool, they will be referred to a speech therapist. There is limited evidence in research with regard to the presence and use of risk-based tools in all contexts of care.

Diagnostic dysphagia assessments can only be conducted by speech therapists (Artiles et al., 2021). These assessments require time and resources to complete, can be done at the bedside, and can determine the need for an instrumental evaluation (Garand et al., 2020). Diagnostic assessments can also determine the location of the difficulty, its severity and treatment plan (Garand et al., 2020). Due to the limited availability of speech therapists and the large caseloads they face, it makes it difficult for them to conduct diagnostic assessments (Knight et al., 2020; Pillay et al., 2020). Therefore the use of methods mentioned above (i.e. screening, risk-based tools, triage and bedside assessments) are often the initial point of dysphagia identification.

Taking heed of the above shortcomings, as well the dilemma of dysphagia amongst the ageing population, particularly in care facilities where speech therapists are few, there is a need for an accurate tool. This tool should be simple to administer with ease of scoring, and one that does not require formal training in dysphagia. It should allow caregivers to identify dysphagia in the elderly and subsequently refer to a speech therapist for further intervention if indicated (Chen et al., 2022; Clark & Ebersole, 2018).

1.1.4. Caregivers

Caregivers play a critical role in the care of the elderly in care facilities (Mapira et al., 2019). Caregivers can be defined, according to the South African Government as “someone who provides assistance to another person who cannot live fully independently due to physical, psychological, or mental disability” (Myeza et al., 2015). Caregivers should be differentiated from nurses, who are professionals involved in medication administration as well as prescribing the standard of care in care facilities (Nicholson & Damons, 2022).

Modernisation of society with regard to population mobility, the change in female roles, household structures and cultural norms has resulted in the change for the way elderly are cared for (Lloyd-Sherlock, 2019). This has resulted in a greater need for employed caregivers with abilities to provide a higher level of care that may not be available at home (Lloyd-Sherlock, 2019). The number of caregivers employed within care facilities are often lower than what is recommended which results in large resident-caregiver ratios (Kunkle et al., 2021). The pressure that these caregivers are placed under coupled with the needs of the residents results in what is known as caregiver burden (Kunkle et al., 2021). There is also a high turnover of caregivers in care facilities (Castle, 2021). Despite the disadvantages associated with caregivers in care facilities, many families feel that the care provided by trained caregivers is better than what they can offer (Toot et al., 2017). The caregiver burden

faced by families is often worse due to relationship strains that comes with caring for the elderly (Rangira et al., 2022; Toot et al., 2017). This burden is further exacerbated if activities of eating and drinking are involved (Rangira et al., 2022).

There are relatively fewer nurses than caregivers in care facilities; therefore, caregivers assist with routines such as feeding assistance, personal hygiene, bathing and dressing known as ADLs (Mapira et al., 2019; Marais, 2020; Nicholson & Damons, 2022). Caregivers, therefore, spend the most time with the elderly individual, they are the ideal person to identify and observe those who may be experiencing difficulty swallowing (Marais, 2020). The training that is required for one to be eligible to become a caregiver is a Grade 9 secondary level of education. With this, a six-month, non-accredited course is available for one to become a caregiver (Marais, 2020). Dysphagia is a specialised field, and since research is limited in this regard, it can be assumed that the training caregivers receive with regard to recognising those at risk of dysphagia is limited. Despite the limited training, caregivers could be the link between the elderly in care facilities and early identification of dysphagia since they spend most of their time with them. Caregivers will therefore be the focus in this study.

A scoping review is therefore required to collate all tools being used in care facilities globally to identify dysphagia, specifically methods being used to identify the elderly population, with a specific focus on person administering the tool as well as resource requirements required, time taken for tool administration, training required, tool format and specific signs and symptoms observed. In turn, this will allow the researcher to develop a tool to be potentially used by caregivers when they suspect that a resident may be at risk of dysphagia.

1.2. Rationale

There is a high prevalence of dysphagia-related conditions in elderly residents in care facilities, with many of these cases occurring due to OD being underdiagnosed (Pede et al., 2016 ; Peladic et al., 2019). It is therefore essential that OD is identified early in individuals at risk so as to prevent malnutrition, dehydration, aspiration pneumonia or death (Peladic et al., 2019). The development and introduction of a tool that can be used within care facilities to identify dysphagia early may be useful in reducing the occurrence of the above mentioned conditions.

There are a variety of screening tools developed for recognising dysphagia which include The Yale Swallow Protocol, the EAT-10 and The GUSS among others (Artiles et al., 2021).

The use of these tools gives rise to multiple concerns. The first one is that the available tools have not been specifically designed to identify dysphagia in the elderly population, therefore, it may not consider the elderly individual holistically and may not be accurate (Artiles et al., 2021). The second concern is that the current tools that exist have not been assessed for validity and reliability in the South African context. Research surrounding this is also limited. This necessitates the need for further research by way of a scoping review that can provide further information on current tools being used globally with the elderly population. This would further guide the development of a tool that can be used that would be suitable for use with the elderly.

There is also a shortage of speech therapists in South Africa which gives rise to the need for a tool that can be completed by others involved in care provision (Knight et al., 2020; Pillay et al., 2020). This will allow these individuals, who are not experts in dysphagia, the ability to identify whether those at risk require referral to a speech therapist (Knight et al., 2020). Caregivers tend to spend the most time with the residents of care facilities which would make them the ideal individual to identify dysphagia (Marais, 2020). Given their demanding workload and responsibility in caring for the elderly, the use of a risk-based checklist would therefore be ideal for their use. The current study is critical in establishing if a new researcher developed tool is valid and reliable for use in South Africa by caregivers as they are most involved in care provision in care facilities.

1.3. Statement of the Problem

As is evident from the literature people are living longer due to advances in medical care (Chalise, 2020; Chipps & Jarvis, 2015; Lee et al., 2020). As the ageing population increases, the number of elderly people moving into and residing in care home facilities is also increasing (Artmann et al., 2017). These facilities can offer independent living, assisted living and dependent/frail care living (Artmann et al., 2017).

Caregivers are typically at the forefront of the care that is provided to the elderly living in these facilities (Mapira et al., 2019). Caregivers are therefore placed in an ideal position, where they interact daily with the elderly in care homes, provide assistance, observe them during ADLs, and may refer residents who are concerning to the nursing Sister for further consultation by a health or medical professional (Mapira et al., 2019). Globally, there is currently no existing tool that caregivers can use to enable them to identify when an elderly resident is at risk for unsafe eating and drinking, or when that resident may be experiencing disordered swallowing (Howells et al., 2021). Thus, this study aimed to understand which

tools are being used with the elderly by way of a scoping review. This further guided the development of a risk-based tool, called the Caregiver Checklist for Dysphagia Risk (CCDR) which was developed for the purpose of the proposed study. It should be noted that the CCDR should be a tool that can be used globally, however, due to the location of the research, the preliminary evaluation of the reliability, validity and diagnostic accuracy was assessed in the South African context.

2. Methodology

The methodology examines the specifics about what the researcher explored and the context of the research. It includes the research question, the aims and objectives that were targeted. The research design is described and why this was the most ideal design for this study. The methods of data collection, the research instruments used as well as the research process are also discussed. The methodology section concludes with descriptions of how data was analysed and how data quality was assessed.

2.1. Overarching Research Question

Is the CCDR an appropriate tool that can be used by caregivers to identify elderly individuals in care facilities who may be at risk for dysphagia as determined from the preliminary diagnostic data?

2.2. Aims and Objectives

Overarching aim: To describe the development of the CCDR and establish preliminary diagnostic data regarding its use in the elderly population who may be at risk for dysphagia.

- a) To document current tools administered with regard to dysphagia identification or swallowing difficulty of elderly residents at mealtimes.
 - I. To establish the content validity of a researcher developed caregiver completed tool to identify residents at risk for dysphagia.
- b) To determine the reliability as a measure of internal consistency of the CCDR.
- c) To explore the correlation between the CCDR and EAT-10.
- d) To determine the preliminary diagnostic accuracy of the CCDR
 - I. To determine the sensitivity of the CCDR
 - II. To determine the specificity of the CCDR

2.3. Research Design

This study was conducted in two parts:

Part one involved a scoping review, which was conducted using the scoping review methodological framework proposed by Arksey and O'Malley (2005) and updated by Levac et al. (2010), further enhanced as part of the Joanna Briggs Institute (JBI) approach by Peters et al., (2015). This methodological framework outlines six stages for conducting a scoping review, including (1) Identifying the research question, (2) identifying relevant

studies, (3) study selection, (4) charting the data, (5) collating, summarising and reporting the results (6) analysis and reporting results (Levac et al., 2010). The use of a scoping review is particularly advantageous because it explores a specific topic that has not been reviewed comprehensively (Khalil et al., 2016). The scoping review is reported according to the PRISMA-ScR guidelines (Tricco et al., 2018).

Part two was conducted using a quantitative, cross-sectional correlational research design, which aimed to obtain data at one point in time and compare single variables across different cohorts (Cummings, 2018). The current study used two groups, purposefully chosen, to investigate the correlation between the CCDR and EAT-10, an existing standardised survey-type tool available that has been used with the elderly (Schindler et al., 2023). In quantitative designs, quantifiable data is obtained with the use of standardised assessment measures (Rutberg & Bouikidis, 2018). Within this study, it was important that the researcher had control over the variables, as this allowed for development of the CCDR to be more accurate when determining the correlation (Becker et al., 2016).

The specific methodology for part one and part two of the study will be explained below.

Part One: Scoping Review

2.4. Research Question

What dysphagia related tools are being used by caregivers within care facilities globally?

2.5. Research Aims

- a) To identify tools being used to identify dysphagia in the elderly population.
- b) To provide a critical review of each tool in terms of:
 - I. Dysphagia identification
 - II. Administration time
 - III. Dysphagia symptomology and signs
 - IV. Reliability and validity of the tool
 - V. Diagnostic accuracy
 - VI. Resources required for administration
 - VII. Person administering the tool
 - VIII. Format of the tool

2.6. Search Framework

The PIO conceptual framework (Table 1) was used to formulate the research question as well as determine the search terms that were used for this scoping review (Bornman et al., 2022). The PIO framework is a variation of PICO which excludes the comparison between interventions aspect. PIO was chosen for this scoping review as it explores areas of knowledge specific to the topic.

Table 1

The PIO Conceptual Framework

Concept	Determinants
P – Population	Elderly population and caregivers
I – Intervention	Tool being used to identify dysphagia
O – Outcome	Critique of tool

2.7. Eligibility Criteria

2.7.1. Types of Sources

Only electronic articles were considered for the current scoping review.

2.7.2. Inclusion and Exclusion Criteria

The following inclusion and exclusion criteria were set out (Table 2) so that articles identified, and data extracted included information most relevant to what the researcher would like to explore and answered the research question and aims.

Table 2*Inclusion and Exclusion Criteria*

	Inclusion criteria	Exclusion criteria
Geographical location	Studies conducted globally	n/a
Language	Studies in the English language	Studies not in English
Period of Interest	Studies published from January 2003 to September 2023	Studies published before January 2003 or after September 2023
Source Types	Published peer-reviewed journal articles, peer-reviewed theses and dissertations.	Textbooks, newspaper/magazine articles, articles with abstract access only and reviews.
Population	People over the age of 60	People under the age of 60

2.8. Information Sources and Search Strategy**2.8.1. Databases**

The identification of databases to collect comprehensive literature for review is essential so that the researched population is represented ideally within the study (Tricco et al., 2016). The following electronic databases were used to gather relevant literature: Scopus, Medline, Pubmed, CINAHL, Cochrane and University repositories. The databases chosen are most relevant to the field of allied health, nursing and dysphagia.

2.8.2. Search Terms

Searches on each database consisted of terms that have been formulated based on the aim of the research study. They have also been arranged in a way that follows the PIO framework. The following phrases have been used to complete the searches across all databases:

Table 3*Search Terms*

Search terms used		
Population (P)	Elderly	Or
	Nursing home	Or
	Care Facilities	Or
	Residential Care Facilities	Or
	Aged	Or
	Long Term Care Facilities	Or
	Geriatric	Or
AND		
Intervention (I)	Dysphagia	Or
	Swallowing Difficulty	Or
	Swallowing Disorder	Or
	Oropharyngeal Dysphagia	Or
	Deglutition disorder	Or
AND		
	Tools	Or
	Measures	Or
	Screening	Or
	Assessment	Or
	Identification	Or
AND		
Outcome (O)	Resources	Or
	Administration Time	Or
	Training	Or
	Reliability	Or
	Validity	Or
	Accuracy	Or
	Signs	Or
	Symptoms	Or

2.9. Pilot Study

A pilot study was conducted in order to identify if databases and repositories selected were appropriate, and search terms chosen yielded adequate results. The search terms initially described included caregivers specifically as tool administrators; however, results yielded were minimal (Table 4). The researcher amended the search terms used and looked at tool administration by any persons involved. Results yielded were then appropriate and all search terms were used across all databases and repositories initially set out.

Table 4

Pilot study results

Electronic database	Number of hits	Number of full text articles	Number of hits in 20 years	Number of hits in English
Scopus	33	2	1	1
Medline	28	19	19	18
Pubmed	293	280	256	255
CINAHL	20	14	14	13
Cochrane	171	171	171	171

2.10. Data Extraction

Data was extracted from the chosen articles (Appendix Q) and arranged on a Microsoft Excel spreadsheet. Data was also arranged according to the following headings (Appendix P):

- Author
- Title of study
- Year of publication
- Name of tool
- Resources required
- Time to administer
- Reliability and validity
- Dysphagia identification
- Sensitivity and specificity
- Signs and symptoms
- Person administering the tool
- Format of the tool

2.11. Data Analysis

The study made use of descriptive statistics to analyse the collected data and this was completed using Microsoft Excel (Hajesmaeel-Gohari et al., 2023). Descriptive statistics, including mean and frequency, were employed. Thematic analysis has been used to organise and synthesise the information extracted from the selected studies (Braun & Clarke, 2019). Thematic analysis illustrates themes that are important in the description of the phenomenon under study and is based on the research aims.

Part Two: Caregiver Checklist for Dysphagia Risk (CCDR)

2.12. Correlation

The comparison of results obtained from administration of the EAT-10 and the CCDR were used to investigate the following correlations in the current study:

- a) Positive correlation: As the signs/symptoms of eating, drinking or swallowing difficulties increase. The sensitivity of the CCDR increases.
- b) Negative correlation: As the signs/symptoms of eating, drinking or swallowing difficulties decrease. The specificity of the CCDR decreases.
- c) No correlation: The presence of signs and symptoms have no correlation with the results of the CCDR.

2.13. Population and Sample

2.13.1. Access to Participants and Site of Study

Caregivers and residents were recruited from a single research site in Johannesburg, South Africa. The care facility consists of a dementia unit, a high care unit, intensive care unit, frail care unit and assisted living unit. A public facility was chosen as it can serve as a median between a private facility and an unregistered low-cost facility. It is home to approximately 320 residents and consists of residents from all walks of life; thus, it provided a holistic overview of the elderly population. There were 219 residents in the frail care section (including the dementia unit), with 47 caregivers per shift over 24 hours, indicating there was one caregiver per four or five residents. There were ten residents that were more independent and had two caregivers, resulting in one caregiver per five residents (the researcher recruited residents that required more assistance that are not at risk for dysphagia to make up the sample size). The facility also has a long standing relationship with the University of the Witwatersrand in terms of service provision.

The researcher invited both caregivers and residents from the frail care and assisted living units of the facility to participate in the study, and permission to proceed with the study was obtained prior to any discussion or information provision to these two sub-groups i.e. the caregivers and residents (Appendix A and Appendix B). For the caregivers, the study was introduced to them in their weekly meeting by the head nurse. There were two boxes labelled with the information sheet and consent form, respectively, which caregivers could voluntarily fill out if they were interested in participating in the study. For the residents, they were introduced to the study by the researcher and were provided with the information sheet and consent form. The residents were given 48 hours to decide if they wanted to participate and could let the caregiver know their decision so that they did not feel obligated to participate in the study by the researcher. If a resident was unable to provide consent by themselves, consent was sought from their legal guardian.

2.13.2. Sampling Strategy

Non-probability convenience and purposive sampling was employed to recruit participants. Caregivers and residents from the frail care and assisted living units at the facility were invited to participate. *Caregivers*: Convenience sampling relies on availability of people in a specific place making it the most effective sampling strategy in recruitment of the caregivers (Stratton, 2021). The study sample of caregivers selected were homogenous, meaning that using any other sampling method would have yielded the same or similar results (Etikan et al., 2016). *Residents*: Residents were recruited using purposive sampling. Two cohorts of residents were invited: i. residents from the frail care section who are typically medically-frail and at higher risk of swallowing difficulty, and ii. Residents from the assisted living section who are typically healthier and not at high risk of swallowing difficulty. Purposive sampling was most effective as it aimed to identify participants based on a specific trait (Campbell et al., 2020).

2.13.3. Sample Description

a) Caregivers

I. Inclusion Criteria:

- Caregivers employed by the care facility and with a minimum of a six-month training certificate.
- Caregivers working in the frail care or assisted living units of the facility.

b) Residents

Resident Group One (Suspected of presenting with dysphagia)

I. Inclusion Criteria:

- Individuals residing in the frail care section of the facility and suspected of having dysphagia by caregivers.
- Individuals over the age of 60 years old.

II. Exclusion Criteria

- Individuals that have been diagnosed with dysphagia.
- Individuals on enteral feeds.

Resident Group Two (No Suspicion of dysphagia)

I. Inclusion Criteria:

- Individuals residing in the assisted living section of the facility and not suspected of having dysphagia by caregivers.
- Individuals over the age of 60 years old.

II. Exclusion Criteria

- Individuals on enteral feeds.

Due to the nature of the target population, some of the residents presented with conditions that has affected their cognitive abilities. This affected their ability to provide consent, in which, the guardian who is the conservator of the elderly resident was contacted with information about the study (Appendix H) and to obtain permission (Appendix I) on behalf of the resident. The current study required understanding of the task and their ability to convey their understanding, therefore ability to participate was determined by their conversational level with the researcher. Whereby, permission was obtained by the guardian for the participation of the resident, consent was sought from them as well prior to any participation. It was necessary for such residents to be considered and included as it was essential for determining the diagnostic accuracy of the CCDR in the entire population and not a selected sample.

2.13.4. Sample Size

Caregivers that work with participants they suspected of having dysphagia and those that they did not suspect in the frail care and assisted living units, respectively, were invited to participate. Therefore, although it was not stipulated, fourteen different caregivers participated. For the residents, the CCDR was administered to both cohorts of residents by the caregivers from the respective section. The sample was calculated, with the help of a statistician, using an expected sensitivity and specificity of 80%, an expected prevalence of 50%, a confidence interval of 20% and a confidence level of 95%. This resulted in a sample size of 31, with 15 or 16 residents recruited per group.

2.14. Data Collection

The data collection occurred in two distinct phases that are described below:

- a) Phase one: The researcher conducted a scoping review of existing literature that investigated dysphagia screening tools available and their use within care facilities. This included the time, training, and resources required to administer those tools. This further looked at the validity and reliability of the tools used in elderly specifically. The scoping review then led to the compilation of the CCDR (Appendix N).
- b) Phase two: Each resident received two different evaluations. First, a caregiver administered the CCDR on residents that have agreed to participate but who the caregiver suspected of presenting with dysphagia. This was done at the place where the resident consumes their meals and administered by the caregiver in charge of the specific resident. Secondly, the same resident completed the self-administered EAT-10 (Appendix K) (assistance provided by the researcher if required which included filling in the tool based on the responses by the resident if they were unable to write or see appropriately which allowed the researcher to remain neutral) which was done at the resident's bedside. The same procedure was followed for residents that were not suspected of being at risk for dysphagia.

2.15. Method of Data Collection

- a) Phase one: The researcher conducted a scoping review that aimed to identify current dysphagia tools available as well as their use within care facilities. The CCDR (Appendix N) was then established using the results of the scoping review.

- b) Phase two: Caregivers were required to identify residents that they suspected as being at risk for dysphagia. Following this, the researcher approached the residents who were required to complete the self-administered EAT-10 (Appendix K) (assistance provided by the researcher if required). The results of the EAT-10 were stored in a box housed by the researcher.
- c) Phase three: Caregivers were then required to identify residents that were not suspected of being at risk of dysphagia. Following this, the researcher again, approached the residents, who were required to complete the self-administered EAT-10 (Appendix K) (assistance provided by the researcher if required). The results of the EAT-10 were stored in a box housed by the researcher.
- d) Phase four: In the final phase of data collection, within 48-60 hours of the EAT-10 administration, the CCDR was administered by caregivers during mealtimes. This was to ensure presentation is similar at administration of the CCDR and EAT-10 while also preventing fatigue in participants. The results of the CCDR were stored in a different box housed by the head nurse and was only obtained by the researcher once all data had been collected. When the sample size was reached this phase of data collection concluded.

2.16. Research Process

The following steps were taken for completion of the research study:

- a) The researcher contacted the research site to have meetings with management, where information about the study was provided and preliminary permission for the study (Appendix A and Appendix B) to take place was sought. The management at the site were assured that the study and permission letter were preliminary and subject to ethical clearance being obtained.
- b) Once provisional approval for the study was obtained from the site (Appendix L), the researcher applied for ethical clearance from the University of the Witwatersrand Human Research and Ethics Committee (Medical) which was obtained (Appendix M)(Protocol No. M230907) as well.
- c) A scoping review of existing literature was conducted. It investigated dysphagia screening tools available and their use within care facilities. The tools were explored according to the time, training, and resources required to administer them. The

scoping review also included the validity and reliability of the tools used in care facilities specifically.

- d) The scoping review then led to the compilation of the CCDR (Appendix N).
- e) A pilot study of the CCDR was conducted to investigate its appropriateness in terms of time to administer, ease of administration and method of administration. This consisted of a sample size of four residents - two in each participant group and their respective caregivers. Informed consent was obtained from caregivers and residents to participate in the pilot study. The caregivers were required to administer the CCDR on residents. Once the CCDR has been administered, the appropriateness of it was examined, and modifications were made prior to data collection.
- f) Participant recruitment then commenced for the study. It should be noted that English is the primary medium of communication at the care facility. For this reason, all participants (caregivers and residents) were required to have conversational English. Caregivers were required to have a six-month training certificate; therefore, some ability to read, write and understand were required to be present. As for the residents, if there was apparent difficulty with reading or writing, assistance was provided by the researcher.
- g) Caregivers at the site, who fit the inclusion criteria were invited to participate in the study. For those who were interested, an information letter (Appendix C) and consent form (Appendix D) were provided, whereby written consent was required.
- h) As consent was obtained from the caregiver/s, data collection commenced. The caregiver participants then identified resident/s that they suspected of being at risk for dysphagia for the Frail Care Section group and residents they did not suspect of having dysphagia for the Assisted Living group. Caregivers identified residents based on a brief explanation of signs that may be present in the residents and notified the researcher. The researcher then invited the residents to participate. Residents were provided with an information letter (Appendix E) and consent form (Appendix F), which they needed to sign. In the case that a resident was unable to provide consent, the legal guardian was contacted. Information of the study was then provided (Appendix H) to them and an invitation to participate was extended. Guardian assent (Appendix I) was obtained. An adapted letter (Appendix G) was provided to elderly residents that presented with visual impairment and hearing difficulties, while for others, who required information was relayed verbally and signature or thumb print, for those with physical challenges, was acquired. The form provided to the resident was determined based on their conversational level with the researcher (no formal assessment was conducted), as the resident was only required to understand the task and convey their understanding as part of their participation.

- i) Once the residents (who the caregiver identified as part of either of the groups) consented to participate, the researcher required the resident to complete the self-administered EAT-10 (Appendix K) (assistance provided by the researcher if required) in the privacy of their room. The results of the EAT-10 were stored in a box and kept by the researcher.
- j) Once the EAT-10 was completed, caregivers were required to administer the CCDR at the place where the resident consumes their meal, i.e. in the dining room or their room. Administration of the CCDR occurred within a 48–60-hour timeframe following completion of the EAT-10. The CCDR required an observation by the caregiver who is generally present in the dining room during meals, therefore not bringing attention to the resident and maintaining their privacy. The results of the CCDR were stored in a box and kept by the head nurse. Results of the CCDR were not shared with the researcher during the data collection process. It should be noted that both, the CCDR and EAT-10 did not require the ingestion of food, therefore, religious dietary requirements were not considered. Any difficulties that were identified by the researcher, resulted in resident being referred (Appendix J) to the speech therapy students from the University of the Witwatersrand Speech Therapy Department who provide speech therapy services under supervision at the care facility,
- k) At the end of data collection, the researcher cleaned the data and collated the findings of the CCDR and EAT-10 for each resident participant. Residents were coded using their date of birth, therefore allowing the researcher to identify which CCDR will go with which EAT-10. Data collected will be stored safely for a period of six years from the date of collection.
- l) Once all data was collected, data was analysed, and the research write-up occurred.
- m) Based on the results of the research, feedback and information will be provided to the caregivers. Results will be made available to participants/guardians in certain cases, as well as management of the facility. This is a pilot study, and future studies may be conducted to establish the validity and reliability of the CCDR.

2.17. Data Quality

Reliability and validity are essential to improving accuracy in research (Mohajan, 2017). Since the current study was based on tool development, which is based on measure, it was also necessary to assess sensitivity and specificity (Swift et al., 2020).

2.17.1. Validity

Validity refers to when a tool assess what it was set out to measure (Mohajan, 2017). Two types of validity have been explored.

a) Content Validity

Content validity refers to if a measure serves the purpose of what it was developed to do (Kater & Seedat, 2023). In the current study, content validity was assessed using a scoping review based on existing literature of tools currently being used with the elderly. This informed the development of the CCDR. This was an aim of this study and was, therefore, essential.

b) Concurrent Validity

Concurrent validity refers to whether a tool, when compared to an already valid tool, produces similar results (Mohajan, 2017). Pearson's Correlation and Spearman's Rank Order Correlation were used to assess whether a correlation between the CCDR and EAT-10 exists. This allowed the researcher to understand whether the CCDR is a good measure in identifying residents at risk of dysphagia and referring accordingly.

2.17.2. Reliability

Reliability refers to the trustworthiness of a measure in producing consistent results (Hajjar, 2018). In the current study, reliability was measured in the form of internal consistency. Internal consistency refers to whether items in a measure, i.e. the CCDR is able to measure the same general construct i.e., dysphagia (Hajjar, 2018).

2.17.3. Sensitivity and Specificity

Sensitivity refers to the number of individuals that present with the disorder under investigation, which in this study were those identified of being at risk of dysphagia (Swift et al. 2020). Specificity, in contrast to sensitivity, refers to the number of individuals that do not present with the disorder under investigation, which in this study, were those who do not present with any signs of dysphagia risk when an assessment was conducted and have normal swallowing ability (Swift et al., 2020). Sensitivity and specificity was calculated as a percentage based on true positives and true negatives respectively (Kater & Seedat, 2023). This was determined based on the pass/fail criteria of the CCDR in relation to the EAT-10.

2.18. Data Analysis

Descriptive and inferential statistics were used to analyse data in the current study. Correlational analysis was used for data pertaining to the CCDR and the EAT-10, which allowed the researcher to determine the relationship between these two variables (Kim & Lee, 2023). This correlation coefficients that were used is Pearson's correlation and Spearman's rank order which is a number between -1 and 1 (Gogtay & Thatte, 2017). Based on this, the researcher was able to determine the direction and strength of the correlation (Gogtay & Thatte, 2017). It should be noted that a statistician was consulted to assist with statistical analysis.

3. Ethical Considerations

Ethical considerations will provide information of how autonomy, beneficence, non-maleficence and justice were considered in this study.

3.1. Autonomy

- a) Informed consent: All participants of this study were given information (Appendix C and E) with regard to what the study was about and what it would entail for them. Both groups of participants had adequate time to decide if they would like to participate and were not forced into participating. All caregivers that fit the criteria were invited to participate in the study and were required to provide written consent (Appendix D). Since, some members of the elderly population had difficulty with hearing or processing information, information was simplified and explained in a way that was fully understood using a modified information sheet (Appendix G). If they were able to, residents were required to provide written consent (Appendix F). Due to the inability to write or if the individual presented with reduced cognitive ability, information (Appendix H) and permission (Appendix I) was sought from the legal guardians of the resident. The residents that required such were identified by the head nurse.
- b) Right to withdraw: Caregivers and residents were informed that their participation is voluntary and that they have a right to withdraw at any point during the study without reason or consequences on them. With regard to permission received from legal guardians, the resident still had the right to withdraw their participation should they want to.
- c) Confidentiality:
 - I. Caregivers: No identifying information was/will be provided in any publications on caregivers and their administration of the CCDR.
 - II. Residents: All information obtained about residents was stored under a specific code and was safely stored in a locked draw that was only accessed by the researcher. Furthermore, information that was summarised in the Microsoft Excel sheet contained no identifying information. Similarly, no identifying information was/will be used in any publications however, where dysphagia risk was identified, a referral (Appendix J) was made and therefore confidentiality could not be maintained. Data collected will be stored for six years from the date of collection.

- d) **Anonymity:** Due to the nature of this study, anonymity could not be maintained with both participant groups. The researcher became familiar with caregivers due to her presence within the frail care and assisted living units of the facility during data collection. The researcher also became familiar with residents as all aspects of data collection involved direct contact with them. Some level of rapport was also built between the researcher and the residents to ensure compliance.

3.2. Beneficence

- a) **Caregivers:** The CCDR shows promise in providing a tool to identify residents at risk of dysphagia in order for referrals to be made appropriately.
- b) **Residents:** This study allowed residents in a care facility to receive a free dysphagia screening and referral (Appendix J) if dysphagia was a concern.
- c) **The residents** had their screening results communicated to them or their guardians after it was conducted and if they required the results of the study, that too has been provided accordingly to caregivers, residents or their guardians.

3.3. Non-Maleficence

- a) **Residents:** When a participant had signs of dysphagia based on the screening, a referral was made accordingly (Appendix J). This ensured that any risks associated with participating were minimised.
- b) **Caregivers:** There were no risks associated with participating for caregivers.

3.4. Justice

All participants were treated fairly and with respect throughout the research study. The researcher ensured cultural sensitivity and was objective in decisions as well as different views that participants had.

4. Results

The results from the data collection process are set forth. It begins by including the scoping review as part of ensuring content validity of the CCDR was established. It further includes results of the comparison between the EAT-10 and CCDR as well as the correlation and diagnostic accuracy. Data was analysed under the guidance of a statistician using the SPSS statistical software.

The results are first discussed separately specific to the separate parts of the study, thereafter results will be discussed as a collective.

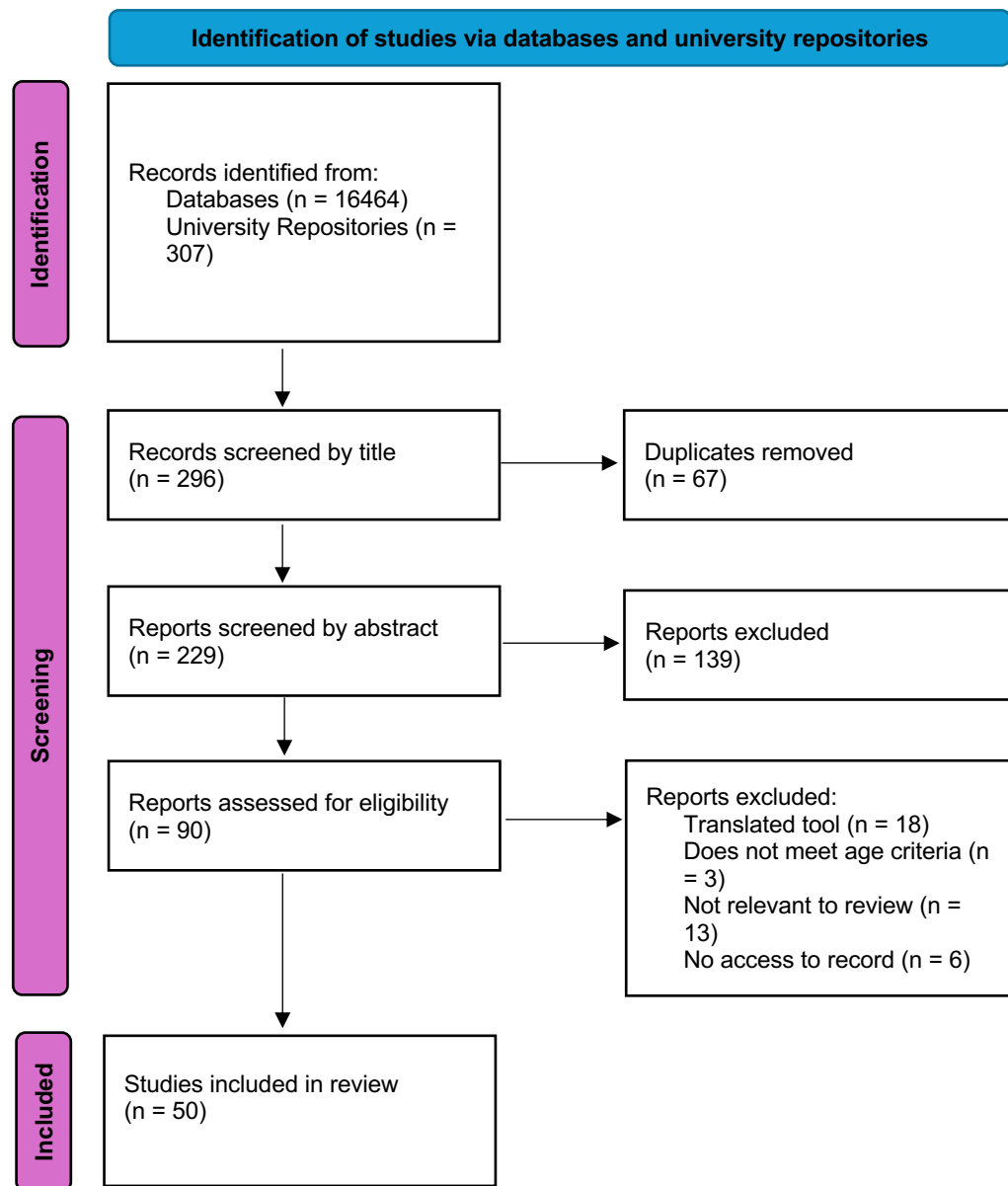
Results for Part 1: Scoping Review

4.1. Article Screening

A total of 16464 articles were identified across five databases (Scopus, Medline, Pubmed, CINAHL and Cochrane) and twenty university repositories. The articles underwent further screening (Figure 1) according to title, removal of duplicates and abstract screening until the final selection included 50 articles.

Figure 1

Article Selection Process Using PRISMA-ScR



Note. n is the number of articles

4.2. Tools Used

A total of 23 tools (Table 5) were used across articles which included the EAT-10 (n=21; 42%), the Volume-Viscosity Swallow Test (V-VST) (n=7; 14%) and the 100ml Water Swallow Test/Modified Water Swallow Test/ Timed Water Swallow Test (TWST) (n=6, 10%) being the most frequently used tools amongst the elderly.

Table 5*Tools used*

Name of tool	Frequency of tool use (n = number of articles)	Percentage (%) of articles
Eating Assessment Tool (EAT-10)	n=21	42%
Volume-Viscosity Swallow Test (V-VST)	n=7	14%
100ml Water Swallow Test/Modified Water Swallow Test/ Timed Water Swallow Test (TWST)	n=6	10%
3-Ounce Water Swallow Test	n=4	8%
Yale Swallow Protocol	n=2	4%
Dysphagia Handicap Index (DHI)	n=3	6%
Sydney Swallow Questionnaire (SSQ)	n=3	6%
SCREEN-II/SCREEN-II-AB	n=2	4%
Dysphagia Risk Assessment for the community-dwelling elderly (DRACE)	n=2	4%
The Gugging Swallow Screen (GUSS)	n=2	4%
Dysphagia Outcome Severity Scale (DOSS)	n=2	4%
Test of Mastication of Solids (TOMASS)	n=2	4%
Minimal Eating Observation Form (MEOF-I/MEOF-II)	n=1	2%
24-Item Mealtime Observation Checklist (MOCL)	n=1	2%
Swallowing Disturbance Questionnaire (SDQ)	n=1	2%
Modified Mann Assessment of Swallowing Ability (mMASA)	n=1	2%
National Outcomes Measurement System (NOMS)	n=1	2%
Dysphagia Self-test	n=1	2%
Dysphagia Screening Questionnaire	n=1	2%
Quality of Life in Swallowing Disorders (SWAL-QOL)	n=1	2%
Functional Oral Intake Scale (FOIS)	n=1	2%
Frailty Checklist	n=1	2%
Community Dwelling Older Adults (CDOA) Screening Tool	n=1	2%

4.3. Tool Characteristics

4.3.1. *Resources Needed*

The resources required to administer the tools were also explored and comprised of all perishable and non-perishable items required. There were twenty articles (n=20; 40%) that mentioned resources (Table 6), while thirty articles (n=30; 60%) did not mention resources or no resources were required. Water was the most common edible resource required, other tools required three different textures and one required just a cracker. Additionally, aspects of measures, such as a pulse oximeter, stopwatch or viscosimeter, were also required at times.

Table 6*Resources Used Within Tools*

Name of tool	Resources used	Frequency (n = number of articles)	Percentage (%) of articles
SCREEN-II/SCREEN-II-AB, DRACE, MEOF/MEOF-II, MOCL, DOSS, SDQ, mMASA, NOMS, Dysphagia Self-test, SSQ, Dysphagia Screening Questionnaire, SWAL-QOL, FOIS, Frailty Checklist, CDOA Screening Tool	- No report of any specific resources used	n=23	46%
EAT-10	- No report of resources used	n=21	42%
V-VST	- Liquid	n=6	12%
	- Nectar		
	- Pudding		
100ml Water Swallow Test/Modified Water Swallow Test/TWST	- Pulse oximeter	n=5	10%
	- Viscosimeter	n=1	2%
	- Water	n=6	12%
3-Ounce Water Swallow Test	- Stopwatch	N=2	4%
	- Water	n=3	6%
Yale Swallow Protocol	- Stopwatch	n= 2	4%
GUSS	- Semi-solid	n=2	4%
	- Liquid		
	- Solid		
TOMASS	- Cracker	n=2	4%

4.3.2. Tool Administration Time

The time taken to administer the tools was also examined, with only nine articles (n=9, 18%) (Table 7) mentioning an aspect of time. The time differed from, the time required to complete a meal to time required to complete swallowing of a liquid. Additionally, in tools that had a specified time, both tools required less than ten minutes for completion.

Table 7

Administration Time of Tools

Name of tool	Administration time	Frequency of tool use (n = number of articles)	Percentage (%) of articles
Tools that require water swallowing	Dependent on the time it takes the participant to drink the necessary amount of water plus a minute after	n=4	8%
V-VST	Less than ten minutes	n=2	4%
MEOF-I/MEOF-II	Duration of a mealtime	n=1	2%
MOCL	Duration of a mealtime	n=1	2%
EAT-10	Less than two minutes	n=1	2%

4.4. Reliability and validity of tools

Information about reliability and validity were reported thirty-one times (Table 8) across twenty-nine articles (n=29; 58%). Reliability was discussed (n=5, 10%) while validity was discussed (n=9; 18%) on its own. Both reliability and validity were discussed more frequently together (n=17; 34%). There was no mention of reliability and validity in majority of articles (n=21; 42%).

Table 8*Reliability and Validity of Tools*

Name of tool	Reliability and validity	Frequency (n = number of articles) percentage of articles)	Percentage (%) of articles
EAT-10	- Test-retest reproducibility - Internal consistency - Criterion-based validity	n=10	20%
	- Deficits in construct validity	n=1	2%
	- Reliable due to its high specificity but also has low sensitivity and should be used with caution	n=1	2%
DOSS	- Validated against Videofluoroscopic swallow study (VFSS)	n=2	4%
100ml-WST	- Valid due to high sensitivity	n=1	2%
MEOF-II	- Satisfactory reliability for inter-observer agreement and internal consistency - Good validity due to its structure	n=1	2%
3-Ounce Water Swallow Test	- Use of validated protocols	n=1	2%
DHI	- Use of validated protocols	n=1	2%
	- High internal validity	n=1	2%
	- High test-retest reliability		
DRACE	- Sufficient reliability and validity	n=1	2%
V-VST	- Validation against the VFSS for most frequent aetiologies	n=1	2%
	- Validated specifically for stroke patients	n=1	2%
SDQ	- Acceptable reliability according to Cronbach's alpha	n=	2%

Table 8 (continued)

Name of tool	Reliability and validity	Frequency (n = number of articles) percentage of articles)	Percentage (%) of articles
mMASA	- Reported to assess dysphagia consistently when compared to the VFSS	n=1	2%
SSQ	- Strong content validity, face validity, construct validity - Strong test-retest reliability - Lacked longitudinal validity	n=1	2%
	- Validation in neuromyogenic patients when compared to instrumental evaluation	n=1	2%
Dysphagia Screening Questionnaire	- Studied a modified version that was previously validated which also indicated that the reliability was the same between the two versions	n=1	2%
TOMASS	- Strong test-retest and inter-rater reliability - Strong measurement validity when compared to instrumental evaluation	n=1	2%
CDOA Screening Tool	- Reliable according to preliminary data and psychometric analysis	n=1	2%
GUSS	- Excellent inter-rater reliability for all categories	n=1	2%

4.5. Sensitivity and Specificity

Sensitivity and specificity were discussed in twenty articles (n=20; 40%) (Table 9) while it was not discussed in thirty articles (n=30; 60%). Varied results occurred across the same tools as well as different tools.

Table 9*Sensitivity and Specificity of Tools*

Name of tool	Sensitivity and specificity	Frequency (n = number of articles)	Percentage (%) of articles
EAT-10	Identification of dysphagia: high sensitivity of between 85% and 94% and a specificity of between 70,9% and 82%	n=4	8%
	Predicting aspiration: sensitivity of 70,6% and specificity of 52,7%	n=1	2%
100ml WST/Water Swallow Test	Sensitivity of 85,5% and specificity of 50%	n=4	8%
Yale Swallow Protocol	High sensitivity but a relatively low specificity when detecting aspiration	n=2	4%
Modified Water Swallow Test	Lower sensitivity of 70% and a higher specificity of 88%	n=1	2%
V-VST	Sensitivity of 98% for dysphagia, 92% for impaired efficacy of swallow, 80% for impaired safety and 100% for aspiration	n=1	2%
	Sensitivity of 88,2% and a specificity of 64,7% for aspiration or penetration	n=1	2%
	Sensitivity of 100% for scores of 14 points	n=1	2%

Table 9 (continued)

Name of tool	Sensitivity and specificity	Frequency (n = number of articles)	Percentage (%) of articles
GUSS	Sensitivity of 100% for scores of 13 or less, 19 points or less resulted in a sensitivity of 95,4%. Specificity of 64,3% was found for score of 13 or less and a specificity of 94,4% when a score of 19 points or less was considered	n=1	2%
	Sensitivity of 100% for scores of 14 points	n=1	2%
MOCL	Sensitivity of 75% and a specificity of 37,4%	n=1	2%
SDQ	With a cut off score of 12,5 had a sensitivity of 71,88% and a specificity of 78,38%	n=1	2%
DHI	Reported sensitivity to differences in scores dependent on the severity of the dysphagia present	n=1	2%

4.6. Dysphagia Identification

The identification of dysphagia (Table 10) using the various tools was described in thirty-three (n=33; 66%) articles while seventeen articles (n=17; 34%) had no mention of this. Dysphagia identification varied across different tools, different settings where the elderly reside, severity of dysphagia present and different consistencies of food screened.

Table 10*Dysphagia Identification*

Name of tool	Identification of dysphagia	Frequency (n = number of articles)	Percentage (%) of articles
EAT-10 (score of ≥3)	Between 20%-30% and >30% (when living in residential care)	n=6 and n=5	12% and 10%
	Less than 20% (when living in the community)	n=5	10%
V-VST	Between 23% and 86,6% (overall)	n=4	8%
	42,5% - 75,3% for liquids, 14,8% - 39,2% for nectar and 3,8%-27,6% for pudding (per consistency)	n=2	4%
DOSS	8.9% - normal swallow, 20,5% - minimal impairment, 36,6% - mild dysphagia, 33,9% - mild to moderate dysphagia	n=2	4%
SCREEN-II	43,7%-46,9% for high risk	n=2	4%
	23,9% for moderate risk	n=1	2%
	32,4% for low risk	n=1	2%
100ml Water Swallow Test	93,2% when compared with VFFS	n=1	2%
	5.8%	n=1	2%
3-Ounce Water Swallow Test	35,3%	n=1	2%
	93,2% when compared to the FEES	n=1	2%
	23,9% for moderate risk	n=1	2%
	32,4% for low risk	n=1	2%
SCREEN-II-AB	Weight loss: 18.4%	n=1	2%
	Poor or fair appetite: 13,2%	n=1	2%
	Swallowing: 13,7%	n=1	2%

Table 10 (continued)

Name of tool	Identification of dysphagia	Frequency (n = number of articles)	Percentage (%) of articles
SSQ	Between 9,49% and 14,2%	n=3	2%
DRACE	More than half had a risk of dysphagia	n=1	2%
GUSS	52,7%	n=1	2%
Dysphagia screening questionnaire	13,8% of community-dwelling elderly	n=1	2%
Frailty Checklist	12.4% of community-dwelling elderly	n=1	2%
DHI	16% - normal swallow, 31% - mild dysphagia, 44% - moderate dysphagia, 9% - severe dysphagia	n=1	2%
DST and 3-Ounce Water Swallow Test	40,1% (collectively)	n=1	2%
EAT-10, GUSS and WST	43,1% (collectively)	n=1	2%

4.7. Signs and Symptoms of Dysphagia and/or Aspiration

There were twenty-five articles (n=25; 50%) that mentioned signs and symptoms of dysphagia and /or aspiration (Table 11) and twenty-five articles (n=25; 50%) that did not. The most common signs identified included coughing or choking (n=18; 36%), wet-hoarse voice/changes in vocal quality (n=13; 26%) and food getting stuck or remaining in oral cavity or throat and throat clearing (n=14; 28%).

Table 11*Signs and Symptoms of Dysphagia and/or Aspiration*

Signs and symptoms of dysphagia and/or aspiration	Frequency (n = number of articles)	Percentage (%) of articles
Coughing/choking	n=18	36%
Wet-hoarse voice or changes in voice quality	n=13	26%
Food getting stuck or remaining in oral cavity or throat and throat clearing	n=14	28%
Anterior spillage or drooling	n=8	16%
Extra effort and increased duration of meals	n=7	14%
Piecemeal deglutition	n=6	12%
Avoidance of food textures	n=6	12%
Inability to complete task	n=4	8%
Decrease in oxygen saturation	n=4	8%
Executive functioning and independence when consuming meals	n=4	8%
Weight loss	n=2	4%
Emotional aspects	n=2	4%
Pneumonia and pyrexia	n=1	2%

4.8. Person Administering the Tool

The administrator of the tool was mentioned forty-two (n=42; 84%) times in articles (Table 12) while only eight (n=8; 16%) articles had no mention of this. The most common method of administration was either self-administered/patient reported (n=28; 56%) followed by administration by a speech therapist (n=7; 14%) .

Table 12*Person/s Adminstrating the Tool*

Name of tool	Person/s administering the tool	Frequency (n = number of articles)	Percentage (%) of articles
EAT-10, SCREEN-II/SCREEN-II-AB, SDQ (if able to), DHI, SSQ, Frailty Checklist, Dysphagia Self-Test, CDOA Screening Tool	Self-administered/ patient reported	n=28	56%
MOCL, 3-Ounce Water Swallow Test, Yale Swallow Protocol, TWST and EAT-10 (if assistance was required)	Speech therapist	n=7	14%
V-VST, MOCL, Yale Swallow Protocol, MEOF-II and SDQ (if assistance was required)	Nurses	n=6	12%
V-VST	Trained general practitioners	n=2	4%
V-VST and DOSS	Geriatricians	n=2	4%
DRACE and MOCL	Caregivers	n=2	4%
EAT-10 and SDQ (if assistance was required)	Caregivers	n=2	4%
3-Ounce Water Swallow Test, DHI and GUSS	Trained research assistant (unspecified)	n=2	4%
Yale Swallow Protocol	Speech therapist trained in protocol administration	n=1	2%
TWST and TOMASS	Speech therapist trained in administration of TWST and TOMASS as part of SLP training	n=1	2%
MEOF-II	Nursing students	n=1	2%
GUSS	Nurses that had three or more years of experience and a further two hours of training	n=1	2%

Table 12 (continued)

Name of tool	Person/s administering the tool	Frequency (n = number of articles)	Percentage (%) of articles
MOCL	Physicians and dentists	n=1	2%
SDQ (if assistance was required)	Physician	n=1	2%
mMASA (to confirm results)	Dysphagia trained physician	n=1	2%
DRACE	Healthcare professionals (unspecified)	n=1	2%
V-VST	Specialised personnel (unspecified) trained in examination techniques	n=1	2%
MEOF-II	Hospital staff (unspecified) and clinical tutors	n=1	2%
MOCL	Dieticians	n=1	2%
mMASA	Supervision by occupational therapist	n=1	2%
V-VST	Expert swallow therapists	n=1	2%
EAT-10 (if assistance was required)	Staff or volunteers to assist	n=1	2%
FOIS	Clinician (unspecified)	n=1	2%

4.9. Format of Tools

The format of tools (Table 13) that were used across studies was mentioned in thirty-three (n=33; 66%) articles while seventeen articles (n=17; 34%) had no mention of tool format.

The most common format was Likert scale questions (n=26; 52%) followed by yes/no questions (n=7; 14%). Additionally, it should be noted that certain tools use a combination of format types.

Table 13

Format of Tools

Name of tool	Format type	Frequency (n = number of articles)	Percentage (%) of articles
EAT-10, MEOF-II, DRACE, DOSS, SDQ, NOMS, DHI, Dysphagia Screening Questionnaire, SSQ (last question), SWAL-QOL, SCREEN-II, SCREEN-II-AB	Likert Scale	n=26	52%
Yale Swallow Protocol, MEOF-II, MOCL, SDQ (one question), DST, Frailty Checklist, CDOA Screening Tool	Yes/no questions	n=7	14%
GUSS, SCREEN-II, SCREEN-II-AB	Scored using a points system	n=4	8%
SSQ	Visual analogue scale	n=2	4%
Yale Swallow Protocol	Direct questions	n=1	2%

4.10. Age Discrepancy

Despite including the elderly, who were the focus of this study, some studies also included other age groups (n=8) varying from >18 years old (Belafsky et al., 2008; Garand et al., 2020; Heijnen et al., 2019; Huckabee et al., 2018; Kurosu et al., 2021; Silbergleit et al., 2012; Wilmskoetter et al., 2017; Wu et al., 2004). These studies were included as they provide valuable information about tool development and use. The use of these studies will be used with caution, as the results have not been categorised but rather collectively analysed and described, therefore, not considering the elderly independently to other age groups. There was an exception of one article which indicated an abnormal score on the EAT-10 which had an 11% difference when comparing the youngest category to the oldest category (Garand et al., 2020).

4.11. Summary of Results of Scoping Review

It is evident that there are a variety of tools being used to identify dysphagia with the elderly; however, the EAT-10 (n=21; 42%) appears to be the tool used most consistently with this population. It is quick to administer, with a time of less than two minutes (n=1; 2%). The EAT-10 is reported to have good test-retest reproducibility, internal consistency and criterion-based validity (n=10; 20%) while also having high sensitivity but a slightly lower specificity (n=5; 10%). Identification of dysphagia using the EAT-10 varied which could be attributed to the fact that it is a self-administered tool and has a Likert scale format which rates severity which may be interpreted differently by different individuals.

The second most commonly used tool was the V-VST (n=7; 14%) which has a significantly lower rate of use than that of the EAT-10. It also requires more resources such as different food consistencies (n=6; 12%) and a viscosimeter (n=1; 2%). The duration to administer the V-VST was also a relatively low time of less than ten minutes (n=2; 4%). Despite being validated against a VFSS for most frequent aetiologies (not specified) as well as validation for stroke patients (n=2; 4%), it has not been specifically validated for the elderly population. Additionally, the V-VST has had high rates of sensitivity and specificity in with one article indicating a lower specificity which may be a concern. This could be echoed in terms of dysphagia identification in which results significantly varied (n=4; 8%). A variety of healthcare professionals/medical personnel are required to administer the V-VST, and the format of results reporting has not been explicitly explored.

Similarly, the use of the 100ml Water Swallow Test/Modified Water Swallow Test/ Timed Water Swallow Test (TWST) (n=6; 12%) was also common. The above tools all have the same premise, with water (n=6; 12%) required for administration with additional mention of a stopwatch (n=2; 4%) and the administration time being dependent on the time it takes the participant to swallow the water plus a minute after (n=4; 8%). The 100ml Water Swallow Test being valid due to its high sensitivity (n=1; 2%), however, reliability and validity of the other variations of water swallowing tools were not discussed. Furthermore, sensitivity and specificity amongst these tools had a contrast in rates. The same was noted with regard to dysphagia identification rates using these tools. A speech therapist was required to administer the water swallowing tools mentioned above with its format of reporting results not being explicitly explored.

Lastly, the signs and symptoms explored were not tool specific with the most common being coughing/choking (n=18; 36%) followed by food getting stuck or remaining in oral cavity or

throat and throat clearing (n=14; 28%) and a wet-hoarse voice or changes in voice quality (n=13; 26%). Less frequent symptoms included were pneumonia and pyrexia (n=1; 2%), emotional aspects (n=2; 4%) and weight loss (n=2; 4%).

4.12. Development of the Caregiver Checklist for Dysphagia Risk (CCDR)

The CCDR (Appendix N) was developed after the scoping review was conducted. The scoping review identified existing dysphagia screening tools that have been standardised for use in care facilities. The CCDR follows the Recognition-Primed Decision Model (RPDM) which is based on the premise that workers in healthcare are able to use available information and quickly come to a diagnosis (Pillay & Pillay, 2021). This model avoids incorrect decisions to be made by using a time-efficient and minimal resource process based on intuition (Pillay & Pillay, 2021). The tool was also developed according to guidelines set out such as with the use of short questions and clear instructions for improved understanding and reliability of answers, question placement for relevance and prevention of pattern answering, and consideration for layout, font style and size etc. to improve ease to the reader (Johnson & Christensen, 2013). Furthermore, the MEASURE approach was used to guide the steps needed to develop a new tool as well as assessing the effectiveness of it (Kalkbrenner, 2021).

4.12.1. Description of the CCDR

The CCDR comprises of different sections which considers various aspects that should be considered before, during and after a mealtime as well as additional factors that may impact the safety of meal consumption. This includes:

a) Comorbidities (if applicable to patient)

The CCDR considers various comorbidities such as chronic diseases, neurological conditions, cancer and progressive neurological disease which are the most common aetiologies of dysphagia in this population (Banda et al., 2022, Madhavan, 2021).

b) Feeding mode, dependent versus independent, posture, positioning, orientation and awareness of resident.

The next section of the CCDR consisted of five subsections which relied on the actual observation of the resident. The first was external factors and consisted of whether a modified diet is followed, physical factors and orientation which are important determinants of safe swallowing.

- c) Dentition and/or abnormalities or structural impairments in the oral cavity.

The next subsection explored dentition, in terms of natural teeth, dentures, hygiene and drooling. Poor oral health, gum disease, and edentulism becomes more common in the elderly and increases when dysphagia is present, necessitating its inclusion within the CCDR (Remijn et al., 2022).

- d) Observation of signs of eating and drinking difficulty during mealtime and observation of resident during and after meal/ swallow of food/drink.

The next two subsections considered signs observed by caregivers during meals and within thirty minutes after. The items for observation were based on items of other tools found across the articles screened within the scoping review, as well as consideration of other signs that can be observed after a meal which may also be a concern for dysphagia.

- e) Resident report.

Lastly, the tool focuses on whether or not a resident has reported difficulty or discomfort when consuming a meal. Having a resident report aspect ensured that the opinion or concern a resident may have of themselves is also valid and is vital for the caregiver to consider during CCDR administration.

4.12.2. Administration of the CCDR

The CCDR is required to be administered by a caregiver based on the observation of a meal of the at-risk resident. The caregiver would need to indicate using a “1 – Present” or “0 – Not Present” for each item placing the resident at risk for dysphagia. The score was then totalled of present items at the end of each subsection. This was then totalled to a score out of 30.

4.12.3. Pass/Fail Criteria

A score of ≥ 3 in subsection 3 or 4 indicates a fail and an immediate referral to a speech therapist. The same is required if a total score of > 10 was achieved. A total score of ≤ 10 requires a re-administration of the CCDR at another meal time.

Results for Part Two: Caregiver Checklist for Dysphagia Risk (CCDR)

4.13. Descriptive Statistics

The total sample consisted of 32 residents recruited as part of two groups i.e. the at risk group and no risk group with 15 and 17 residents in each group respectively. Results have, however, been reported per tool used rather than per group as results of the CCDR were most important for the purpose of this study.

Table 14

Participant Age

	N	Minimum	Maximum	Mean	Std. Deviation
Participant age	32	61	96	75,69	10,325

Table 14 shows the age range of the participants indicating a mean age of 75,69. The youngest participant had an age of 61 and the oldest participant aged 96 years old.

Table 15

Data Collection Instrument Scores

	N	Minimum	Maximum	Mean	Std. Deviation
EAT-10_total	32	0	31	3,78	7,400
CCDR_total	32	0	14	4,62	3,957

The scores of the tools as described in Table 15 indicate that both tools had the same minimum score (0) with varying maximum scores at 31 for the EAT-10 and 14 for the CCDR which could be due to different scoring methods. The mean score for the EAT-10 and CCDR were 3,78 and 4,62 respectively and standard deviations was 7,400 and 3,957 for each tool respectively. A higher mean score on the CCDR could be due to the perceptions of the resident being different as compared to the caregivers when each tool is administered.

4.14. Reliability

Reliability in the form of internal consistency refers to how well the items in a tool measures what it was set out to measure (Robertson & Evans, 2020). Cronbach's Alpha is used to measure internal consistency and is the most common way used to measure this (Robertson

& Evans, 2020). It is also the most important statistical construct in tool construction and use (Robertson & Evans, 2020). In order for the Cronbach's Alpha threshold to be acceptable or sufficient it has to be 0,7, anything lower than this indicates an insufficient internal consistency (Robertson & Evans, 2020). The CCDR consists of 30 items with a Cronbach's Alpha of 0,815. Similarly, the Cronbach's Alpha of the 10-item EAT-10 was measured at 0,937. The CCDR and EAT-10 both have a strong internal consistency and the similarity of the scores shows that the CCDR is able to measure dysphagia appropriately according to the items the tool contains.

4.15. Data Distribution

In order to test for correlation, data is required to be normally distributed (Mishra et al., 2019). This investigates whether data obtained has been drawn from a population that is well represented. This was demonstrated for both, the CCDR and EAT-10 graphically, using Histograms and Q-Q plots and is used to compare expected distribution and actual distribution of data (Mishra et al., 2019). The Kolmogorov-Smirnov Test and Shapiro-Wilk Test were calculated methods used to represent data distribution (Mishra et al., 2019).

Figure 2

Histogram Showing the Data Distribution of the EAT-10 with Normal Distribution Curve Overlaid

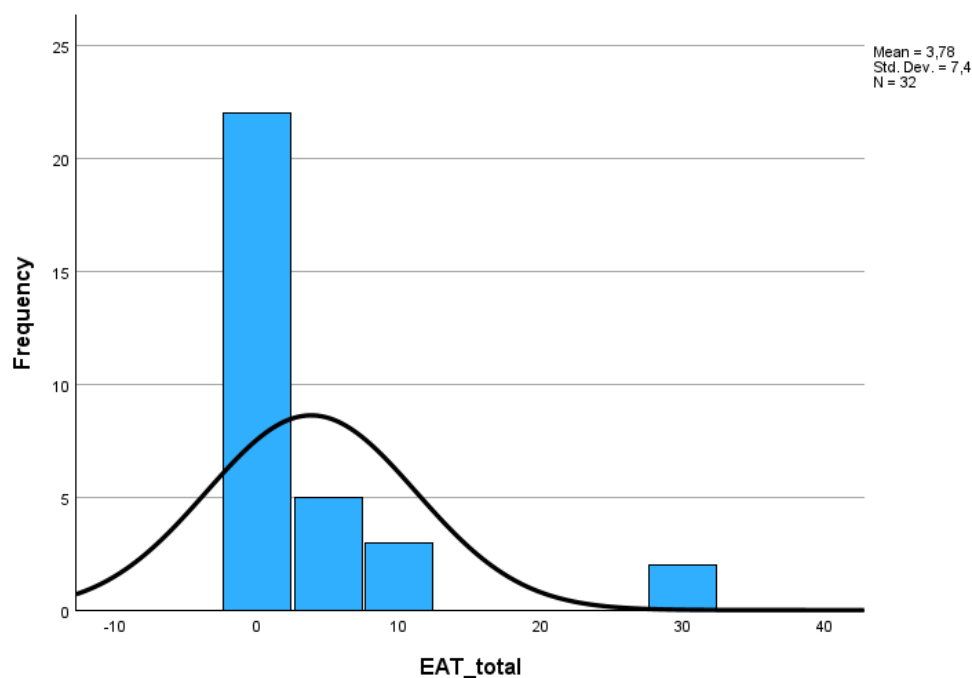
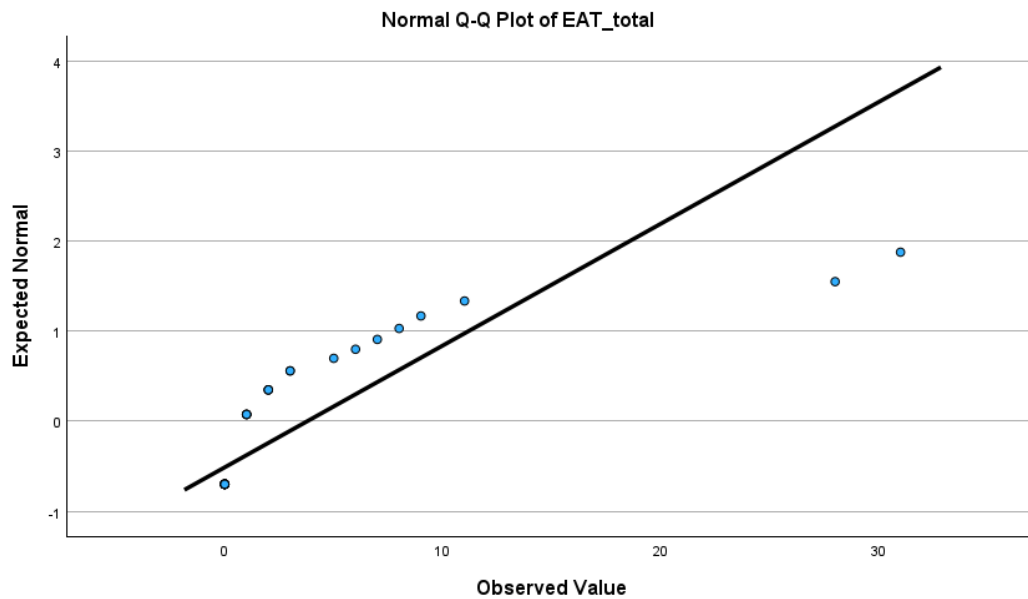


Figure 3

The Q-Q Plot Shows the Data Distribution of the EAT-10



Results (Figure 2) show that data of the EAT-10 is quite non-normal. This means that data obtained is not equally distributed across the tool as most items scored by participants were focused on similar questions. Similarly, in the Q-Q plot (Figure 3) where normal distribution data would have clustered close to the line. The data of the EAT-10 is more scattered also indicating non-normal data distribution.

Figure 4

Histogram Showing the Data Distribution of the CDDR with Normal Distribution Curve Overlaid

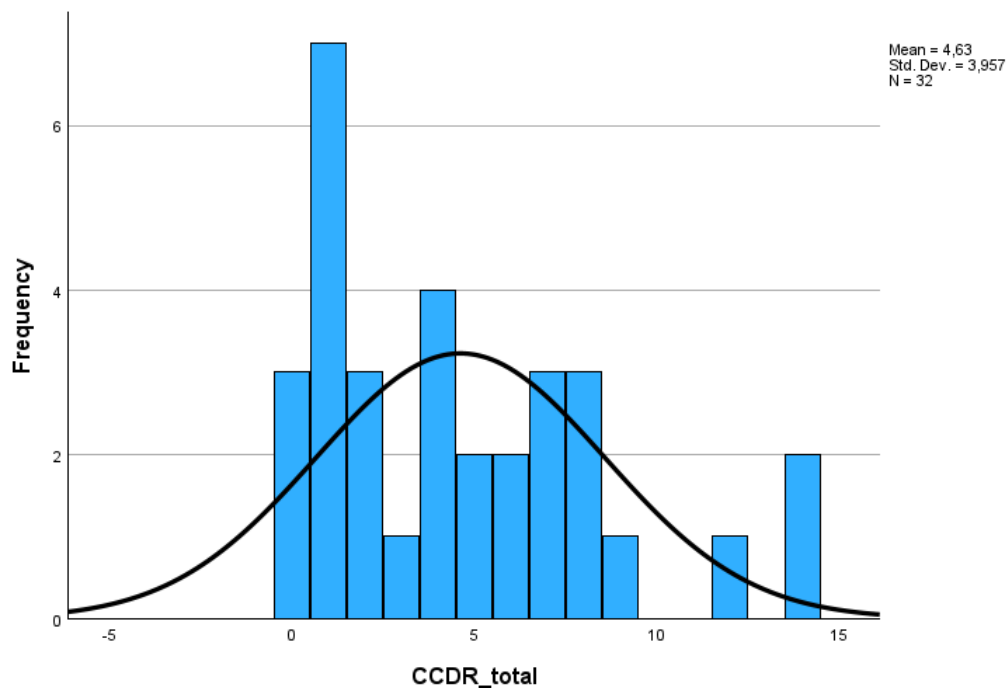
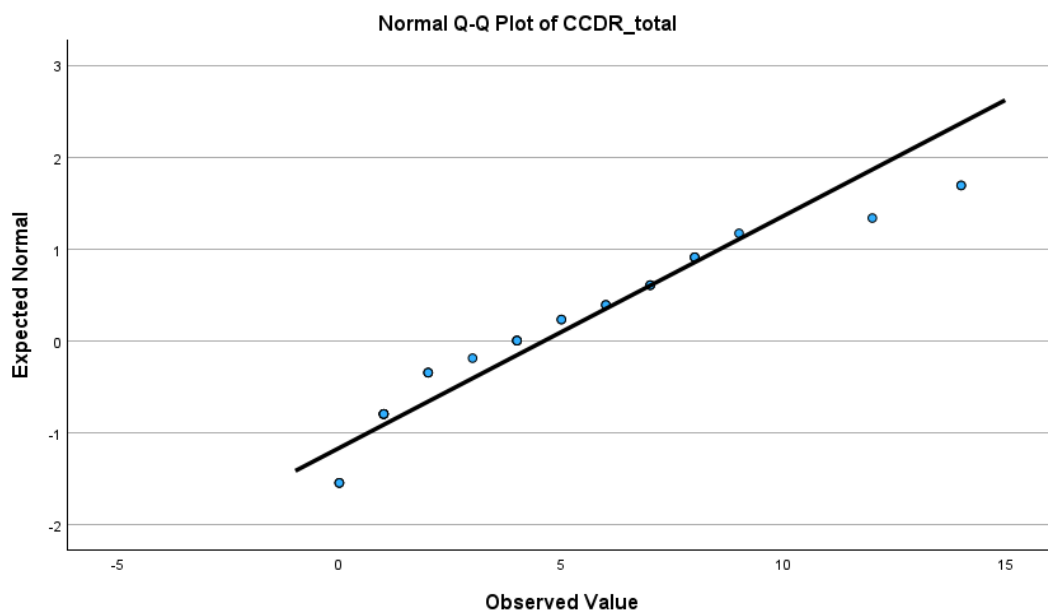


Figure 5

The Q-Q Plot Shows the Data Distribution of the CDDR



When looking at the data of the CDDR on the histogram (Figure 4), it is also non-normal, however appears to be more normal than that of the EAT-10. This means that despite the data not being equally distributed across test items, it is more consistent than that of the

EAT-10. On the other hand, on the Q-Q plot (Figure 5), data of the CCDR appears to cluster more on the line suggesting normality meaning the data is more equally distributed across test items.

The Kolmogorov-Smirnov test is a non-parametric statistical measure used to compare the data between two distributions which is the CCDR and EAT-10 (Yang & Berdine, 2021). The Shapiro-Wilk test is another statistical measure used to assess whether data obtained in the sample is representative of the population studied which was also conducted for the CCDR and EAT-10 (Yang & Berdine, 2021).

Table 16

Tests of Normality (Kolmogorov-Smirnov & Shapiro Wilk)

Tests of Normality						
	Kolmogorov-Smirnov^a			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
EAT-10_total	0,305	32	<0,001	0,562	32	<0,001
CCDR_total	0,153	32	0,056	0,898	32	0,005

Note. a. Lilliefors Significance Correction

Results (Table 16) indicate that both the Kolmogorov-Smirnov and Shapiro-Wilk tests indicated a significance level of less than 0.001 for the EAT-10. This also suggests that the data is non-normally distributed. For the CCDR, the Kolmogorov-Smirnov test showed a significance level of 0.056, which is near the threshold of 0.05, indicating that it is on the border of normality. The Shapiro-Wilk test showed a significance of 0.005, also suggesting non-normality. However, the slight deviation from normality in the CCDR indicates that it may be more normally distributed than the EAT-10. The Lilliefors Significance Correction is often used since it provides more accurate results (Viček & Huth, 2009). It uses the same calculation as that of Kolmogorov-Smirnov but critical values are smaller and therefore, more likely to show normally distributed data (Viček & Huth, 2009). It can be concluded by the results obtained using the Kolmogorov-Smirnov test with Lilliefors Significance Correction and Shapiro-Wilk test as well as the above histograms and Q-Q plots that the CCDR is better suited for the population it is developed to assess than that of the EAT-10.

4.16. Correlation

In healthcare research, assessing correlation is common (Franzese & Iuliano, 2018). It explores the relationship between two continuous variables which in the current study is the relationship between the EAT-10 and the CCDR (Franzese & Iuliano, 2018). Pearson's correlation and Spearman's rank order are the two types of correlation that have been explored. Pearson's correlation is a parametric measure that uses linear relationships and requires data to be normally distributed (Alsaqr, 2021). It was used in this study despite the EAT-10 having non-normal data, and was run with the outlier data being ignored.

Table 17

Correlation Calculated Using Pearson's Correlation Coefficient

		EAT-10 total	CCDR total
EAT-10 total	Pearson Correlation	1	0,499**
	Sig. (2-tailed)		0,004
	N	32	32
CCDR total	Pearson Correlation	0,499**	1
	Sig. (2-tailed)	0,004	
	N	32	32

Note. **Correlation is significant at the 0.01 level (2-tailed).

There was a statistically significant, moderate positive correlation (Table 17) between the scores of the EAT-10 and CCDR, $r(30) = 0.499$, $p < 0,001$. As mentioned above, since the data of the EAT-10 was non-normal, the Spearman's rank order correlation was also conducted.

Table 18*Correlation Calculated Using Spearman's Rank Order*

			EAT-10 total	CCDR total
Spearman's rho	EAT-10 total	Correlation Coefficient	1,000	0,454**
		Sig. (2-tailed)	.	0,009
		N	32	32
	CCDR total	Correlation Coefficient	0,454**	1,000
		Sig. (2-tailed)	0,009	.
		N	32	32

Note. **Correlation is significant at the 0.01 level (2-tailed).

The Spearman's rank order is a non-parametric measure which is suitable for use when data is not normal such as with the EAT-10 and uses ranks of data (Alsaqr, 2021). Spearman's Rank Order examines the strength and direction of a monotonic relationship (Laerd, n.d.). Similar to the Pearson's correlation, the Spearman's rank order showed the relationship to be monotonic which means that scores of the EAT-10 and the CCDR were similar in the sense that higher scores of the EAT-10 resulted in higher scores of the CCDR (Laerd, n.d.). There was a statistically significant, moderate positive correlation (Table 18), $r(30) = 0.454$, $p < 0,001$. The correlation indicates a positive result for the preliminary use of the CCDR.

4.17. Sensitivity and Specificity

Diagnostic accuracy, in the form of sensitivity and specificity analysis are commonly used in screening type studies and was included as it can identify the success of the CCDR (Bujang & Adnan, 2016). When exploring diagnostic accuracy, the way the sample size is calculated (Table 19) is impacted by what you would expect the sensitivity and specificity level to be as well as the expected prevalence, confidence level and confidence interval (Bujang & Adnan, 2016). Since this is a pilot study a higher confidence interval (0,20) and sensitivity (0,80) and specificity (0,80) was chosen to obtain preliminary results of the CCDR.

Table 19*Sample Size Calculated Based on Expected Sensitivity and Specificity*

Construct	Number
Expected sensitivity	0,80
Expected specificity	0,80
Expected prevalence	0,50
Length of confidence interval (precision)	0,20
Confidence level	0,95
Sample size required:	31

Table 20*Crosstabulation Between EAT-10 and CCDR Outcomes*

		Disease (EAT-10)	
		Risk (+)	No Risk (-)
Test (CCDR)	Risk (+)	9	4
	No Risk (-)	1	18

The sensitivity and specificity of the CCDR was calculated using the above table (Table 20) and can be seen below:

Sensitivity: True positive / (True positive + False negative)

$$\begin{aligned}
 &= \frac{9}{(9 + 1)} \\
 &= \frac{9}{10} = 0.90
 \end{aligned}$$

Specificity: True negative / (False positive + True negative)

$$\begin{aligned}
 &= \frac{18}{(4 + 18)} \\
 &= \frac{18}{22} = 0.82
 \end{aligned}$$

The above results indicate a sensitivity of 0,90 and specificity of 0,82. This means that the CCDR is highly sensitive in identifying elderly residents who may be at risk for dysphagia. It also has a high specificity which shows that the CCDR is able to appropriately identify elderly residents who are not at risk of dysphagia within residential care facilities appropriately.

4.18. Summary of Results of Quantitative Study

Results in the quantitative aspect of this study included descriptive and inferential statistics. The total sample consisted of 32 residents recruited as part of either the at-risk group and no risk group. The participants mean age was 75,69.

The scores of the tools indicated that both tools had the same minimum score with varying maximum scores which could be due to different scoring methods. The mean score for the EAT-10 was lower than the CCDR which could be due to the perceptions of the resident being different as compared to the caregivers when each tool is administered.

Both tools, had a strong internal consistency. The similarity of the scores shows that the CCDR is able to measure dysphagia appropriately according to the items the tool contains.

Both the Kolmogorov-Smirnov and Shapiro-Wilk tests indicated that data for the EAT-10 is non-normally distributed as data obtained was not equally distributed across the tool. For the CCDR, the Kolmogorov-Smirnov test indicated that it is on the verge of normality. The Shapiro-Wilk test suggested non-normality. However, the CCDR indicates that it may be more normally distributed than the EAT-10.

There was a statistically significant, moderate positive correlation between the scores of the EAT-10 and CCDR using Pearson's correlation and Spearman's rank order. Spearman's rank order showed the relationship to be monotonic which means that higher scores of the EAT-10 resulted in higher scores of the CCDR.

The CCDR had a high sensitivity and specificity meaning that it is able to identify elderly residents who may be at risk for dysphagia as well as appropriately identify elderly residents who are not at risk of dysphagia within residential care facilities appropriately.

4.19. Overall Summary of Results

In the first part of data collection, which was the scoping review, results indicated that the EAT-10, V-VST and screening tools involving water swallowing were most common and were looked at according to reliability and validity, sensitivity and specificity, resources, time taken for administration, format of the tool and person administering the tool. Additionally the signs and symptoms in terms of most common and least common were explored. This information was critical in developing the CCDR.

In the second part of data collection, preliminary evaluation of the CCDR was conducted which can be seen in the above calculations. The CCDR has a high internal consistency as well as a moderate positive correlation when compared to the EAT-10. It is highly sensitive in identifying elderly residents who may be at risk for dysphagia within residential care facilities. The CCDR also has a high specificity which shows that the CCDR is able to appropriately identify elderly residents who are not at risk of dysphagia within residential care facilities. These results should be taken with caution as this study consists of a small sample size, however, these are promising initial results.

5. Discussion

The current section discusses the research aims and objectives in relation to the results, which is then contextualised within existing research.

This study focused on the elderly residing in care facilities and improving identification of residents who may be at risk for OD by caregivers to improve referral to speech therapists. The CCDR, which is a new tool developed by the researcher, was not compiled for use with any specific disease. By compiling it for use with an elderly individual but without stipulating diagnosis eligibility, the generalisability of the CCDR was promising.

The elderly population is growing rapidly across the world due to advances in education and healthcare and is known as 'population ageing' as coined by the United Nations in 2015 (Muller, 2024). This is evident in South Africa as well, with the population of elderly (>65 years) increasing from 5,3% (Census, 2011) to 6,5% (Census, 2022). Globally, this is set to rise even further by the year 2050 (United Nations, 2022). Based on this, there is a growing need for residential care facilities which provide long-term care (Muller, 2024). The number of people residing in care facilities in South Africa is not known; however, it is considered to be rising at the same level as that of developed countries (Kalideen et al., 2022). The site at which the current study was conducted consisted of approximately 320 residents and approximately 47 caregivers. Caregivers are at the forefront of providing care and assisting the elderly in residential care facilities, and it was no different at this facility (Marais, 2020). The ratio of caregivers to residents confirms that one caregiver is responsible for multiple residents, each of whom has differing care needs, thereby increasing the workload of the caregivers (Marais, 2020). Caregivers receive generalised training and education to receive a caregiving certification (Marais, 2020). This equates to considerably less than that required of other healthcare professionals in terms of length of training, depth, and detail of content (Marais, 2020). Caring for the elderly can be a complex task as they constitute a vulnerable population. It is therefore, imperative that caregivers are equipped with the correct tools, even after they receive their certification, to provide care for this population. As an individual gets older, the chances of developing a comorbid condition increases (Kalideen et al., 2022). Furthermore, secondary conditions that occur together with chronic disease can include mental, motor, cognitive, communication, swallowing difficulties, and weight loss (Kalideen et al., 2022). Swallowing difficulty, with some inclusion of weight loss as a symptom of oropharyngeal dysphagia was considered as part of this study (Thiyagalingam et al., 2021).

Content validity refers to whether a measure is appropriate and represents the target population, which was that the CCDR was able to identify dysphagia risk within the elderly residing in care facilities (Almanasrah et al., 2019). Content validity is not quantifiable and relies on literature and expertise (Almanasrah et al., 2019). This was an aim of the study and therefore, content validity was established through the use of a scoping review, the MEASURE approach (Kalkbrenner, 2021) and the researcher's knowledge in the field of OD.

The MEASURE approach was used as a means to assist in the development of the CCDR as it has been set out as a guide to instrument development (Kalkbrenner, 2021). The approach uses an acronym which stands for “(a) **M**ake the purpose and rationale clear, (b) **E**stablish empirical framework, (c) **A**rticulate theoretical blueprint, (d) **S**ynthesise content and scale development, (e) **U**se expert reviewers, (f) **R**ecruit participants, and (g) **E**valuate validity and reliability” (Kalkbrenner, 2021). This approach was used as a guide in the development of the CCDR with some adaptations in the sequence it was carried out and will be further carried out in future studies.

A variety of factors were considered when analysing the tools used within the studies identified in the scoping review. These included the diagnostic accuracy of the tools, time required in administration, resources required for administration, dysphagia signs and symptoms, identification of dysphagia, reliability and validity of the tools, person administering the tool and format were all important to facilitate the development of the CCDR. The scoping review results are discussed interchangeably with the MEASURE approach.

The use of the scoping review to establish content validity of a newly developed tool formed the rationale and purpose aspect of the MEASURE approach. The empirical framework was set out using the results of the scoping review in order to develop the items of the CCDR. The theoretical blueprint was conducted with the use of the RPDM, as set out by Klein, Calderwood, and Clinto-Cirocco (1986) which is a decision-making framework in which professionals use their experience and expertise to make decisions (Klein, 1993). This model avoids incorrect decisions to be made by using a time-efficient and minimal resource process based on intuition within the healthcare system (Pillay & Pillay, 2021). The CCDR was, therefore, developed together with the scoping review consisting of broad areas that can be quickly observed by caregivers based on a mealtime. This is based on findings in the scoping review. The role of a caregiver is diverse which includes assisting the elderly with ADLs, and assist with treatment regimens, as well as coordinate care (Riffin et al., 2020). Caregivers, were required for administration in 8% (n=4) of reviewed articles and in half of

those articles, they were recruited to assist with administration, only if it was required. Due to the nature of the role of the caregiver, as mentioned above, it can be assumed that caregivers spend the most time with residents making them the ideal person for identifying dysphagia risk. This review also considered the time it takes for tool administration, which was mentioned in less than a quarter of the articles; however, in those articles it was mostly noted that tools required quick administration or the duration of a mealtime to be administered. Screening and assessment of swallowing disorders were most often done during observation in mealtime in nursing homes, as reported in a survey (Engl & Speyer, 2021). Considering the workload of caregivers, it was necessary for the CCDR to be a quickly administered tool that should be administered based on observations of a mealtime.

In order to synthesise the content and develop the CCDR, possible test items were set out according to its frequency and importance as part of the scoping review. Additionally, literature on difficulties faced by the elderly when it comes to OD, and experience by the researcher in the field of OD were also included. In the scoping review, the signs and symptoms observed using the various tools were explored. The tools used were either for detection of dysphagia and/or aspiration, and signs and symptoms were grouped in terms of similarity. Considering the importance of using signs and symptoms to determine further assessment for dysphagia, it was only discussed in 50% of the articles, indicating a lack of information available about this. Coughing/choking, wet-hoarse voice or changes in voice quality, food getting stuck or remaining in oral cavity or throat and throat clearing, anterior spillage or drooling, extra effort and increased duration of meals, piecemeal deglutition, and avoidance of food textures were the most common signs and symptoms across tools, similar to another study (Mourão et al., 2016). These signs and symptoms can all be observed during mealtimes and can be observed by someone not trained in dysphagia such as a caregiver. It is for this reason that these aspects were crucial in the development of the CCDR.

Additionally, the format of the tool and its complexity may also influence the time it takes to administer a tool. A Likert scale was used in more than half of the articles; however, this may also be most time consuming due to the various choices of answers. The use of choice architecture (Thaler, et al., 2014) also known as 'nudge theory' was therefore considered in the design as it pushes decision-making by limiting the choices provided (Szász et al., 2018). Together with this, a dichotomous scale was implemented as it is believed to be better to evaluate the items (Kalkbrenner, 2021). This was done in the form of yes/no responses which was used in 14% of articles and was considered to be the least complex and therefore quicker in administration when developing the CCDR. The caregiver would

just need to indicate whether or not a specific item is present or absent and have to total up the score to determine what kind of action should be taken i.e., a re-administration of the CCDR or a referral to a speech therapist for further diagnostic assessment. When assembling the CCDR, the font, font size, length of instructions, ease of understanding and test items that are brief were included so that the CCDR can be quickly administered and easy to understand by caregivers (Kalkbrenner, 2021).

Furthermore, it is evident from the results of the scoping review that the EAT-10 was the most widely used tool with the elderly population (42%). This may be due to the high sensitivity of between 85% and 94% and a specificity of between 70,9% and 82% as well as good test-retest reproducibility, internal consistency and criterion-based validity (Belafsky et al., 2008). The EAT-10 does not require resources during administration and is quick to administer at less than two minutes. It was for this reason that the EAT-10 was used to inform the development of the CCDR as well its inclusion as the second data collection instrument. However, there were some limitations identified with the EAT-10 as well. Since it is a self-reported/self-administered tool, it may be difficult for those that have communication or cognitive impairment to report their swallowing difficulties appropriately (Schindler et al., 2023). This may be even more common in the elderly population therefore affecting the accuracy of the dysphagia identification (Sobral et al., 2018).

When administering the EAT-10, assistance was provided by the researcher to those residents that had motor or vision difficulties. For residents with cognitive or communication difficulties, caregivers or guardians assisted in completing the administration. There were some challenges experienced with using the EAT-10. Some residents would indicate that they do not have any difficulties despite exhibiting signs of dysphagia during the CCDR administration by the caregiver. In addition to that, when a caregiver or guardian reports on the resident's behalf, certain items on the EAT-10 cannot be observed, such as 'the pleasure of eating is affected by my swallowing' or 'swallowing is stressful,' which makes it difficult to score which also affects the accuracy of the tool. Items of the EAT-10 in terms of content were further criticised using Rasch Analysis (Cordier, 2016). Similarly, caregivers or guardians might not have been able to score the tool accurately on the Likert scale in the way resident may be experiencing in terms of its presence or severity, also affecting the accuracy of the tool (Schindler et al., 2023).

An expert review was not conducted as part of the current study due to this being a pilot study at Masters level, with review only provided by the research supervisors, who, despite being experts in the field, may be biased. This is a possible limitation of the study and to the

use of the CCDR; however, this could still be conducted in future studies. The sample chosen was small in order to represent the target population, which is elderly residents (>60 years) residing in a residential care facility (Kalkbrenner, 2021). Pilot studies allow the researcher to identify any errors in the instrument used or any weaknesses in the implementation of it (Kalkbrenner, 2021). The sample of a pilot study is estimated to range between 25 and 150 participants (Kalkbrenner, 2021). The sample size was calculated with the help of a statistician.

Administration of the CCDR was conducted within 48-60 hours of the EAT-10. Caregivers appeared to be able to administer the CCDR as required without any training, however, at times, the question on comorbidities was not completed, which could be due to not knowing the comorbidity off hand and possibly needing to do a file review. Aside from that, caregivers did not always use “1” or “0” to complete the tool; instead, they would use “yes” or “no”/ “✓” or “x,” however, this could still be easily understood and calculated appropriately to make the necessary recommendations. Furthermore, it should be noted that both, the EAT-10 and CCDR are subjective measures and cannot provide a diagnosis; therefore, they should be used just as a means of referral which is what they have been developed to do. Residents who failed either of the tool administrations were referred for a diagnostic assessment; however, results of this was not obtained due to ethical principles.

Resources were also explored as part of the scoping review. Of the 40% of articles that mentioned resources, the resources used were almost of a similar nature, consisting of either water, a solid food item and a measuring tool, such as a stop watch, were most common. Similar tools that required similar resources have been used by speech therapists across the United States (Dumican et al., 2023) It was not clear whether or not other tools required resources or they were just not discussed. However, the need for specific resources may deter one from using a specific tool, which is especially common in South Africa due to a lack of availability in resources and in turn the time consumed in obtaining the resources needed as compared to a tool that may not require any resources at all. The lack of resources may refer to personnel as well as material resources (Jiyane & Khunou, 2023). The CCDR was not assessed for feasibility, but it was observed to be quickly administered by the caregivers and it was developed in a way that it would not require any resources to administer it which is a good indicator of this.

Initial item analyses (Kalkbrenner, 2021) was conducted to establish baseline data of the CCDR, which can provide information on the possible future success of its use within

residential care facilities. This was done with the assistance of a statistician and consisted of both descriptive and inferential statistics. Reliability refers to how well a tool is able to measure what it was set out to measure, while, validity refers to how accurately a tool is able to measure a specific variable i.e., dysphagia (Ahmed & Ishtiaq, 2021). Reliability and validity varied across articles in the scoping review with most articles relying on previously reported information. Validation was measured according to comparison with instrumental evaluation in 10% of articles. It should also be mentioned that the tools used were reliable and valid across various age groups or disorders and not specifically with the elderly and should be used with caution with the elderly. In terms of the CCDR, reliability in the form of internal consistency was assessed and was calculated using Cronbach's Alpha (Hajjar, 2018). A strong internal consistency is indicated by a Cronbach's Alpha of 0,7 or higher (Hajjar, 2018). Both the CCDR and EAT-10 showed a strong internal consistency of 0,815 and 0,937, respectively. This is known about the EAT-10 (Belafsky et al., 2008), however, this is a positive sign in the way the CCDR has been developed, indicating its ability to identify the risk of dysphagia.

Furthermore, data distribution is necessary as part of data analysis where correlation is explored as part of validity. The results of the data distribution indicated that items across the CCDR ($p > 0,5$) were more normally distributed than that of the EAT-10 ($p < 0,5$). This means that the CCDR covers a broader area of what residents are experiencing, whereas items selected on the EAT-10 were more focused on certain items in the tool rather than others. We can thus conclude that the CCDR could be more suitable for use with the elderly than the EAT-10. This could be due to the fact that items in the CCDR can be more easily understood and can be observed, as compared to the EAT-10, where items are more abstract and may not be clearly understood by someone that is not experienced in OD. The most common items selected as part of the CCDR were comorbidities (chronic disease and neurological conditions) and signs of OD (coughing or choking, wet sounding voice, increased mealtime, food remains in mouth, difficulty chewing and avoidance of meals/textures). Common items on the EAT-10 were "Swallowing solids takes extra effort," "Swallowing pills takes extra effort," and "Swallowing is stressful," as identified by the residents. Other studies have reported that "Swallowing pills takes extra effort" and "when I swallow, food sticks in my throat" as the most common items selected (Garand et al., 2021). This indicates a similarity and variability in presentation; however, neither of them are similar to the items identified by the CCDR.

Content and concurrent validity (Kalkbrenner, 2021) were both necessary in establishing preliminary success of the CCDR. Content validity established through the use of a scoping

review, was discussed in detail above as that was the first step in the development of the CCDR. Concurrent validity refers to whether two measures, taken at the same time are in agreement by examining its correlation (Everton et al., 2020). This was done using the CCDR against the EAT-10 using Pearson's correlation and Spearman's rank order correlation. The distribution of data of the CCDR ($p > 0,5$) and EAT-10 ($p < 0,5$) were calculated in order to determine the correlation. Both correlation methods indicated a statistically significant, moderate positive correlation. This means that if a resident failed the EAT-10, they would fail the CCDR and vice versa. This indicates a positive result for the preliminary use of the CCDR in the sense that it is able to identify what it was set out to do, and that is to identify residents at risk of OD and ensure referral to a speech therapist.

The identification of dysphagia in terms of the success in identifying dysphagia using the various tools was also included in the scoping review. The identification rate varied across different tools, different settings where the elderly reside, severity of dysphagia present and different consistencies of food screened. Based on this, it can be inferred that there is not one specific tool that is favoured with the elderly population. It should be noted that identification rates of over 90% were only found in 4% of articles, which used an instrumental evaluation as well, in the form of a VFSS or a FEES. Majority of articles had an identification rate of less than 55% which may be attributed to the screenings being done on healthy individuals rather than individuals at risk. This is a concern since accuracy in identification can determine the correctness of a tool (Cordier et al., 2016).

Diagnostic accuracy, in the form of sensitivity and specificity analysis are commonly used in screening-type studies and was included as it can identify the success of the CCDR (Bujang & Adnan, 2016). Sensitivity and specificity are good indicators of the accuracy in identifying whether dysphagia is present in affected individuals or not present in healthy individuals respectively (Jiang et al., 2016; Swift et al., 2020). An ideal tool should have a high sensitivity and specificity and is therefore a necessary characteristic to consider in tool development (Swift et al., 2020). Despite this, sensitivity and specificity were mentioned in less than half of the articles reviewed as part of the scoping review and varied across tools used which could be the difficulty faced when analysing this component (Swift et al., 2020). Dysphagia screening measures should have a high sensitivity and specificity (di Pede et al., 2016). The CCDR is highly sensitive in identifying elderly residents who may be at risk for dysphagia within residential care facilities. The CCDR also has a high specificity which shows that the CCDR is able to appropriately identify elderly residents who are not at risk of dysphagia within residential care facilities.

To answer the research question, the CCDR shows promising signs in its use to identify the risk of dysphagia by caregivers in the elderly residing in care facilities. This can be seen by answering the research aims and objectives in which the CCDR has good internal consistency, concurrent validity in the form of moderate positive correlation between the CCDR and EAT-10 and diagnostic accuracy in the form of high sensitivity and specificity. Additionally, content validity was established through a scoping review prior to the development of the CCDR to ensure that the tool was developed using existing literature and information already available in the field.

5.1. Summary of Discussion

The current study aimed to develop the CCDR, a tool, that can be used by caregivers on elderly residents they suspect of being at risk for dysphagia within residential care facilities. Content validity which was an aim of the study was established prior to the development of the CCDR through a scoping review. This, along with the MEASURE approach (Kalkbrenner, 2021) guided this section by discussing the CCDR in terms of the design and format as well as the preliminary evaluation of the CCDR. The EAT-10 was identified as part of the scoping review as the most common tool currently used with the elderly and was therefore chosen as the second data collection instrument was further explained. The need for a pilot study and this being a pilot study is also discussed. Furthermore, preliminary evaluation yielded results that were positive in terms of the use of the CCDR with regard to internal consistency, concurrent validity, sensitivity and specificity which were all aims of the study. The discussion is concluded by answering the research question in which the CCDR may be a useful tool in identifying elderly residents at risk for dysphagia in residential care facilities.

6. Conclusion

In this section, limitations and implications of the study will be explained. The study will also be concluded.

6.1. Limitations

This is a pilot study and consisted of a small sample size; therefore, the above measures may not be completely accurate. In general, studies that measure diagnostic accuracy, in the form of sensitivity and specificity require a much larger sample size than in studies just exploring reliability or validity (Bujang, 2023). This is due to the length of confidence interval as decided by the researcher and level of sensitivity and specificity expected in the study to improve the accuracy of the measure used (Oliveira et al., 2020). A much larger sample will be recruited for further studies to ensure better accuracy of the CDDR in identifying dysphagia risk. This study was also conducted at only one research site; more residential care facilities for data collection may be useful in determining the success of the CDDR in future.

In terms of reliability, this study only explored internal consistency. It may have been valuable to investigate the use of inter-rater reliability when conducting the CDDR by including more than one caregiver in each tool administration to ensure a similar outcome with each administration. This is similar to that of other dysphagia screening tools that have been developed (Vogel et al., 2017).

When developing the CDDR, an expert review was not conducted. Expert reviews assist in ensuring better content validity is obtained by consulting experts in the field who were not involved in the development of the CDDR (Kalkbrenner, 2021). As mentioned above, only the research supervisors provided input within this study, and despite their expertise in the field of dysphagia, their views may be biased due to their involvement in the supervision process. This could be further explored in a study to be conducted in future.

The EAT-10 is the most commonly used screening tool within the elderly, but there are limitations associated with its use. One such limitation is that the EAT-10 has not been specifically developed for use with the elderly (Schindler et al., 2023). It, therefore, does not account for aspects such as cognitive decline (Schindler et al., 2023). Furthermore, the EAT-10 is a subjective measure and no objective measure was used in the current study. The gold standard for diagnosing dysphagia is a VFSS or FEES, however, it also consists of

risks such as that of radiation and feasibility aspects which are not warranted for a pilot study (Zhang et al., 2022). The use of instrumental evaluation may be considered to further improve the reliability of the CCDR in future studies.

6.2. Contributions and Implications

Research surrounding dysphagia in residential care facilities is limited; however, it can be assumed that dysphagia identification protocols do not exist. The prevalence of aspiration pneumonia in such facilities indicates the high rate of dysphagia being underdiagnosed (Pede et al., 2016 ; Peladic et al., 2019). Early identification is, therefore, imperative to reduce rates of aspiration pneumonia as well as other factors such as malnutrition, dehydration, and death (Pede et al., 2016 ; Peladic et al., 2019). Clinical implications were that the development of the CCDR and its use with elderly residents who may be at risk for dysphagia may be beneficial for use by caregivers so that early referrals can be made. Despite being a pilot study, the preliminary results of CCDR use indicates promising results of its use. This can already provide a means for caregivers to identify those at risk for dysphagia and ensure referral for residents at the research site used. This was observed first hand in which caregivers had not previously realised how certain signs exhibited by residents puts them at risk for dysphagia so the use of a tool like the CCDR would be beneficial to them. Since the research study and the use of the CCDR is targeted for use with caregivers, it may be beneficial for further research to include the caregivers feedback of the CCDR and exploration of its feasibility with them. This may contribute to the effectiveness of the tool and its use.

The development of the CCDR has focused on the elderly population residing within residential care facilities. Further research is required on whether the CCDR design and contents would be suitable for use with those residing within the community or within an acute hospital setting. Additional aspects such as context, socio-economic factors and educational level of home based caregivers may be necessary to consider before considering CCDR administration.

Theoretically, the current research study contributes to research surrounding dysphagia within the elderly population in terms of risk identification, need for a tool to identify dysphagia and the harms of their not being a tool present in residential care facilities at present for adequate referrals to a speech therapist. The scoping review provides further information into the tools currently being used with the elderly and the lack of a suitable tool

for use with this population, as well as the lack of research with elderly specifically residing in residential care facilities in the field of dysphagia.

6.3. Conclusion

The results of this study, along with the literature indicates a gap in identifying dysphagia early in elderly residents in care facilities. It was evident that there is also a lack of training provided to caregivers caring for the elderly in dysphagia which is such a common condition in this population. There is, therefore, a need for a tool like the CCDR that can be used by caregivers to identify dysphagia risk to make timely referrals. In turn, this could improve quality of life as well as prevent malnutrition, dehydration, aspiration pneumonia, and death. The CCDR shows good preliminary results in this regard and gives rise to the possibility to future research of its use and effectiveness.

7. References

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8. Appendices

Appendix A – Site Information Letter

INFORMATION LETTER REQUESTING PERMISSION TO CONDUCT RESEARCH

Date:

Dear Ms/Mr

RE: Request for permission to conduct research at _____ (name of site)

My name is Zaakirah Seedat, and I am a Masters student in the Department of Speech-Language Pathology and Audiology at the University of the Witwatersrand. I am conducting research, under the supervision of Dr Jaishika Seedat and Ms Kelly-Ann Kater. The title of my research is *Caregiver Checklist for Dysphagia Risk (CCDR) development and preliminary evaluation: a pilot study*.

Due to advances in education and medicine as well as a reduction in mortality rates globally, people are living longer than they did before. A longer life expectancy, however, does not indicate an improved quality of life in these individuals. Chronic diseases, neurological disorders, cancer and mental disorders become common within this population, while, normal ageing may also affect their quality of life. Dysphagia, a difficulty in swallowing, eating and or drinking, commonly occurs in the elderly. Many elderly individuals reside in care facilities as they become increasingly dependent on someone to assist them with their activities of daily living. Encouragingly, care facilities are able to employ caregivers to provide the required assistance. There are few speech therapists who are specialists in dysphagia (swallowing disorders) in South Africa and specifically in care facilities. This gives rise to the need for the Caregiver Checklist for Dysphagia Risk (CCDR) that caregivers can complete when they suspect that a resident may have dysphagia. Only by conducting research, can the CCDR be compiled effectively. This is what I would like to research at your facility. Should you like to view my proposal, please let me know.

I would, therefore, like your permission to invite caregivers and residents based in the frail care and assisted living units of your facility to participate in this research study.



The study involves caregivers and residents working and residing in the frail care and assisted living units of the facility. Their roles in the study will be described below:

1. For the caregivers: The caregivers will identify residents they suspect as being at risk or not being at risk for dysphagia. Once consent is obtained from the residents, the caregivers will then use the researcher developed CCDR, on resident participants .
2. For the residents: Residents will be recruited into two sub-groups, those that caregivers suspected of being at risk for dysphagia and those that are not. Each resident will receive two different evaluations. First, a caregiver will administer the CCDR. This will be done at the resident's bedside. Secondly, the same resident will be required to complete the Eating Assessment Tool (EAT-10). Should the resident require assistance to complete the tool, this will be provided. This will also be done at the resident's bedside.

Both assessments as described above will happen within a 48 – 60-hour timeframe for each resident, and all necessary consent from the caregiver, resident and/or their guardian will be obtained prior to any assessment happening.

I shall discuss every step of the study before proceeding to ensure that I have your consent and approval. I will be responsible for covering the costs that may be necessary for any equipment required for the study to take place. I am in the process of applying for ethical clearance from the university and will require your preliminary permission to conduct my research at your facility with caregivers who work in the Frail Care and Assisted Living Units of your facility and residents who live in this section. I anticipate starting with the study by March 2024 and ending June 2024.

The procedures and assessments that will be done in my study are not standard and are being done for the purpose of research. I shall be using standardised paper-based tests and questionnaires to capture the information that is required. Importantly I will be testing the reliability and validity of the checklist that I developed. i.e. the Caregiver Checklist for Dysphagia Risk (CCDR). After both assessments (described above), should any resident be identified with a swallowing impairment, I will refer them to the Wits students who conduct therapy under supervision at the facility or a public facility i.e. Charlotte Maxeke Johannesburg Academic Hospital or Helen Joseph Hospital. They will not be required to pay for the services that will be rendered. Completing these assessments which are part of the research study will



require time from the resident, as noted above and completion of the CCDR will require time from the caregiver and resident.

Risks of being involved in the study: There are no direct risks for participation in the study for caregivers and residents.

Benefits of being in the study: There are no direct benefits for participation in the study.

You as the manager of the facility, the resident and the caregiver will be provided with detailed feedback from the study once it is completed. This will be available in hard copy, and arrangements for verbal feedback will be made.

Participation is completely voluntary. You as the manager, the resident as well as the caregiver will be given time to make an informed decision. They will be assured that refusal to participate will involve no penalty or loss of benefits to which the participant is otherwise entitled. There will be no requirement to provide a reason for withdrawing at any time, should you, the resident or the caregiver so wish. Any data collected will in default be destroyed, unless the participant specifically consents to its retention. Each resident and caregiver will be provided with an information letter (hard copy) and if required the information will be provided verbally by the researcher. They will be given time to consider their decision. If agreeable, they will be required to provide formal consent. For residents who may not be able to provide consent, the researcher will need to consult with you as the manager, on who to contact or obtain consent from on behalf of the resident.

Costs: There will be no payment or cost associated with participation. The researcher will be responsible for any materials, or consumables (food, gloves, paper, etc.) that are required for the assessment.

Confidentiality: All personal information will be treated in the strictest of confidence and will only be available to the researcher and their supervisors. If a research assistant is necessary, they will be briefed about all ethical parameters. Any and all identifying information will be replaced with codes. No identifying information will be captured in any publications or conference presentations that emerge from this research. All data collected in the course of this research will be securely retained for two (2) years, if a scientific publication arises from the study and six (6) years, if there is no publication. Thereafter it will be destroyed accordingly.



Anonymity: Given the nature of the study, anonymity cannot be maintained for residents nor, for caregivers as the researcher will spend time in the Frail Care and Assisted Living units therefore she will come to know caregivers and residents in this process. It is also important for the researcher to build rapport with the resident due to the hands on nature of the assessment that will be conducted.

Outputs: The results of the research will be made available via publications in journal articles and the results may also be presented at a conference. The intention of this study is to confirm if the CCDR is a valid and reliable checklist that caregivers can use to identifying dysphagia in elderly residents in care facilities.

Thank you for reading this research information sheet. Please take time to consider the participation of your facility, and kindly let me know of your decision. I am happy to arrange a telephonic discussion or a meeting to provide any additional information you may require. As has been noted, your permission is subject to me obtaining ethical clearance from the Human Research and Ethics Committee (Medical) of the University of the Witwatersrand. You will be informed about the outcome of my ethics application, and I will provide you with a copy of my ethical clearance certificate prior to me commencing the study. You may either send me confirmation of your permission to conduct the research at your facility on a letterhead. Alternately, you may sign the permission letter below.

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Paul Ruff, who may be contacted via any one member of the secretariat. The telephone numbers for the Committee secretariat are 011 717 2700/1234/2656/1252 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za, Rhulani.Mukansi@wits.ac.za, Mapula.Ramaila@wits.ac.za and Iain.Burns@wits.ac.za.

Please feel free to contact me or my supervisors for further information:

- Zaakirah Seedat – 074 777 4786 – zaakirahseedat@gmail.com
- Dr Jaishika Seedat (supervisor) - jaishika.seedat@wits.ac.za
- Ms Kelly-Ann Kater (Co-supervisor) - kelly-ann.kater@wits.ac.za

Your permission to conduct this study, subject to ethical clearance will be truly appreciated.

Yours sincerely,



Seedat

Zaakirah Seedat (Researcher)

Jaishika Seedat (Supervisor)

Kelly-Ann Kater (Co-Supervisor)



Appendix B – Site Permission Letter

Permission to participate in this study

This letter confirms permission from _____ (Manager's name), as the manager of _____ (name of care facility) for research to be conducted at _____ (name of facility) under the title: *Caregiver Checklist for Dysphagia Risk (CCDR) development and preliminary evaluation: a pilot study*. This permission is preliminary and is subject to final ethical clearance and approval by the University of the Witwatersrand Human Research and Ethics Committee (Medical).

1. We have been given an information sheet which explains the nature and processes involved in this study, which is attached hereto.
2. I was given time to read it, or had it read to me.
3. I was given time to ask any questions I wanted to and found any answers given to me to be reasonable and satisfactory.
4. I believe I fully understand why the study is being conducted and what the intended outcomes will be.
5. I understand that there will be no immediate benefit for the caregivers. However dependent on the results of the study, the use of the Caregiver Checklist for Dysphagia Risk (CCDR) will make dysphagia identification easier and more accurate.
6. I understand that there will be no direct benefits to the residents to participate.
7. I understand that no costs will be incurred by (name of facility). Costs associated with the research will be covered by the researcher, Zaakirah Seedat.
8. I understand that time will be required from the caregivers and the residents.
9. I understand that, even if I initially consent to take part in the study, I may subsequently withdraw at any time and would not be required to give any reasons; in which case, any data collected about me for the purposes of the study would immediately be destroyed, unless I give consent for it to be retained.
10. I have been given a range of contact details. If I require further information or become concerned about any aspect of this study, I am free to speak to any of these contacts.

Name of Facility and Manager: _____

Date: _____

Place: _____

Signature or mark _____



Witnessed by:

Name of Witness: _____

Signature: _____

Date: _____



Appendix C – Caregiver Information Letter

Caregiver Information Letter

To Whom It May Concern:

Facility_____

Title: Caregiver Checklist for Dysphagia Risk (CCDR) development and preliminary evaluation: a pilot study

My name is Zaakirah Seedat, and I am a Masters student in the Department of Speech-Language Pathology and Audiology at the University of the Witwatersrand. I am conducting research, to establish a new caregiver completed tool, namely the Caregiver Checklist for Dysphagia Risk (CCDR), for identifying swallowing difficulty in the elderly. As, the caregivers are regularly involved in and assisting at mealtimes as part of your job, I would like to invite you to take part in this research. Due to advances in education and medicine as well as a reduction in death rates, people globally are living longer than they did before, therefore, having access to this information will contribute to existing research as well as ensure for efficient referral of the elderly if dysphagia is identified, which can improve their overall quality of life. This research may also contribute to the use of the CCDR in other residential facilities.

You can take your time to decide, and ask me any questions that you may have. If you do agree to take part in this research, this is what will happen:

- Data collection will require the administration of the CCDR to the residents. The administration of the CCDR can be completed by you, at any time so as to not disturb other routines. The CCDR will specifically be designed to be quick, short, and only require ticks and/or crosses. It should not take any longer than 2-3 minutes to complete.
- Informed consent would have already been obtained by the researcher prior to this. Residents who you think are at risk and those not at risk will require the CCDR administered to them by the caregiver that looks after them. The results obtained will be collated against a standardised assessment for the researcher to establish its reliability and validity.
- You will be asked to sign a consent form for your participation in the study.
- Since the primary mode of communication at the care facility is English, the study will be conducted in English.



Risks of being involved in the study:

There are no risks for caregiver participation.

Benefits of being in the study:

There is no immediate benefit for participation in this study.

Your rights if you agree to participate in the study: You can stop at any time if you wish without any consequences and without providing a reason. There will be no negative consequences. As I will be spending a large amount of time at the facility, I will get to know who you are over time. I would like to assure you that your personal identifying information will not be revealed in any of my results nor in publications that may arise from this research. You will not have to provide identifying information on the CCDR and therefore your participation will not be linked to your actual name. If I don't use any information from the research, all the data will be destroyed after six years.

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Paul Ruff, who may be contacted via any one member of the secretariat. The telephone numbers for the Committee secretariat are 011 717 2700/1234/2656/1252 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za, Rhulani.Mukansi@wits.ac.za, Mapula.Ramaila@wits.ac.za and Iain.Burns@wits.ac.za.

Thank you for reading this Study Information Sheet. Please feel free to contact me or my supervisors for further information:

Zaakirah Seedat, Researcher, telephone no. 074 777 4786, or by email at zaakirahseedat@gmail.com.

Jaishika Seedat, Research Supervisor, by email at Jaishika.seedat@wits.ac.za.

Kelly-Ann Kater, Co Supervisor, by email at kelly-ann.kater@wits.ac.za.

Zaakirah Seedat

Masters Student (Department of Speech-Language Pathology & Audiology)

University of the Witwatersrand



Jaishika Seedat (Supervisor)

Kelly-Ann Kater (Co-Supervisor)



Appendix D – Caregiver Consent Form

Consent to participate: Caregivers

Title: Caregiver Checklist for Dysphagia Risk (CCDR) development and preliminary evaluation: a pilot study

1. I have been given a Participant Information Sheet which explains the nature and processes involved in this study, which is attached hereto;
2. I was given time to read it in the language I understand;
3. I was given time to ask any questions I wanted to and found any answers given to me to be reasonable and satisfactory;
4. I believe I fully understand why the study is being conducted and what the intended outcomes will be;
5. I understand that there will be no immediate benefit to me, should I agree to participate, nor will I receive any payment; conversely, participation will not cost me anything but my time;
6. I understand that I am giving consent to Administer the CCDR
7. I understand that, even if I initially consent to take part in the study, I may subsequently withdraw at any time and would not be required to give any reasons; if that happened, any data collected about me for the purposes of the study would immediately be destroyed, unless I give consent for it to be retained
8. I understand that only the researcher will have my contact details, which she will not reveal to anyone or I may remain anonymous should I desire.
9. I have been given a range of contact details. If I require further information or become concerned about any aspect of this study, I am free to speak to any of these contacts.

Name of Participant: _____

Date: _____

Place: _____

Signature or mark _____

Witnessed by:

Name of Witness: _____

Signature: _____

Date: _____



Appendix E – Resident Information Letter

Participant Information Letter: Resident

To Whom It May Concern:

Facility_____

Title: Caregiver Checklist for Dysphagia Risk (CCDR) development and preliminary evaluation: a pilot study

My name is Zaakirah Seedat, and I am a Masters student in the Department of Speech-Language Pathology and Audiology at the University of the Witwatersrand. I am conducting research, in developing a new tool that can be completed by a caregiver and used to identify swallowing risk in the elderly. I would like to invite you to take part in this research because in order to see how effective this tool is, it is important for an additional assessment to also be conducted to ensure accurate results. Swallowing difficulties are common in the elderly population and early identification is key in preventing further complications, therefore making this tool something that is needed in care facilities.

You can take your time to decide, and ask me (Zaakirah) or a caregiver any questions that you may have. If you do agree to take part in this research, this is what will happen:

- Firstly, the newly developed CCDR will be completed by a caregiver in which she would look if she suspects anything that may put you at risk of an eating, drinking or swallowing difficulty or if you are not at risk, however, this will require a report of any difficulty you may be experiencing and will take approximately 2 – 3 minutes to complete.
- Secondly, on a different day, I (Zaakirah), will require you to complete a self-evaluation called the Eating Assessment Tool (EAT-10) (assistance provided if required). This will take approximately 10 minutes of your time.
- The primary mode of communication at the facility is English, therefore, assessment will be conducted in English. If there is apparent difficulty with reading, writing, or understanding, assistance will be provided by myself or the caregiver.

You can stop participating in the study at any time if you wish. If you feel tired or do not wish to do anything you can let me know and we will stop and take a rest, or stop altogether. I will be sure not to mention your name in any of my reports – I will use a 'false name'. If I find that



you need any additional help with your swallowing of food or liquids, I will refer you to receive the necessary help to the Wits speech therapy students that are supervised or a public-sector facility i.e. Charlotte Maxeke Johannesburg Academic Hospital or Helen Joseph Hospital. You will not be required to pay for your participation in this study.

Risks of being involved in the study:

There are no direct risks to participating in this study.

Benefits of being in the study:

There are no direct benefits to participating in this study.

If you agree to take part in this research project, you will need to sign a form. If you are not able to sign but would still like to take part, you can let me know with a yes or by nodding your head, and I will make a note that you agree. If you do not wish to take part, this is also fine, and you can let me know.

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Paul Ruff, who may be contacted via any one member of the secretariat. The telephone numbers for the Committee secretariat are 011 717 2700/1234/2656/1252 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za, Rhulani.Mukansi@wits.ac.za, Mapula.Ramaila@wits.ac.za and Iain.Burns@wits.ac.za.

Thank you for reading this Study Information Sheet. Please feel free to contact me or my supervisors for further information:

Zaakirah Seedat, Researcher, telephone no. 074 777 4786, or by email at zaakirahseedat@gmail.com.

Jaishika Seedat, Research Supervisor, by email at Jaishika.seedat@wits.ac.za.

Kelly-Ann Kater, Co Supervisor, by email at kelly-ann.kater@wits.ac.za.

Zaakirah Seedat

Masters Student (Department of Speech-Language Pathology & Audiology)

University of the Witwatersrand



Jaishika Seedat (Supervisor)

Kelly-Ann Kater (Co-Supervisor)



Appendix F – Resident Consent Form

PARTICIPANT CONSENT SHEET: RESIDENT

Title: Caregiver Checklist for Dysphagia Risk (CCDR) development and preliminary evaluation: a pilot study

1. I have been given a Participant Information Sheet which explains the nature and processes involved in this study, which is attached hereto;
2. I was given time to read it, or had it read to me, in the language I understand;
3. I was given time to ask any questions I wanted to and found any answers given to me to be reasonable and satisfactory;
4. I believe I fully understand why the study is being conducted and what the intended outcomes will be;
5. I understand that there are no direct benefits for participating.
6. I understand that, even if I initially consent to take part in the study, I may subsequently withdraw at any time and would not be required to give any reasons; if that happened, any data collected about me for the purposes of the study would immediately be destroyed, unless I give consent for it to be retained
7. I understand that only the researcher will have my contact details, which she will not reveal to anyone
8. I understand that the researcher may write up and publish the results of what she observes anonymously
9. I have been given a range of contact details. If I require further information or become concerned about any aspect of this study I am free to speak to any of these contacts.

Name of Participant: _____

Date: _____

Place: _____

Signature or mark _____

Witnessed by:

Name of Witness: _____

Signature: _____

Date: _____



Appendix G – Resident Adapted Letter and Consent Form

PARTICIPANT INFORMATION SHEET: RESIDENT

To Whom It May Concern:

Facility _____



Title: Caregiver Checklist for Dysphagia Risk (CCDR) development and preliminary evaluation: a pilot study



My name is Zaakirah Seedat, I am a student at the University of the Witwatersrand. I am doing research that will look at the way you eat, drink and swallow.



There are 2 parts in this study:



1. Your caregiver will do the first part where you will not have to do anything but can report if you have difficulty eating, drinking or swallowing. This will take 2-3 minutes.



2. The next part will be done by me (Zaakirah), on a different day and you will complete



a form, with my help, if you need. This will take around 10

minutes





You can stop taking part at any time, it is your choice and there will be no



problem. If you have any difficulty with eating, drinking or swallowing . I will



refer you to someone that can help . There will be no cost point that you take part or require help.



to you at any

Risk of study:



There are no direct risks to participating in this study

Benefit of study:

There are no direct benefits ~~benefits~~ to participating in this study.



If you want to take part, you will have to sign a form  and if you have questions



, you can ask me (Zaakirah), the caregiver or the nurse.

Thank you for reading this Study Information Sheet. Please feel free to contact me or my supervisors for further information:

Zaakirah Seedat, Researcher, telephone no. 074 777 4786, or by email at zaakirahseedat@gmail.com.



Jaishika Seedat, Research Supervisor, by email at Jaishika.seedat@wits.ac.za.

Kelly-Ann Kater, Co Supervisor, by email at kelly-ann.kater@wits.ac.za.

A handwritten signature in black ink, appearing to read 'Seedat', on a light-colored background.

Zaakirah Seedat

Masters Student (Department of Speech-Language Pathology & Audiology)

University of the Witwatersrand

Jaishika Seedat (Supervisor)

Kelly-Ann Kater (Co-Supervisor)



ADAPTED PARTICIPANT CONSENT SHEET: RESIDENT

Title: Caregiver Checklist for Dysphagia Risk (CCDR) development and preliminary evaluation: a pilot study

Resident Consent Form

I, _____ (NAME OF PARTICIPANT), the undersigned,

agree to volunteer in this study in writing or using a mark . In giving consent I understand the following:

1. I have been given an information sheet  that explains what this study is about.

2. It was read to me  in the language I understand and I could ask



3. I will allow my eating and drinking  to be screened by the speech therapist.

4. The study will last for 2 days and if I have any difficulty swallowing . Zaakirah will

refer me to another speech therapist for help 

5. If I feel uncomfortable or am worried  about anything in the study, I have the right

to leave the study immediately .



6. I will not have to pay for any of these things.



7. The results will be written up



8. My name will be on my assessment

and all the staff



that work here



will know who I am and that I am part of the study.

9. My name will not be used after the study in any material.



10. I can leave the study
consequences to myself.

at any stage, for any reason and without negative



11. I have read or spoken about this document and the information sheet. I recognise Zaakirah Seedat as the primary researcher for this project and agree to participate in her study.



12. I can contact either Zaakirah, Dr Seedat, Ms Kater or Prof Ruff if I have any concerns:

Name of Facility and Manager: _____

Date: _____

Place: _____

Signature or mark _____

Witnessed by:

Name of Witness: _____

Signature: _____

Date: _____



Appendix H – Guardian Information Letter

GUARDIAN/CONSERVATOR CONSENT FOR RESIDENT: GUARDIAN

Dear _____(Guardian) of _____(Resident)
Facility _____

Title: Caregiver Checklist for Dysphagia Risk (CCDR) development and preliminary evaluation: a pilot study

My name is Zaakirah Seedat, and I am a Masters student in the Department of Speech-Language Pathology and Audiology at the University of the Witwatersrand. I am conducting research, in developing a new tool that can be completed by a caregiver and used to identify swallowing risk in the elderly. I would like to invite _____ who is a resident at _____ to take part in this research because in order to see how effective this tool is, it is important for an existing assessment tool to also be conducted to ensure accurate results. Swallowing difficulties are common in the elderly population and early identification is key in preventing further complications, therefore making this tool something that is needed in care facilities. . There is currently very little information available with regard to this in South Africa and there is currently no tool available for this purpose. Due to advances in education and medicine as well as a reduction in mortality rates, people globally are living longer than they did before, therefore, having access to this information will contribute to existing research as well as ensure for efficient referral of the elderly if dysphagia is identified using the self-developed Caregiver Checklist for Dysphagia Risk (CCDR) which can improve their overall quality of life. This research may also contribute to the use of the CCDR in other residential facilities.

If you do agree for your dependent/custodian to take part in this research, this is what will happen:

- Firstly, the newly developed tool will be completed by a caregiver in which she would identify the resident and place them in a group with suspected risk of eating, drinking or swallowing difficulty or in a group that are not at risk. The caregiver will look for any signs that may put the resident at risk of a swallowing difficulty however, this will not require anything additional from them and will take approximately 2 – 3 minutes to complete.



- Secondly, on a different day, I (Zaakirah), will require them to complete the Eating Assessment Tool (EAT-10), with assistance from me, if required. This will take approximately 10 minutes of their time.

Your dependent/custodian can stop at any time if they wish. If they feel tired or do not wish to do anything they can let me know and we will stop and take a rest, or stop altogether. I will be sure not to mention your dependent's/guardian/s name in any of my reports – I will use a 'false name'. If I find that they need any additional help with swallowing of food, liquids or medication, I will refer them to the Wits speech therapy students who are under supervision or a public-sector hospital i.e. Charlotte Maxeke Johannesburg Academic Hospital or Helen Joseph Hospital., that will assist them accordingly. They will not be required to pay for their participation, or any additional services they may require.

Risks of being involved in the study:

There are no direct risks to participating in the study.

Benefits of being in the study:

There are no direct benefits to participating in this study.

If you agree for your dependent to take part in this research project, you will need to sign a form. If you do not wish your dependent to take part, this is also fine, and you can let me know.

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Paul Ruff, who may be contacted via any one member of the secretariat. The telephone numbers for the Committee secretariat are 011 717 2700/1234/2656/1252 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za, Rhulani.Mukansi@wits.ac.za, Mapula.Ramaila@wits.ac.za and Iain.Burns@wits.ac.za.

Thank you for reading this Study Information Sheet. Please feel free to contact me or my supervisors for further information:

Zaakirah Seedat, Researcher, telephone no. 074 777 4786, or by email at zaakirahseedat@gmail.com.

Jaishika Seedat, Research Supervisor, by email at Jaishika.seedat@wits.ac.za.

Kelly-Ann Kater, Co Supervisor, by email at kelly-ann.kater@wits.ac.za.

Zaakirah Seedat

Masters Student (Department of Speech-Language Pathology & Audiology)

University of the Witwatersrand

Jaishika Seedat (Supervisor)

Kelly-Ann Kater (Co-Supervisor)



Appendix I – Guardian Consent Form

GUARDIAN/CONSERVATOR CONSENT FOR RESIDENT: GUARDIAN

Title: Caregiver Checklist for Dysphagia Risk (CCDR) development and preliminary evaluation: a pilot study

1. I have been given a Participant Information Sheet which explains the nature and processes involved in this study, which is attached hereto;
2. I was given time to read it, or had it read to me, in the language I understand;
3. I was given time to ask any questions I wanted to and found any answers given to me to be reasonable and satisfactory;
4. I believe I fully understand why the study is being conducted and what the intended outcomes will be;
5. I understand that there are no direct benefits for participation in the study.
6. I understand that, even if I initially consent for my dependent to take part in the study, I may subsequently withdraw at any time and would not be required to give any reasons; if that happened, any data collected about me for the purposes of the study would immediately be destroyed, unless I give consent for it to be retained
7. I understand that only the researcher will have my contact details and those of my dependent , which she will not reveal to anyone
8. I understand that the researcher may write up and publish the results of what she observes anonymously
9. I understand that anonymous quotations may be used
10. I have been given a range of contact details. If I require further information or become concerned about any aspect of this study I am free to speak to any of these contacts.

Name of Participant: _____

Date: _____

Place: _____

Signature or mark _____

Witnessed by:

Name of Witness: _____

Signature: _____

Date: _____



Letter of referral

Date of assessment: _____

Date of referral: _____

Dear, _____ (Participant)

Thank you for taking part in my research study.

The following referral is based on the assessment results obtained from the dysphagia assessment conducted.

I, Zaakirah Seedat, speech-language pathology masters student from the University of the Witwatersrand, recommend that you receive further assessment and treatment regarding possible dysphagia.

Referral to supervised students at site/ public hospital for speech therapy evaluation and treatment due to _____ (brief motivation for referral).

Regards.

Zaakirah Seedat

074 777 4786

zaakirahseedat@gmail.com

Appendix K – Eating Assessment Tool (EAT-10)



EATING ASSESSMENT TOOL (EAT-10)

Name: _____ EMR# _____

Birthdate/Age: _____ Todays Date: _____

The purpose of the EAT-10 questions is to help measure swallowing problems.
Answer each question by circling the number that matches how bad you feel the problem is for you.

To what degree to you experience the following problems? Circle an answer between 0 and 4	0 = No problem 4 = Severe problem				
1. My swallowing problem has caused me to lose weight.	0	1	2	3	4
2. My swallowing problem interferes with my ability to go out for meals.	0	1	2	3	4
3. Swallowing liquids takes extra effort.	0	1	2	3	4
4. Swallowing solids takes extra effort.	0	1	2	3	4
5. Swallowing pills takes extra effort.	0	1	2	3	4
6. Swallowing is painful.	0	1	2	3	4
7. The pleasure of eating is affected by my swallowing.	0	1	2	3	4
8. When I swallow food sticks in my throat.	0	1	2	3	4
9. I cough when I eat.	0	1	2	3	4
10. Swallowing is stressful	0	1	2	3	4
Add up the sum of the numbers you circled for a TOTAL EAT-10 Score:					

If your score is greater than 3 you may have swallowing problems. We suggest that you share your EAT-10 results with your doctor.

Reference: Belafky PC, Mouadeb DA, Rees CJ, Pryor JC, Postma GN, Alen J and Leonard RJ. Validity and reliability of the Eating Assessment Tool (EAT-10). Ann Otol Rhinol Laryngol 2008; 117(12):919-924.

Appendix L – Provisional Permission Granted

Permission to participate in this study

This letter confirms permission from MANDA PRETORIUS (Manager's name), as the manager of PARK CARE CENTRE (name of care facility) for research to be conducted at PARK CARE CENTRE (name of facility) under the title: *Establishing the reliability and validity of a Caregiver Checklist for Dysphagia Risk (CCDR) in the elderly*. This permission is preliminary and is subject to final ethical clearance and approval by the University of the Witwatersrand Human Research and Ethics Committee (Medical).

1. We have been given an information sheet which explains the nature and processes involved in this study, which is attached hereto.
2. I was given time to read it, or had it read to me.
3. I was given time to ask any questions I wanted to and found any answers given to me to be reasonable and satisfactory.
4. I believe I fully understand why the study is being conducted and what the intended outcomes will be.
5. I understand that there will be no immediate benefit for the caregivers. However dependent on the results of the study, the use of the Caregiver Checklist for Dysphagia Risk (CCDR) will make dysphagia identification easier and more accurate.
6. I understand that there will be benefits to the residents in that if they agree to participate, their swallowing will be assessed, and if required, referral will be made if needed. Swallowing of both food and liquid will be determined.
7. I understand that no costs will be incurred by Park Care. Costs associated with the research will be covered by the researcher, Zaakirah Seedat.
8. I understand that time will be required from the caregivers and the residents.
9. I understand that, even if I initially consent to take part in the study, I may subsequently withdraw at any time and would not be required to give any reasons; in which case, any data collected about me for the purposes of the study would immediately be destroyed, unless I give consent for it to be retained.
10. I have been given a range of contact details, listed below. If I require further information or become concerned about any aspect of this study, I am free to speak to any of these contacts.



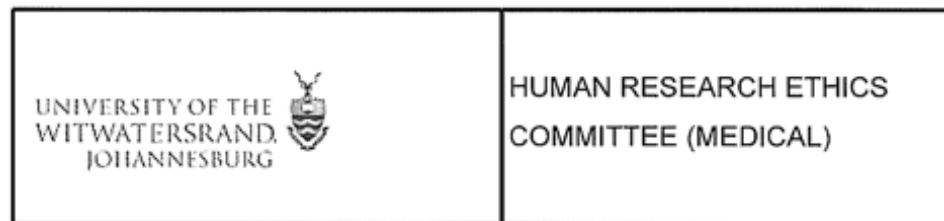
Name of Facility and Manager: PARK CARE CENTRE
Date: 22/6/2023
Place: PARKTOWN
Signature or mark: [Signature]

Witnessed by:

Name of Witness: L A SALOBS
Signature: [Signature]
Date: 22/6/2023

PARKSORG / PARK CARE
ESCOMBELAAN 36
PARKTOWN 2193
POSBUS 72061 PARKVIEW 2122
TEL: 011 482 2060
FAX: 011 726 8219

Appendix M – Ethical Clearance



Office of the Deputy Vice-Chancellor (Research and Innovation)

TO: Ms Z Seedat
School of Human and Community Development
Department of Speech Pathology and Audiology
University

E-mail: zaakirahseedat@gmail.com

CC: Supervisor: Dr J Seedat and Ms K-A Kater
Jaishika.Seedat@wits.ac.za
and <HREC-Medical Research Office@wits.ac.za>

FROM: Mr Iain Burns
Human Research Ethics Committee (Medical)
Tel: 011 717 1252

E-mail: Iain.Burns@wits.ac.za

DATE: 29 February 2024

REF: R14/49

PROTOCOL NO: **M230907** (This is your ethics application reference number. Please quote it in all enquiries, oral or written, relating to this study.)

PROJECT TITLE: *Establishing the reliability and validity of a caregiver checklist for dysphagia risk (CCDR) in the elderly*

Please find attached the Clearance Certificate for the above project. I hope it goes well and that an article in a recognized publication comes out of it. This will reflect well on your professional standing and contribute to Government funding of the University.



MSWorks2000/Iain0007/Clearscan.wps



R49 Ms Z Seedat

**HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M230907**

NAME: Ms Z Seedat **DEGREE:** MA
(Principal and Co-Investigators)

DEPARTMENT: School of Human and Community Development
Department of Speech Pathology and Audiology
University

PROJECT TITLE: *Establishing the reliability and validity of a caregiver
checklist for dysphagia risk (CCDR) in the elderly*

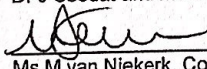
DATE CONSIDERED: 29 September 2023

DECISION: Approved unconditionally

CONDITIONS:

NOTE: If contact information regarding student study participants is required,
please contact the Registrar's office <Nicoleen.Potgieter@wits.ac.za>

SUPERVISOR: Dr J Seedat and Ms K-A Kater

APPROVED BY: 
Ms M van Niekerk, Co-Chairperson, HREC (Medical)

DATE OF APPROVAL: 29 February 2024

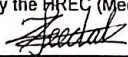
EXPIRY DATE: 28 February 2029

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

DECLARATION OF INVESTIGATORS

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

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to submit details to the Committee. I agree to submit a yearly progress report in the format available at <https://wits.ac.za/research/researcher-support/research-ethics/ethics-committees/>. This report is due annually, for the duration of the Clearance Certificate, beginning on the first anniversary of Date of Approval above. Unreported changes to the study may invalidate the clearance given by the HREC (Medical).


Signature of Principal Investigator

01/03/2024
Date

Appendix N – Caregiver Checklist for Dysphagia Risk (CCDR)

Caregiver Checklist for Dysphagia Risk (CCDR)

Name of resident: _____

Date: _____

Name of caregiver: _____

Criteria for use:

1. To be completed if there is concern about a resident's eating/swallowing.
2. To be completed based on the observation of a mealtime and 0-30 minutes after.
3. To be completed as often as needed when there is concern about a resident's eating/swallowing.

Disclaimer: This is in no way a diagnostic tool, should there be any risk of eating/swallowing difficulty identified, the resident should be referred to a speech therapist immediately.

Scoring Key: 1 = present 0 = not present

Section A: Comorbidities

- ☐ Chronic diseases (hypertension, diabetes, etc.)
- ☐ Neurological conditions (stroke, traumatic brain injury, etc.)
- ☐ Cancer
- ☐ Progressive neurological disease (dementia, ALS, Huntington's disease, Parkinson's disease etc.)
- ☐ Other
- ☐ None

Specify above: _____

Section B: External Factors, dentition, observed signs during meals, observed signs after meals and resident report

Subsection 1: External Factors

Criteria	Response
Modified special diet	
Requires assistance during meals	
Unable to be positioned upright	
Disorientated to self/ place	
Score: _____ (Total the number of 1 responses)	

Subsection 2: Dentition

Criteria	Response
Need for dentures	
No teeth present	
Poor hygiene	
Drooling	
Score: _____ (Total the number of 1 responses)	

Subsection 3: Observed signs during meals

Criteria	Response
Coughing or choking	
Spillage of food from mouth	
Wet sounding voice	
Increased mealtime	
Food remains in mouth	
Difficulty chewing	
Visible pain during swallowing	
Decreased food intake	
Avoidance of meals/textures	
Score: _____ (Total the number of 1 responses)	

Subsection 4: Observed signs 0-30 minutes after meals

Criteria	Response
Sweating or fever	
Wheezing	
Coughing	
Fatigue	
Shortness of breath	
Score: _____ (Total the number of 1 responses)	

Subsection 5: Resident Report

Criteria	Response
Has the resident reported pain when they have a meal?	
Has the resident reported discomfort when swallowing during a meal?	
Has the resident reported food getting stuck in their throat during a meal?	
Score: _____ (Total the number of 1 responses)	

Total Score: _____ (Max. points = 30)

Scoring Key:

- A score of ≥ 3 in **subsection 3** OR **subsection 4** should have referral to a speech therapist.
- A total score of > 10 should have referral to a speech therapist.

Recommendations:

- ☐ Referral to speech therapist
- ☐ No referral

Appendix O – Amended Ethical Clearance



R49 Ms Z Seedat

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL) CLEARANCE CERTIFICATE NO. M230907

NAME:
(Principal Investigator)

Ms Z Seedat

DEGREE: MA

DEPARTMENT:

School of Human and Community Development
Department of Speech Pathology and Audiology
Faculty of Humanities

TITLE:

Caregiver checklist for dysphagia risk (CCDR)
development and preliminary evaluation : a pilot study

Change of study title noted on 19 September 2024

DATE CONSIDERED:

29 September 2023

DECISION:

Approved unconditionally

CONDITIONS:

NOTE:

If contact information regarding student study participants is required,
please contact the Registrar's office <Nicoleen.Potgieter@wits.ac.za>

SUPERVISORS:

Dr J Seedat and Ms K-A Kater

APPROVED BY:

Professor P Ruff, Chairperson, HREC (Medical)

DATE OF APPROVAL: 29 February 2024

EXPIRY DATE: 28 February 2029

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

DECLARATION OF INVESTIGATORS

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

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to submit details to the Committee. **I agree to submit a yearly progress report** in the format available at <https://wits.ac.za/research/researcher-support/research-ethics/ethics-committees/>. This report is due annually, for the duration of the Clearance Certificate, beginning on the first anniversary of Date of Approval above. Unreported changes to the study may invalidate the clearance given by the HREC (Medical).

Signature of Principal Investigator

Date

Appendix P – Scoping Review Data Table Template

Author & Title of Study	Name of Tool	Resources Required	Time to administer	Reliability & Validity	Dysphagia Identification	Sensitivity & Specificity	Signs & Symptoms	Person administering the tool	Format of tool
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Appendix Q – Articles Included in Scoping Review

Validation of the Yale Swallow Protocol: a prospective double-blinded videofluoroscopic study (Suiter et al., 2014)
Self-reported Swallowing and Nutrition Status in Community-Living Older Adults (Jardine et al., 2020)
Nutritional status and dysphagia risk among community-dwelling frail older adults (Takeuchi et al., 2014)
Impact of dysphagia and malnutrition on the survival of hospitalized patients (Rodríguez et al., 2022)
A risk prediction model for dysphagia in older patients: a single-center prospective study (Lili Yu et al., 2022)
Evaluating swallowing dysfunction using a 100-ml water swallowing test (Wu et al., 2004)
Malnutrition risk of older people across district health board community, hospital and residential care settings in New Zealand (Wham et al., 2017)
Minimal eating observation form: reliability and validity (Westergren et al., 2009)
Dysphagia Assessed by the 10-Item Eating Assessment Tool Is Associated with Nutritional Status and Activities of Daily Living in Elderly Individuals Requiring Long-Term Care (Wakabayashi & Matsushima, 2016)
Clinical utility of the 3-ounce water swallow test (Suiter et al., 2007)
Prevalence of oropharyngeal dysphagia and impaired safety and efficacy of swallow in independently living older persons (Serra-Prat et al., 2011)
Factors associated with signs of aspiration in older adults: A prospective study (Pu et al., 2020)
Prevalence of signs of dysphagia and associated risk factors in geriatric patients admitted to an acute medical unit (Olesen et al., 2020)
Validation of the applicability of the mealtime observation checklist in predicting the risk of aspiration pneumonia in older adults receiving oral intake support: A retrospective cohort study of four long-term care facilities (Nishioka et al., 2023)
Swallowing Changes in Community-Dwelling Older Adults (Mulheren et al., 2018)
Evaluation of chewing and swallowing disorders among frail community-dwelling elderly individuals (Miura et al., 2007)
Buccofacial Apraxia, Oropharyngeal Dysphagia, and Dementia Severity in Community-Dwelling Elderly Patients (Michel et al., 2020)
Oropharyngeal Dysphagia in Community-Dwelling Older Patients with Dementia: Prevalence and Relationship with Geriatric Parameters (Michel et al., 2018)
Dysphagia is associated with functional decline during acute-care hospitalization of older patients (Matsuo et al., 2017)
Swallowing disturbance questionnaire for detecting dysphagia (Cohen & Manor, 2011)

Is the modified Mann Assessment of Swallowing Ability useful for assessing dysphagia in patients with mild to moderate dementia? (Ji et al., 2019)
Validation of dysphagia perception to predict the risk for dysphagia in non-institutionalized older adults (Figueira et al., 2023)
Screening dysphagia risk in 534 older patients undergoing rehabilitation after total joint replacement: a cross-sectional study (de Sire et al., 2021)
Accuracy of the volume-viscosity swallow test for clinical screening of oropharyngeal dysphagia and aspiration (Clavé et al., 2008)
Construct validity of the Eating Assessment Tool (EAT-10) (Wilmskoetter et al., 2017)
The risk of dysphagia is associated with malnutrition and poor functional outcomes in a large population of outpatient older individuals (Tagliaferri et al., 2018)
Signs for Early Detection of Dysphagia in Older Adults with Severe Alzheimer's Disease (Simões et al., 2020)
The Dysphagia handicap index: development and validation (Silbergleit et al., 2012)
Swallowing disorders in nursing home residents: how can the problem be explained? (Nogueira & Reis, 2013)
A Longitudinal Study of Symptoms of Oropharyngeal Dysphagia in an Elderly Community-Dwelling Population (Nimmons et al., 2015)
Factors Associated with Self-Reported Dysphagia in Older Adults Receiving Meal Support (Kurosu et al., 2021)
Prevalence of dysphagia among community-dwelling elderly individuals as estimated using a questionnaire for dysphagia screening (Kawashima et al., 2004)
A Within-Subject Comparison of Face-to-Face and Telemedicine Screening Using the Timed Water Swallow Test (TWST) and the Test of Mastication and Swallowing of Solids (TOMASS) (Karlsson et al., 2022)
The Test of Masticating and Swallowing Solids (TOMASS): reliability, validity and international normative data (Huckabee et al., 2018)
Prevalence and symptom profiling of oropharyngeal dysphagia in a community dwelling of an elderly population: a self-reporting questionnaire survey (Holland et al., 2011)
Prediction of aspiration in dysphagia using logistic regression: oral intake and self-evaluation (Heijnen et al., 2020)
Relationship Between Dysphagia and Sarcopenia with Comprehensive Geriatric Evaluation (Firat Ozer et al., 2019)
Association between risk of dysphagia and signs suggestive of sarcopenia, nutritional status and frequency of oral hygiene in hospitalized elderly (Ferreira et al., 2023)
The Ability of the 10-Item Eating Assessment Tool (EAT-10) to Predict Aspiration Risk in Persons With Dysphagia (Cheney et al., 2015)
Validity and Reliability of the Eating Assessment Tool (EAT-10) (Belafsky et al., 2008)

The Influence of Dysphagia on Nutritional and Frailty Status among Community-Dwelling Older Adults (Nishida et al., 2021)
Dysphagia is associated with oral, physical, cognitive and psychological frailty in Japanese community-dwelling elderly persons (Nishida et al., 2020)
Preliminary Development of a Screening Tool for Pre-Clinical Dysphagia in Community Dwelling Older Adults (Madhavan et al., 2018)
Construct Validation of Three Nutrition Questions Using Health and Diet Ratings in Older Canadian Males Living in the Community (Akhtar et al., 2015)
Oropharyngeal dysphagia as a risk factor for malnutrition and lower respiratory tract infection in independently living older persons: a population-based prospective study (Serra-Prat et al., 2012)
Comparison of Self-Report of Dysphagia Using the Eating Assessment Tool and the Sydney Swallowing Questionnaire in Community Dwelling Older Adults (Madhavan et al., 2021)
Aging Effects on Eating Assessment Tool-10 (EAT-10) Total Scores in Healthy, Community-Dwelling Adults (Garand et al., 2020)
Decreased swallowing function in the sarcopenic elderly without clinical dysphagia: a cross-sectional study (Chen et al., 2020)
Prevalence and associated factors of dysphagia in nursing home residents (Park et al., 2013)
Prevalence of dysphagia in a regional hospital setting: Acute care hospital and a geriatric sociosanitary care hospital: A cross-sectional study (Peñalva-Arigita et al., 2019)