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Dysphagia management in community/home settings: A scoping review investigating practices in Africa

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Abstract

Purpose: Little is known about how people living with dysphagia in rural, socioeconomically impoverished contexts in Africa are supported and manage their disability. This scoping review sought to map and synthesise evidence relating to the management of dysphagia in adults in community/home settings in Africa as a starting point for a broader study on this topic.

Method: A multifaceted search strategy involved searches of electronic databases and grey literature, hand searches, ancestry searches, and consultation with expert advisors. Records were screened by two blinded researchers. Characteristics of included studies were summarised, and their findings synthesised using the Framework approach.

Result: Six studies were included, relating to services for people with dysphagia secondary to various aetiologies. No grey literature was identified that provided service delivery descriptions or practice guidance. This limited evidence suggests little professional support is available to people living with dysphagia in the community. Individuals and carers use a range of strategies, including choosing different food and drink items and modifying how food is chewed and swallowed.

Conclusion: Further research is required to understand current practice in managing dysphagia in the community in Africa, and the needs and priorities of community members who experience dysphagia and their carers.

Keywords: adults; Africa; dysphagia; community; disability; speech-language pathology

Introduction


The global burden of illness of disease and associated disability has increased exponentially over the last three decades (Institute for Health Metrics & Evaluation, 2018). In economically developing, low-middle-income contexts (LMIC), people with disabilities remain underserved regarding their access to specialist dysphagia services, access to appropriate food and diet modification methods/tools, supported products like food thickeners, care staff, and family/community support (Pillay, 2022). This is particularly the case in African countries, with Africa remaining the poorest continent in the world (Maathai, 2010). Its economy explains why sub-Saharan Africa accounts for only 1% of global health expenditure

(World Health Organization, 2013). Africans constitute 11–13% of the world population with a disproportionate global disease burden of 24% (Azevedo, 2017). Consequently, African healthcare workers constitute 3% of the global health workforce, but serve over 24% (Hollingworth et al., 2023). Needless to say, this human healthcare workforce is untenable, especially when one considers the need for a greater dysphagia rehabilitation workforce.

Dysphagia (both developmental and acquired) affects 16–23% of the general population globally, rising to 27% in those over 76 years (Smithard, 2016). Prevalence data for dysphagia are not available for African countries, although it is very likely that similar, if not higher, rates exist. For example, a global

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study on Parkinson's disease (Gong et al., 2022) established that the prevalence of dysphagia in Africa was 39.5% for people with the disease. However, the authors acknowledged that there are few relevant studies from Africa to support these epidemiological statements. There may be multiple reasons for this, including the established relationship between poverty and disability (Banks et al., 2018). The impacts of dysphagia, on the individual and on society, are significant. Dysphagia can cause choking or inhalation of food or liquid into the lungs (pulmonary aspiration), which can lead to aspiration pneumonia and ultimately death. Dysphagia is associated with increased levels of mortality and morbidity, malnourishment and dehydration, prolonged disability, and reduced quality of life (González-Fernández et al., 2013).

Dysphagia management practices in low-resource contexts in Africa can be challenging for several reasons. These include a significant shortage of skilled dysphagia practitioners, including, but not exclusively, speech-language pathologists (SLPs). Notably, only 15 African countries have speech-language pathology and audiology pre-registration training courses (South African Speech-Language Hearing Association, 2021); it is unclear how many countries have postgraduate speech-language pathology degrees or dysphagia training courses. Additionally, there is unequal distribution of healthcare services/facilities between urban and rural areas. In South Africa, the mainly urban-based, White, English/Afrikaans-speaking speech-language pathology workforce poorly serve people living with swallowing disabilities (Pillay et al., 2020).

Globally, little is known about how healthcare practitioners prepare in-patients who experience dysphagia to manage their swallowing disabilities, following discharge from hospital. Many adults living with dysphagia (e.g. resulting from stroke, traumatic brain injury, or dementia) will need to manage their dysphagia at home (i.e. in the community), following discharge from hospital. Howells et al. (2021) were only able to identify eight published studies that described the experiences of caregivers of people living with swallowing disabilities. These eight studies focused mostly on high-income contexts, in countries such as Australia, USA, Canada, and in Europe. The studies found that caring for a person living with dysphagia had significant and wide-ranging practical, social, and emotional impacts on caregivers and on family relationships. Furthermore, little is known about how persons with dysphagia, who have been hospitalised, manage when they leave hospital to return home to live in their communities (Andrews & Pillay, 2017).

Management in high-income settings and/or in hospital typically involves a combination of behavioural change approaches, including diet modification, postural changes, and changes in the amount and/or timing of meals. In resource-poor settings, for

example in rural and poor African settings, people with dysphagia who are not in hospital may not be able to afford and/or access ongoing support, including medical interventions for the medical sequelae of poor dysphagia management (e.g. chest infections, dehydration, malnutrition). Associated poor health, and insufficient economic and social infrastructure to provide adequate rehabilitation/care, suggest that rural contexts are vulnerable spaces to live with a swallowing disability (Andrews & Pillay, 2017; Pillay & Kathard, 2018).

We therefore sought to identify and review published evidence about these topics, in order to identify examples of good practice and gaps in knowledge within the context of African care ecologies. These data will be used to inform further research, targeting the development of services in Africa for people living with dysphagia at home.

When planning to review such evidence, we were aware, after Pillay's (2017) ecological-epistemological analysis of the dysphagia literature, that dysphagia healthcare literature is saturated with "usual care" that axiomatically references the values of White, heteronormative, Protestant Christian mainstream cultures. We wanted to be aware of, and acknowledge, if and/or how the review findings were congruent with African concepts such as ubuntu—a cultural care ecology—: "I am because you are" (Cornell & Muvangua, 2011). Please see the Discussion section, below, for elaboration of the concept of ubuntu.

A preliminary search of MEDLINE was conducted, to identify studies reporting approaches to managing dysphagia in community settings in Africa. No current systematic or scoping reviews on the topic were identified. This apparent lack of published evidence provided the rationale for undertaking a scoping review. A qualitative, literature scoping study is best suited to answer a research question that is about "what is happening" in a particular subject or field of inquiry (Arksey & O'Malley, 2005). Such studies, as a genre of evidence-synthesis methods, have been used since the early 1990s by health science researchers and are close to systematic reviews on the continuum of literature analysis methods (Levac et al., 2010). Scoping reviews involve the synthesis of different types of evidence, including peer-reviewed, published studies, and grey literature.

The aim of this review was therefore to scope the current literature in the field to develop a broad appreciation of the management of dysphagia in community (i.e. home) settings in Africa. In this paper we use the term *community* to refer to any setting where people with dysphagia might live, that does not include hospitals. It can include private homes and care homes. We aimed to include a variety of peer-reviewed and publicly available grey literature, published between January 2000 and September 2020. This timeframe was chosen because more SLPs have become skilled in dysphagia management over this

period, with practices changing significantly. Furthermore, our preliminary search of MEDLINE indicated that any literature that appeared relevant to the topic had been published since 2000. We sought to identify different types of grey literature including student theses, service delivery reports, audits, and policy documents. This review was designed as a starting point to a broader program of research exploring practices, services, and care for people living with dysphagia in African community settings.

Review question

How is dysphagia in adults managed in community/home settings in Africa?

Subquestions:

- i. How do hospital-based healthcare/other professionals prepare in-patients with acquired dysphagia to manage their dysphagia, post-discharge from hospital settings, in Africa?
- ii. How do healthcare/other professionals support people in community/home settings to manage their dysphagia, in Africa?
- iii. How do people with dysphagia and their carers (paid and unpaid) understand and/or manage their dysphagia in community/home settings, in Africa?

Method

Research design: Scoping review

The York Methodology for scoping reviews described by Arksey & O'Malley (2005), with enhancements by Levac et al. (2010) and JBI (<https://jbi.global/>), was used to guide the review process. This review was used to identify and describe the evidence that exists in relation to the broad topic and any gaps in evidence that indicate the need for further research. It did not include appraisal of evidence quality.

An expert advisory board was established consisting of five academics based in Africa, with experience of review methodology and dysphagia. The expert advisors were selected by members of the research team based in Africa, because these individuals are considered as experts by their peers. Advisors were consulted via email throughout the research process and asked to direct the research team on different aspects of the scoping review process.

Search strategy

Selected criteria for included studies were developed iteratively, using the Population, Concept, Context (PCC) framework. Appendix 1 shows inclusion and exclusion criteria. These were developed by the research team and project advisors. A multifaceted search strategy was used to avoid a biased yield and included the following:

Firstly, electronic database searches: Medline via PubMed, CINAHL via EBSCO, Cochrane via

Cochrane Library, EMBASE via NICE HDAS, Africa Wide via EBSCO.

Secondly, a hand search of the content pages of the specialist topic journal *Dysphagia*.

Thirdly, a grey literature search, including electronic data found in student theses and dissertations. These were searched using the ProQuest database of research thesis reports. We also asked advisory board members and the research team members who were based in Africa to suggest electronic sources containing service delivery reports, audits, and policy documents.

Fourthly, ancestry searches (i.e. reference lists) of all records included in the full review.

Fifthly, any additional items for consideration suggested by members of the research team and advisory group.

Between November 2020 and April 2021 databases were searched for publications. Search terms were developed relating to key concepts using the PCC framework. These were broadly “dysphagia,” “swallowing,” “Africa” and all named African countries and regions, “home,” and “community”. These terms were verified with the expert advisory group. Database thesauri, including Medical Subject Heading (MeSH) terms, truncation, and wildcards, were used to generate synonyms and alternative forms and spellings for each term. Free-text searches for each term were combined using Boolean operators. The search strategy was piloted with two databases (CINAHL and PubMed) by Author 1, assisted by a specialist librarian. The results of the search were reviewed by the research team and no amendments were made to the inclusion and exclusion criteria or search strategy. Author 1 then applied the strategy to Medline via PubMed, CINAHL via EBSCO, Cochrane via Cochrane Library, and EMBASE via NICE HDAS. Author 2 applied the strategy to Africa Wide via EBSCO and ProQuest. Search terms are shown in Appendix 2 and an example of the search strategy is in the Supplementary Materials.

Selection of studies

Identified sources from all search methods (titles and abstracts, if available) were inputted to reference management software (Covidence and Rayann), to remove duplication. Authors 1 and 3 piloted the selection process by screening 25 items (by title and abstract) from databases of peer-reviewed journal papers (i.e. not grey literature), against the inclusion and exclusion criteria in a double-blinded manner, to determine if they should be included in the dataset and to establish inter-rater consistency. Only items meeting all inclusion and exclusion were included. Conflicts were resolved through discussion and 100% inter-rater agreement was achieved. All remaining sources were screened by Authors 1 and 3.

Records obtained from a ProQuest grey literature database search were screened independently by title,

abstract, and full text against the inclusion and exclusion criteria by Authors 2 and 4. Only items meeting all inclusion and exclusion were included. Conflicts were resolved through discussion and 100% inter-rater agreement was achieved.

The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR; Tricco et al., 2018) and an adapted version of the PRISMA flow diagram (Page et al., 2021) were used to record and report the source selection process (see Figure 1).

Data extraction

A structured data-charting form was developed by Author 1 (see Supplementary Materials) to use for all selected records. Authors 1, 3, and 4 each tested the form with one record and all authors reviewed the outcomes to check the accuracy of data extraction. No changes were made to the form. Subsequent data extraction for each included record was completed by a single author (either Author 1, 3, or 4). No critical quality appraisals of studies' methodology were performed.

Analysis

The extracted data were entered onto charting forms and then analysed using an adapted form of Framework Analysis (Gale et al., 2013), as outlined below:

Stage 1. Data familiarisation: Authors 1 and 3 read the extracted data and noted any initial thoughts or impressions.

Stage 2. Coding: As the data extraction process had already acted as form of initial data coding (data were extracted in relation to the review question), Authors 1 and 3 coded each extracted record using deductive codes that aligned with the three review subquestions, summarised briefly as: (a) preparation for discharge, (b) professionals' support in the community, and (c) practices of people living with dysphagia/carers.

Additionally, each record was open coded to allow the addition of inductive (sub)codes. If the extracted data lacked clarity, Authors 1 and 3 went back to the original evidence source (i.e. the publication).

Stage 3. Developing a working analytical framework: Authors 1 and 3 met to compare codes and developed the working analytical framework, using subcodes and codes.

Stage 4. Applying the working analytical framework: Author 1 applied the working analytical framework to all records. This was done by hand directly onto the data extraction forms, as the dataset was very small.

Stage 5. Charting onto the framework: Author 1 pasted the relevant data extraction notes directly into the Analytical Framework.

Stage 6. Interpretation: All authors met to discuss, synthesise, and attempt to explain the findings, and to identify gaps in the data.

Result

In this section, we firstly report the search results before providing a narrative description of the characteristics of included studies. Finally, we present a qualitative synthesis of the findings of

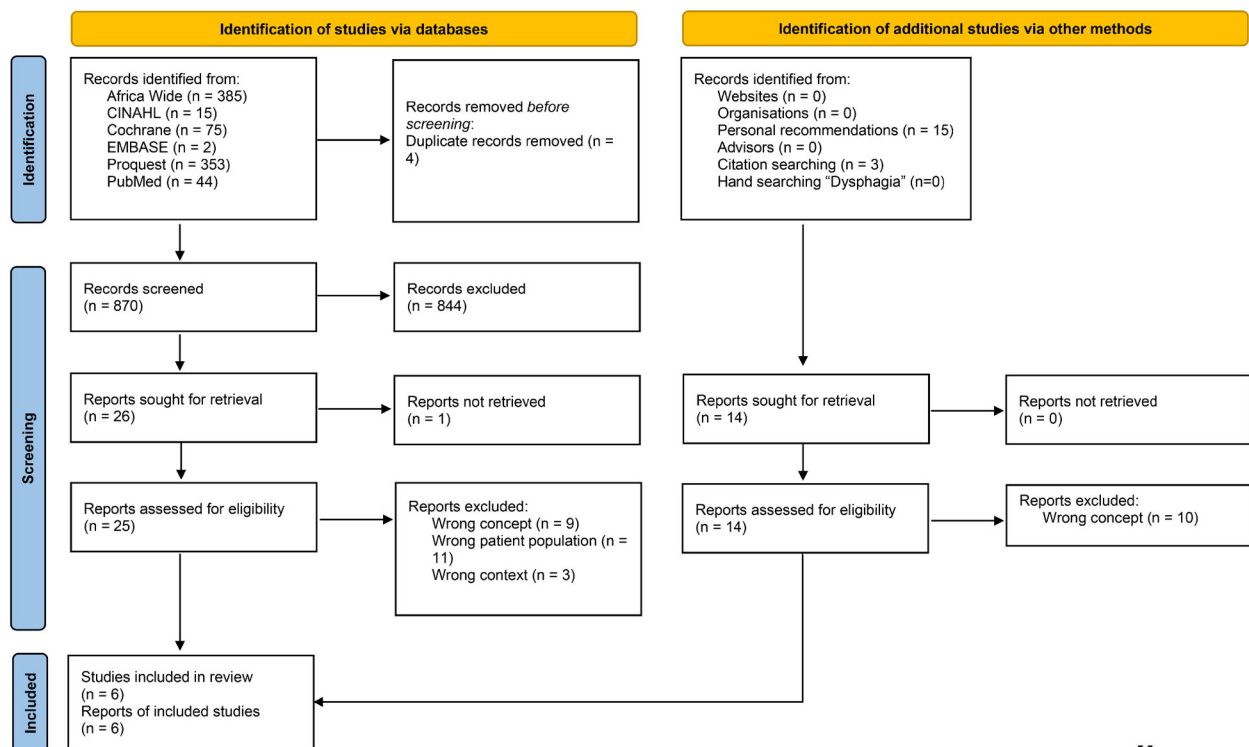


Figure 1. PRISMA 2020 flow diagram (Page et al., 2021) showing the review process.

included studies, in relation to each of the review subquestions.

Search results

The search results are presented in [Figure 1](#), in the form of a PRISMA 2020 flow diagram (Page et al., 2021). We identified 874 studies through database searches and 18 through other sources. In total, 852 studies were excluded following deduplication and title and abstract screening, and 33 following full-text screening. Six studies were included for review.

Study characteristics

[Table I](#) summarises characteristics of the six included studies. Studies were published between 2005 and 2019. Four studies were published in peer-reviewed journals (Ali et al., 2019; Andrews & Pillay, 2017; Bladon & Ross, 2007; Garbusinski et al., 2005), one was a doctoral thesis (Seedat, 2013), and one a Master's degree thesis (Larson, 2018). Three of the included studies took place in South Africa (Andrews & Pillay, 2017; Bladon & Ross, 2007; Seedat, 2013), whilst the others were conducted in Kenya (Ali et al., 2019), Gambia (Garbusinski et al., 2005), and Malawi (Larson, 2018). The studies used a range of qualitative, quantitative, and mixed-methods research designs. Three studies directly aimed to describe practice in relation to supporting people living with dysphagia (Ali et al., 2019; Andrews & Pillay, 2017; Larson, 2018). The other studies aimed to describe clinical outcomes (including presence of dysphagia) post-stroke (Garbusinski et al., 2005), dysphagia symptoms associated with human immunodeficiency virus (HIV; Bladon & Ross, 2007), and outcomes associated with a dysphagia intervention (Seedat, 2013). The studies involved two main groups of participants: people living with dysphagia and their family carers, and professionals involved in working with these people. Sample sizes ranged from one to 148. Where specified, the context for data collection included urban hospital and outpatient clinic settings, and a patient's home.

Qualitative synthesis of findings

Overall, this scoping review identified a lack of published evidence relating to how dysphagia in adults is managed in community/home settings in Africa. We were unable to identify any studies specifically describing how hospital-based healthcare and other professionals prepare in-patients with acquired dysphagia to manage their dysphagia post-discharge from hospital settings in Africa (Subquestion 1). We were able to identify only very limited evidence relating to professional support available to help people to manage their dysphagia in community/home settings in Africa (Subquestion 2) or relating to how people with dysphagia and their carers (paid and unpaid) understand and/or manage their dysphagia in

community/home settings in Africa (Subquestion 3). Below we summarise the limited evidence that this review does provide in relation to the review questions, in addition to findings from these studies that relate to future research and practice recommendations.

Professional involvement in dysphagia management (Subquestions 1 and 2)

Nature of involvement

Limited evidence from one study (Larson, 2018) in Malawi suggests a range of professionals may be involved in dysphagia management in hospital settings, not necessarily only SLPs. These professionals include otolaryngologists, nurses, audiologists, clinical rehabilitation officers, and rehabilitation technicians. However, none of the studies that collected data relating to practice in hospital settings (Andrews & Pillay, 2017; Garbusinski et al., 2005; Larson, 2018) included any specific evidence about the activities undertaken by healthcare professionals to prepare patients with dysphagia for discharge.

The findings of three studies (Bladon & Ross, 2007; Garbusinski et al., 2005; Seedat, 2013) suggest there is a lack of access to formalised or professional support to manage dysphagia in the community. Where support is available, it is reportedly provided by a range of professionals, including doctors, but rarely SLPs: "All the individuals who had received treatment had received medical treatment and very few had accessed alternative resources such as a dietician or speech therapist" (Bladon & Ross, 2007, p47).

Again, there is a lack of evidence about the nature of the support provided.

Professional resource availability

Limited evidence from one study (Larson, 2018) suggests that limited access to professional resources, for example clinical tools, may impact negatively on service provision. In Larson's study, professionals reported needing to seek support from other professionals (within and outside Africa) to help them develop their practice in relation to services for people with dysphagia. For example, one professional sought mentoring support from an SLP working in New Zealand. Professionals in the study appeared to lack knowledge about international treatment standards and some made inadequate practice recommendations. Professionals reported that they would like to access additional training on dysphagia aetiology and approaches to assessment and management.

Professional attitudes towards/feelings about dysphagia management

Limited evidence from one study (Larson, 2018) suggests professionals are concerned about, and feel

Table 1. Summary characteristics of included papers.

| Authors & year | Source of evidence: | Type of evidence: | Geographical focus of evidence (country, region) | Setting e.g. urban/rural | Population of focus in study e.g.: | Participants e.g.: |
|---------------------------|---|---|--|---|--|--|
| Bladon and Ross (2007) | <ul style="list-style-type: none"> Peer reviewed journal Postgraduate by research theses Organisational report Web page | <ul style="list-style-type: none"> Primary research: Aim, methodology and design Service description: Aim Audit: Aim | South Africa | <ul style="list-style-type: none"> Socioeconomic status Hospital Community (health/social care/spiritual) services Private homes and care homes | <ul style="list-style-type: none"> Age Gender Clinical diagnosis Economic/educational status | <ul style="list-style-type: none"> Health workforce e.g. nurses, SLPs, medics Social care staff PW Experience dysphagia Carers/family members Other community members and N = |
| Ali et al. (2019) | Peer reviewed journal | <ul style="list-style-type: none"> Primary research Aim: To investigate presence of swallowing difficulties in a sample of adults diagnosed with HIV/AIDS Methodology: Mixed methods Design: Semi-structured interviews and medical record review | Kenya | <ul style="list-style-type: none"> Outpatient clinic at secondary government hospital in Johannesburg | <ul style="list-style-type: none"> Adults aged 19–58 years All genders People diagnosed with HIV/AIDS No other information provided about participant demographics | 108 patients with HIV/AIDS attending a clinic. |
| Andrews and Phllay (2017) | Peer reviewed journal | <ul style="list-style-type: none"> Primary research Aim: To describe decision making related to nutritional management of patient with dysphagia at end of life Methodology: Qualitative case study Design: Case report | South Africa | <ul style="list-style-type: none"> Electronic survey | <ul style="list-style-type: none"> 74-year-old Male Diagnosed with dysphagia secondary to stroke Living in rural Kenya with wife | 1 person with dysphagia |
| Seedat (2013) | PhD thesis | <ul style="list-style-type: none"> Primary research Aim: To investigate effect of free water protocol on outcomes for patients with dysphagia secondary to stroke or traumatic brain injury in an acute government hospital Methodology: Mixed methods pragmatic paradigm Design: Sequential exploratory mixed methods design | South Africa | <ul style="list-style-type: none"> Acute hospital | <ul style="list-style-type: none"> Adults aged 45–80 years All genders Hospital patients diagnosed with oropharyngeal dysphagia secondary to stroke or traumatic brain injury | <ul style="list-style-type: none"> 139 nurses 23 patients with acquired oropharyngeal dysphagia |
| Larson (2018) | Master of Science thesis | <ul style="list-style-type: none"> Primary research Aim: To provide baseline description of service provision in Malawi for | Blantyre, Malawi | <ul style="list-style-type: none"> Region of Malawi | <ul style="list-style-type: none"> All ages All genders People with dysphagia | 5 multidisciplinary hospital staff experienced in assessing and treating people with dysphagia |

(Continued)

Table I. (Continued).

| | | | | | | |
|---------------------------|-----------------------|--|--------|----------------------------|--|---|
| Garbusinski et al. (2005) | Peer reviewed journal | feeding and swallowing disorders • Methodology: Mixed methods • Design: Survey (written, answered using verbal interview) • Primary research • Aim: To describe clinical outcomes for patients diagnosed with non-subarachnoid stroke admitted to one hospital and propose preventive and therapeutic measures • Methodology: Quantitative • Design: Prospective observational study | Gambia | Urban hospital (inpatient) | • All ages over 15 years old • All genders • Patients diagnosed with non-subarachnoid stroke | 148 inpatients with dysphagia at Royal Victoria Teaching Hospital, Gambia |
|---------------------------|-----------------------|--|--------|----------------------------|--|---|

responsible for, supporting their patients with dysphagia. In this study, professionals' levels of confidence in their ability to provide this support appeared to vary; some professionals appeared to be confident about their ability although they demonstrated a lack of knowledge of international treatment standards.

Approaches used by people living with dysphagia and their carers (Subquestion 3)

Types of approaches

Only one study (Bladon & Ross, 2007) reported how people living with dysphagia manage their eating, drinking, and swallowing difficulties in community/home settings. In this study, people living with dysphagia and HIV/AIDS (acquired immunodeficiency syndrome) in South Africa used a variety of “self-help” approaches to manage their eating, drinking, and swallowing difficulties. These approaches involved changing the types of items they ate and drank, and how they chewed and swallowed food. Specific strategies included increased water intake, cyclic ingestion (alternating liquid/water with solids), modified placement of bolus in the oral cavity, postural/positional compensations (e.g. neck extensions), oral care/hygiene, and use of homemade remedies such as drinking garlic in boiled water. Participants reporting these practices appeared to have varied views about their effectiveness.

Implementation of professional recommendations

Evidence from two studies (Larson, 2018; Seedat, 2013) suggests professional advice about dysphagia management may include dietary recommendations that may not be compatible with religious/cultural attitudes to food and eating. Furthermore, some recommended dietary modifications may be difficult for patients to achieve, due to local food insecurity and/or due to financial challenges: “when it comes to recommendations at the time of discharge ... there may be implications for diet modification which implies cost” (Seedat, 2013, p.66). Evidence from another study conducted in South Africa (Andrews & Pillay, 2017) indicates that some people with dysphagia may not perceive the treatment provided by medical professionals to be effective. In Larson’s (2018) study, professionals supporting people with dysphagia also identified concerns about how community and family members might respond to a person receiving a diagnosis of dysphagia; professionals indicated that this response could impact on the community and family’s acceptance of the condition and the support offered to the person with dysphagia.

Recommendations for management of dysphagia in adults in community/home settings in Africa

Four studies (Ali et al., 2019; Andrews & Pillay, 2017; Bladon & Ross, 2007; Garbusinski et al., 2005) made recommendations about future service provision for people living with dysphagia in the community. These recommendations relate to improving public awareness of dysphagia, enhancing diagnosis and treatment, creating evidence-based policies and guidelines to aid professionals, and the promotion and facilitation of socially- and culturally-sensitive practice. Increased partnership working with local professionals, family members, and carers was also recommended; one study (Garbusinski et al., 2005) recommended that family participation in provision of care for people with dysphagia in hospital and at home is essential. The study's authors suggest that family members (particularly women) could be trained by community nurses to support their relatives to manage dysphagia at home.

Discussion

There is a marked paucity of literature in the field regarding dysphagia management in community/home settings in Africa. There may be several reasons for this including the health-based search strategy used and because our searches did not identify any service guidelines, reports, or websites. Most research about African dysphagia may be done at undergraduate or postgraduate study level, housed in university libraries, and generally hard to find, even in upper middle-income African countries like South Africa. One of the authors, an African dysphagia researcher, attests to the numerous mainstream journal editor rejections to publish work that appears "faulty", or as variations of Eurocentric methods whereby Africans have to innovate methodologies to fit within, for example, scoping review frameworks.

Also health, social, and related care systems around disability are certainly not the same as those in European or North American contexts, with different family and community systems, social structures, and economic and political infrastructures. Therefore, local, African-produced research is rarely included in mainstream dysphagia literature and, even when it is, it has to comply with research conventions that may decontextualise African realities regarding peoples' lives, and how data collection and analysis should occur in an African context.

Notably, across peer-reviewed published and grey literature, our search strategies yielded large numbers of published items, but few were eligible for inclusion. Indeed, it is probable that authors make comments in research reports about the transition of people with swallowing disabilities from hospital to community/home settings. Such data, however, may be buried in papers and may not have emerged in our review, due

to the search strategy/words used. We (the authors) can offer personal testimonies to practices in the field that go unreported. Therefore, a lack of published evidence does not necessarily imply a lack of practice.

In relation to preparation for discharge of hospital in-patients with dysphagia, there is a lack of published evidence. The data reported in Larson (2018) indicate a wide range of professionals who are interacting with clients in hospital. These could, going forward, be engaged in providing advice and support in preparation for discharge.

In terms of professionals' support for people with dysphagia living in the community, post-hospital discharge, the published evidence (Bladon & Ross, 2007; Garbusinski et al., 2005; Seedat, 2013) indicates that little support is provided and, where support is available, it is rarely provided by SLPs. Again, this has implications for services. Lack of clinical tools, resources, and training is also significant and indicates the need for input of local support.

Evidence about the practices of people living with dysphagia/carers is very limited (only Bladon & Ross, 2007, report on it). Several community self-capacitating strategies were reported, for example, eating and diet textural selections/modifications and upskilling caregiver mealtime management. Specific strategies, with varying perceptions of effectiveness, included cyclic ingestion, postural/positional compensations, oral care/hygiene, and use of homemade remedies like garlic in boiled water. It is clear that caregivers and communities generate their own interventions and treatment technologies. These reported strategies are similar to practices used in high-income countries, e.g. Mathers-Schmidt and Kurlinski (2003), Bateman et al. (2007), Pettigrew and O'Toole (2007), Carnaby and Harenberg (2013), Martino et al. (2000), and Rumbach et al. (2018), as well as in LMIC contexts such as South Africa, e.g. Andrews and Pillay (2017) and Masipa (2017). These dysphagia-related community self-capacitating care patterns align with contemporary positive African attitudes to disability (Adugna et al., 2020).

These findings again suggest the need for more data, not only about what people do but also the evidence of its effectiveness and people's sense-making or understanding of any advice received. Notably, the countries where these studies were developed (South Africa, Kenya, Malawi, Gambia) are neither culturally nor linguistically homogenous, implying that the socioeconomic and political contexts of each place require a deeper, nuanced understanding in order to fully appreciate how people live with dysphagia. For example, the role of indigenous African care systems, which are often the first point of care for Africans living with disabilities (Andrews & Pillay, 2017; Ojok & Musenze, 2019; Pillay, 1992), may need to be prioritised.

Across all the studies in this dataset, it was apparent that professional support for dysphagia in

communities was necessary but seemed to be negligible. Indeed, four studies recommended that services should be developed to meet this need. When present, community support was rarely delivered by SLPs as key providers. While social capital (Agampodi et al., 2015) is how/why community care systems develop, it is a cultural care ecology that goes beyond formal healthcare workers that matters. Therefore, family and other community caregivers should be considered (Pillay, 2017) as key to change, because culture mediates meaning-making of critical life events like “disability”. Enacted in communities, ubuntu is a cultural care ecology. As noted in the Malawian study (Larson, 2018), cultural (or what Larson referred to as informal) care systems are essential to consider for the care of people living with dysphagia. Ubuntu reinforces care that falls between Western medical systems (e.g. a hospital) and indigenous African care systems, which are often the first point of care for Africans living with disabilities (Pillay, 1992, Andrews & Pillay, 2017, Ojok & Musenze, 2019). This implies that meaningful professional dysphagia support in African communities requires Eurocentric healthcare practitioners (like SLPs) to negotiate African cultural ecologies and indigenous care systems, such as that provided by traditional healers.

Limitations

We acknowledge a need to address the limitations of this review, which was designed to serve as a starting point for further research. We acknowledge that data collection ended in September 2020 and recognise that more recent evidence may provide more comprehensive answers to our review questions. Unfortunately, the grey literature identified in this review was limited to student theses and did not include any service delivery reports, audits, or policy documents. The project advisors who were based in Africa were unable to suggest any of these types of documents and the research team lacked the resources to complete internet searches for these items, some of which may have been freely accessible on the internet. We also acknowledge that, due to resource limitations, we were only able to include English-language records. These limitations mean that research, policy, and practice evidence relevant to our review questions may exist but was not identified by our search strategy.

Implications for future research

The research literature represents a very limited perspective of what actually is occurring in practice. It behoves us, as researchers, to continue to directly research with African practitioners who are in the field to develop a richer, granular perspective of dysphagia practice, given that further literature reviews

may provide little more information about the subject at hand.

In our next steps, we aim to include analyses of service delivery reports, audits, policy documents, and other types of grey literature, including best practice guidelines, patient literature (including dysphagia-related instructions and/or guidance provided by healthcare practitioners), practitioner training curricula, procedural manuals, and textbooks. This should enable us to gain a comprehensive and rich overview of current services and practice and to consider our findings further within the context of African cultural care ecologies. To achieve this, we propose to work with a larger pool of local advisors, to complete Google searches for other forms of grey literature, and to survey service providers and practitioners, to ask them to describe service delivery and share practice-related materials. We aim to ensure this work is inclusive of a range of African languages. We propose to use the findings from this additional analysis to design interview or observational studies to help us map current practice more comprehensively (i.e. the detail of what we originally planned to achieve with this review). These studies will allow us to identify good practice and to identify gaps in healthcare policy and practitioner education that relate to services for people living with dysphagia in community settings. The results of this mapping work could inform future policy and education development work, and the design of studies to develop and evaluate new community-based interventions to provide equitable support for people living with dysphagia in Africa. This research should be coproduced with local stakeholders to ensure interventions are culturally sensitive and congruent with local care ecologies; this should increase the likelihood that interventions are feasible and acceptable to local stakeholders and can be implemented successfully in practice. Within this work, it will be important to try to capitalise on ongoing developments in practice, given that service provision for people living with dysphagia is likely to be rapidly changing across much of Africa, due to the creation of new services and the growth in availability of SLPs (Wylie et al., 2013, 2018).

Conclusion

To the authors’ knowledge, this scoping review is a unique study that highlights the need for further research to consider ongoing and unreported practice relating to dysphagia management in home/community settings in Africa. Identifying this need is a vital first step to exploring the contexts, needs, priorities, and wishes of those community members who experience dysphagia and those who support them in rural and socioeconomically deprived areas of Africa. We hope that these initial findings will serve as a call to action to others to engage in research that explores the realities of dysphagia management within these contexts. Future research should aim to identify and,

where necessary, fill gaps in healthcare policy, practitioner education, and service delivery models to ensure that people living with dysphagia in community settings in Africa have equitable access to support to manage their swallowing disability.





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Appendix 1: Inclusion and exclusion criteria for included sources

Review question: How is dysphagia managed in community/home settings in Africa?

| Parameter | Inclusion criteria | Exclusion criteria |
|--------------------------|---|--|
| Population | Adults (aged 18 years and above) and/or their carers living with dysphagia | <ul style="list-style-type: none"> Adults without dysphagia Children with dysphagia |
| Concept | <ul style="list-style-type: none"> Work done by healthcare professionals/other professionals to prepare hospital patients and their families to manage their dysphagia in the community/home; Work done by healthcare/other professionals to help people and their carers to manage their dysphagia in the community/home; Patients' and their carers' understanding of dysphagia; Patients' and/or carers' management of dysphagia in the community/home. | <ul style="list-style-type: none"> Sources that focus on aspects of swallow physiology and not the management of dysphagia symptoms; Work done by healthcare/other professionals to help hospital patients to manage their dysphagia symptoms inside hospital; Work done by healthcare/other professionals to prepare hospital patients and their carers to manage other health conditions in the community/home; Work done by healthcare/other professionals to help people manage other health conditions in the community/home; Patients' and their carers' understanding and management of other health conditions. |
| Context | Africa | Other locations |
| Types of evidence source | <ul style="list-style-type: none"> Externally peer-reviewed primary research studies: all research designs, including higher education institution student theses and reports; Externally peer-reviewed evidence reviews: all types; Service description reports or audits; Policy documents; Above could be produced by international/national/local governments, professional regulatory bodies, research organisations, non-governmental organisations, United Nations organisations, higher education institution students; All sources must be easily found and traceable documents (print/electronic) in the public domain. | <ul style="list-style-type: none"> Published text books; Commentaries; Expert opinion. |
| Reporting language | English | Other languages |
| Time period | From 1st January 2000 | Before 1st January 2000 |

Appendix 2: Search strategy terms

| Databases | Africa Wide, CINAHL, EMBASE | Medline via PubMed, Cochrane |
|------------|--|---|
| Population | (MH "Adult+") OR adult* OR elder* OR older* | "Adult"[MeSH Terms] OR "adult*" [All Fields] OR "elder*" [All Fields] OR "older" [All Fields] OR "olders" [All Fields] |
| Construct | (MH "Deglutition Disorders") OR dysphagi* OR aphagi* OR swallow* | "Deglutition Disorders"[MeSH Terms] OR "dysphagi*" [All Fields] OR "aphagi*" [All Fields] OR "swallow*" [All Fields] |
| Context i | (MH "Africa+") OR Africa* OR Tanzania OR Uganda OR Ethiopia OR Eritrea OR Rwanda OR Somalia OR Sudan OR Burundi OR Mozambique OR South Sudan OR Zambia OR Djibouti OR Malawi OR Lesotho OR Benin OR Burkina Faso OR Senegal OR Sierra Leone OR Mali OR Liberia OR Gambia OR Guinea Bissau OR Niger OR Togo OR Angola OR Central African Republic OR Chad OR Democratic Republic of the Congo OR Sao Tome and Principe OR Zimbabwe OR Cameroon OR Congo OR Cote d'Ivoire OR Kenya OR Tunisia OR Egypt OR Morocco OR Eswatini OR Nigeria OR Cabo Verde OR Ghana OR Algeria OR Liberia OR Mauritania OR Namibia OR South Africa OR Botswana OR Gabon OR Equatorial Guinea | "Africa"[MeSH Terms] OR "africa*" [All Fields] OR ("tanzania" [All Fields] OR "uganda" [All Fields] OR "ethiopia" [All Fields] OR "eritrea" [All Fields] OR "rwanda" [All Fields] OR "Somalia" [All Fields] OR "Sudan" [All Fields] OR "burundi" [All Fields] OR "mozambique" [All Fields] OR "South sudan" [All Fields] OR "Zambia" [All Fields] OR "djibouti" [All Fields] OR "malawi" [All Fields] OR "lesotho" [All Fields] OR "benin" [All Fields] OR "Burkina faso" [All Fields] OR "senegal" [All Fields] OR "sierra leone" [All Fields]) OR "mali" [All Fields] OR "liberia" [All Fields] OR "gambia" [All Fields] OR "guinea bissau" [All Fields] OR "Niger" [All Fields] OR "togo" [All Fields] OR "Angola" [All Fields] OR "central African republic" [All Fields] OR "chad" [All Fields] OR "democratic republic of the Congo" [All Fields] OR "sao tome and principe" [All Fields] OR "Zimbabwe" [All Fields] OR "Cameroon" [All Fields] OR "Congo" [All Fields] OR "Cote d'ivoire" [All Fields] OR "Kenya" [All Fields] OR "Tunisia" [All Fields] OR "egypt" [All Fields] OR "Morocco" [All Fields] OR "eswatini" [All Fields] OR "Nigeria" [All Fields] OR "cabo verde" [All Fields] OR "ghana" [All Fields] OR "algeria" [All Fields] OR "Liberia" [All Fields] OR "Mauritania" [All Fields] OR "Namibia" [All Fields] OR "south africa" [All Fields] OR "Botswana" [All Fields] OR "Gabon*" [All Fields] OR "equatorial guinea" [All Fields] |
| Context ii | (MM "Home Health Care") OR (MH "Home Rehabilitation+") OR (MM "Community Health Services") OR OR home* OR community* | "Home Care Services"[MeSH Terms] OR "home care services, hospital based"[MeSH Terms] OR "Community Networks"[MeSH Terms] OR "home*" [All Fields] OR "community*" [All Fields] |