

Management of Feeding  
and Swallowing Disorders

in Malawi

by

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## ABSTRACT

Malawi, as a low and middle income country (LMIC), with one of the lowest per capita gross domestic products, faces challenges in the provision of healthcare to its citizens. According to the Centers for Disease Control (CDC), leading causes of death include but are not limited to, lower respiratory disease, stroke, cancer, neonatal disorders, and nutritional deficiencies. Feeding and swallowing disorders can present as a symptom to any of these medical diagnoses. Currently, there are no known studies focusing on the service provision for feeding and swallowing disorders in Malawi.

This pilot study was designed to provide a baseline on how feeding and swallowing disorders are currently being provided for in an emerging country like Malawi. Malawian healthcare professionals who see patients with feeding and swallowing disorders completed a survey and interview pertaining to their personal demographics, caseload, opinions, experiences, and treatment recommendations regarding the management of swallowing disorders (dysphagia).

Results indicate a wide range of occupations (Otolaryngologists, Rehabilitation Technicians, Audiology Technicians, and Nurses) are involved in feeding and swallowing care. Participants expressed a high obligation to provide services for feeding and swallowing disorders, as well as a high concern for their patients. Generally, participants expressed high confidence in their treatment abilities, which did not correspond to knowledge of treatment recommendations that meet U.S. standards of care. Specifically, there was no variation in treatment recommendations across severities and a general lack of resources and tools for assessing and treating dysphagia. Treatment recommendations tended to align with resources currently available in Malawi.

Implications for the utilization of NGOs (non-governmental organizations) and the education of healthcare providers on feeding and swallowing disorders in the social and cultural contexts of this country are discussed.

## DEDICATION

This study is dedicated to the “Warm Heart of Africa,” and future speech-language pathologists who wish to further their service provision passions and create culturally sensitive and sustainable programs in low and middle income countries.

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## **Introduction**

### **Setting the Stage**

As a country with one of the lowest per capita gross domestic products (GDP), Malawi faces challenges in the provision of health care to its citizens, including the treatment for feeding and swallowing disorders (Agyeman-Duah, Theurer, Munthali, Alide, & Neuhann, 2014). Currently, Malawi does not have a specialized degree program in speech-language pathology. Speech-language pathologists (SLPs) are masters-degree healthcare providers who “work to prevent, assess, diagnose, and treat speech, language, social communication, cognitive-communication, and swallowing disorders in children and adults” (“American Speech-Language Hearing Association[ASHA]: About Speech-Language Pathology”, n.d). In Malawi, various healthcare providers are faced with addressing the health concerns that would fall under a speech-language pathologist’s scope of practice in the United States (US). This study focuses on the experiences and viewpoints pertaining to the treatment and intervention of dysphagia and feeding/swallowing disorders in Malawi.

Several prevalent health conditions in Malawi are associated with swallowing disorders. According to the CDC, lower respiratory infection is the 2<sup>nd</sup> leading cause of death, stroke is the 4<sup>th</sup>, and neoplasms are the 6<sup>th</sup> leading cause of death in Malawi, Africa (“CDC: Global Health – Malawi”, 2016). Neoplasms are abnormal growths of tissue somewhere in the body that are characteristic of cancer. In Malawi, esophageal cancer is the 6<sup>th</sup> most common cancer with an estimated incidence of 10 per 100,000 people per year (Thumbs et al., 2012). Additionally, neonatal disorders and nutritional deficiencies

round the list of top causes of death in Malawi (“CDC: Global Health – Malawi”, 2016).

What do all of these medical diagnoses have in common? Dysphagia, a swallowing disorder, can present as a symptom.

Dysphagia is not a singular disease, but is a symptom of an underlying medical diagnosis. It can co-exist with many medical conditions and can occur across the lifespan. Head and neck cancer, stroke, and other neurological disorders are common diagnoses where dysphagia is present (“ASHA: Adult Dysphagia: Overview”, n.d.). Therefore, epidemiological data aren’t available, as dysphagia is tracked only as a symptom (“ASHA: FAQs from the Dysphagia Committee”, n.d.). In a study conducted in 2012 investigating an effective palliative treatment for esophageal cancer in Malawi, Dr. Alexander Thumbs and colleagues found that most patients (64% of the sample) presented with progressive dysphagia (Thumbs et al., 2012). Additionally, the World Health Organization (WHO) collects data on the incidence and prevalence of cardiovascular disease and stroke. In 2003, Malawi reported 7,249 casualties due to stroke (“The Atlas of Heart Disease and Stroke”, n.d.). Dr. Rosemary Martino and colleagues determined the prevalence of dysphagia after stroke to be anywhere from 40-80% of cases from a combined systematic review of published peer-reviewed literature from databases such as Medline, Embase, Mantis, Pascal, Sci Search, etc. (Martino et al., 2005).

Another common problem related to swallowing is feeding disorders. A feeding disorder is a developmental disorder in children characterized as difficulties with gathering food and the processes involved in getting ready to suck, chew, or swallow food (“ASHA: Feeding and Swallowing Disorders (Dysphagia) in Children”. n.d.).

Children with feeding or swallowing disorders are at increased risk of malnutrition, aspiration pneumonia, and death. In 2003, Maleta et al. followed a population-based cohort of 767 rural Malawian children from birth to 36 months. They found that about 40% of the population were underweight and malnourished (Maleta, Virtanen, Espo, Kulmala, & Ashorn, 2003). These statistics and studies show that dysphagia and feeding/swallowing disorders are currently an area of concern in Malawi.

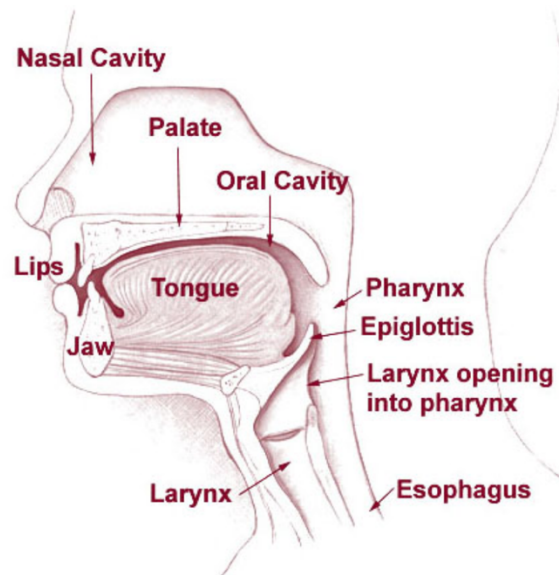
Investigating how dysphagia and feeding/swallowing disorders are currently being treated is important, as the medical consequences of untreated dysphagia and feeding/swallowing disorders include malnutrition, dehydration, aspiration pneumonia, compromised general health, chronic lung disease, choking, and even death.

Additionally, adults and children with dysphagia can experience disinterest in and avoidance of eating/drinking, and embarrassment and/or isolation in social settings surrounding eating (“ASHA: Adult Dysphagia: Overview”, n.d).

### **Normal and Disordered Swallowing**

Swallowing involves structures in the oral cavity, pharynx, esophagus, and gastroesophageal junction (“ASHA: Adult Dysphagia: Overview”, n.d). A regular swallow can be thought of as four separate phases: the oral preparatory stage, the oral transit stage, the pharyngeal stage, and the esophageal stage. In the oral preparatory stage, food is masticated and manipulated into a bolus (small, round, singular mass of chewed-up food). In the oral transit stage, the bolus is transferred from the mouth to the oropharynx. When the bolus is transported around an occluded laryngeal vestibule and through a relaxed cricopharyngeus muscle into the upper esophagus, this phase of the swallow is referred to as the pharyngeal stage. Lastly, in the esophageal stage of the

swallow, the bolus is moved from the esophagus to the gastric cardia (Groher & Crary, 2016). Below in Figure 1 is a representation of the anatomy involved in the swallowing mechanism.



*Figure 1: Anatomy of the swallowing mechanism (“Pharynx Anatomy”, 2012).*

The root deficits of dysphagia can be thought of as two distinct categories. One- a delay in the initiation of a swallow or the propulsion of a bolus as it travels from the mouth to the stomach. Or two- the misdirection of the bolus. In the instance where the bolus travels into the larynx and beyond the true vocal folds, the patient is aspirating. The material of the bolus has now traveled into the patient’s lungs, and if left untreated aspiration pneumonia is a probable outcome (Groher & Crary, 2016). SLPs can diagnose dysphagia at a bedside evaluation, or with a Modified Barium Swallow (MBS), also referred to as a swallow study (“ASHA: Adult Dysphagia: Assessment”, n.d.). An MBS is a procedure in which the patient’s swallow is evaluated via an x-ray in order to obtain a better understanding of the anatomy and physiology of the patient’s swallow mechanism. The patient is asked to swallow various consistencies of liquids and solids that are mixed



in with barium (a contrast in order to be seen on the x-ray) (Groher & Crary, 2016). Another similar procedure that can be done is a fiberoptic endoscopic evaluation of swallowing (FEES) examination. This is where a tube goes down a patient's throat in order to check for aspiration and any abnormal anatomy or physiology of the swallow (Groher & Crary, 2016).

### **Education of US SLPs and Malawi Rehabilitation Technicians**

In the US, the evaluation, treatment and intervention of dysphagia and feeding/swallowing disorders falls within the scope of practice of an SLP ("ASHA: Scope of Practice in Speech-Language Pathology", n.d.). To become an SLP in the US, one must complete a Master's degree in Communication Disorders or Speech-Language Pathology and pass a national comprehensive exam. Upon completion of these requirements, the individual then completes a clinical fellowship (CF). The CF is the first year the individual works as an SLP and is still closely monitored by a supervising SLP who has received a certificate of clinical competence from the American Speech Language Hearing Association. Currently, there are no formal speech-language pathology training programs in Malawi. The role of managing communication and swallowing disorders thus falls upon rehabilitation technicians, who have received generalized rehabilitation training, and other healthcare professionals in the country (Fielder, Mpezeni, Benjamin, & Cary, 2013).

In 1999, a formal rehabilitation training program was introduced through a Rehabilitation Technician School at the Kachere Rehabilitation Centre in Blantyre, Malawi (Fielder et al., 2013). This is a three-year rehabilitation training program designed to educate individuals in the provision of general/basic physical therapy,

occupational therapy, and speech and language therapy (Fielder et al., 2013). Upon graduating from this program, rehabilitation technicians ideally work under the supervision of an experienced therapist, but due to a large need for therapeutic services across the country, new technicians often must work alone in areas that lack other providers (Fielder et al., 2013).

There are only three known individuals in Malawi who focus on speech and language therapy and all of the sub-disciplines that fall under the role of an SLP (i.e. feeding and swallowing disorders). One of these individuals was able to participate in this study. The other two individuals were unavailable. Of the other two, one has started a private clinic called Able Kids Foundation, and the other runs a facility called Sandi Rehabilitation. Neither one of these two identified individuals are currently practicing as rehabilitation technicians. One is now serving as a member of the National Assembly of Malawi, and the other has taken on a more administrative role at Sandi Rehabilitation. The third rehabilitation technician, Participant B in this study, currently works at Able Kids Foundation in Blantyre. But in addition to foundations and private clinics, there are other settings in which healthcare providers provide feeding and swallowing services.

### **Healthcare in Malawi**

In a study of health care in Malawi, Fisher, Lazarus, and Asgary (2017) reported that there are both formal and informal systems for providing medical services. The formal health care sector provides the majority of healthcare services in Malawi (Fisher et al., 2017). This sector can be divided into three levels of care. “The primary level consists of community-based programs and local health posts, the secondary level of private or government-owned district hospitals, and the tertiary level of central district

hospitals. A referral system connects all three levels” (Fisher et al., 2017). The informal sector of healthcare consists of traditional healers, herbalists, and prophets.

In Malawi, this dualistic system consisting of Western medicine and indigenous practices is commonplace (Simwaka, Peltzer, & Maluwa-Banda, 2007). In the survey study by Simwaka et al. (2007), it was found that “These two systems are not mutually exclusive, but they interact with each other on many levels. People choose which system to utilize according to types of symptoms, etiology of illness, its nosology, and the reputation and effectiveness of each health care system in relation to specific diseases.” In another study from Peltzer and Simwaka (1997) results showed that “a patient may even shift back and forth between the two systems during the course of a single episode of illness, depending on the progression of the illness and the efficacy of the medical procedures applied to it.”

In Fisher’s 2017 Northern Malawi community members study, 80% of the women interviewed cited at least one problem when accessing formal healthcare. Frequent problems noted in Fisher’s (2017) study consisted of: distance and transportation to health care facilities, the cost of treatment, and the lack of availability of healthcare providers (Fisher et al., 2017). The Malawian government acknowledges these difficulties and has “taken steps to reduce the financial burden associated with seeking medical care by establishing a comprehensive, free health care system” (Fisher et al., 2017). However, despite best efforts, as of 2010 there were only 444 governmental health care facilities in Malawi, and health personnel remain limited, posing a significant challenge to these policies. The WHO estimated Malawi population to be 17 million in 2015 (“WHO: Malawi Country Statistics”, 2015). Based on this population, each facility

is estimated to be providing care for more than 38,000 people. In Fisher's study it was found that transportation was notably one of the biggest barriers to accessing healthcare and could be perceived as directly related to increased mortality. It is suggested that in order to increase the use of the formal healthcare sector, structural approaches are needed to mitigate this barrier (Fisher et al., 2017). Although these findings focus on the formal healthcare system, another factor influencing healthcare provision in Malawi is the informal sector of traditional healers.

### **Traditional Healers**

The provision of culturally relevant and effective healthcare services necessitates consideration and recognition of traditional beliefs of healing and sickness ("ASHA: Preferred Practice Patterns for the Profession of Speech-Language Pathology", 2004). Traditional healing has been practiced for centuries in Malawi. According to Simwaka et al. (2007) it is estimated that 80 percent of the population uses traditional healers for medical health concerns and needs. Traditional healers use medicine in a holistic approach, taking into account the "physical, mental, psychological, social, and spiritual aspects of an individual and factors contributing to illness" (Simwaka, et al., 2007). The Malawian Theory of Illness takes into account the spiritual aspect of care. This theory attributes health problems to three different influences: a supreme being (God), the ancestors (spirits of the dead), and witches (Simwaka, et al., 2007). Witches or witchcraft is believed to be the most common cause of illness amongst the three according to rural Malawians. If an illness is not responding to treatment (home remedies, western medicine, or herbal medicine), many believe determining the type of witchcraft or the witch who is doing the bewitching will be the only way to heal the illness.

Deceased ancestors are also held accountable for sending illness to their living relatives. The spirits of deceased ancestors are primarily concerned with either protecting or disciplining their living relatives. It is believed that if ancestors have sent an illness to their family member, it is because the family member has erred in some way. This could be due to many factors, but a few are thought to be because an individual (1) did not observe taboos, (2) may have disrespected a senior, or (3) may have neglected an important ritual that marks life cycle points. Common healing practices include dancing, incantations, prayer, induction of trances, and some exorcisms (Simwaka, et al., 2007). When the root cause of an illness is determined by traditional healers to be due to a mechanical or physical injury instead of spiritual reasons, healing practices include the application of remedies of herbal, animal, or mineral origin (Simwaka, et al., 2007). In addition to acknowledging the different branches of healthcare in Malawi, it is important to understand how disability plays a role in service provision.

### **Role of Disability**

When an individual's swallowing mechanism is compromised, it can heavily impact their day to day life. The individual may not be able to participate in community activities revolving around mealtimes. In some cultures, this is a very important component to being an active member of the community, and having a compromised swallow can be seen as a disability. In a study on perspectives of disability, Stone-MacDonald and Butera (2007) reported that "attitudes towards people with disabilities in East Africa have both positive and negative aspects." For example, they noted that some Northern Tanzanians believe a disabled individual satisfies the interests of evil spirits. Therefore, members of the community will protect and care for the disabled in order to

appease the evil spirits (Stone-MacDonald & Butera, 2007). By doing so, they believe they are able to maintain and preserve the current balance needed in life. Generally speaking, Stone-MacDonald and Butera (2007) stated that individuals in East Africa are categorized by how well they can integrate into social and communal life. Therefore, disabled individuals who can participate in important rituals (i.e. coming of age ceremonies, marriage, and childbearing) are more likely to be accepted by their community. But, those who cannot partake in these rituals, may experience isolation and ridicule. Stone-MacDonald & Butera (2007) observed that some East Africans feel that those with physical disabilities could be productive members of society if they are properly trained, but others feel that training is a waste of time. Overall, if those who are disabled are able to participate in community events and can contribute economically, they (and their families) are more accepted in the community (Stone-MacDonald, & Butera, 2007).

Cultural considerations need to be taken into account in service provision, but it is equally as important to provide a standard of care to all patients. In the US, SLPs follow the position statement regarding evidence-based practice written by ASHA (“ASHA: Evidence Based Practice”, 2015). This defines evidence-based practice to be “an approach in which current, high-quality research evidence is integrated with practitioner expertise and client preferences and values into the process of making clinical decisions” (“ASHA: Evidence Based Practice”, 2015).

### **US Standard Treatment for Dysphagia**

SLPs in the US follow a standard of care in the evaluation, assessment, and treatment of patients with feeding/swallowing disorders. This includes the

recommendations of diet modifications and use of compensatory strategies in treatment. Diet modifications are customary for treating and managing individuals who have dysphagia or a swallowing disorder (“ASHA: Adult Dysphagia: Treatment”, n.d.). These modifications can consist of thickening liquids, or manipulating solid food textures. Liquids can be altered to ultra-thin, thin, nectar, honey, and pudding-thick consistencies. Solid foods can be pureed, mechanically chopped, or mechanically softened. In some cases, certain food textures can be eliminated entirely. In most severe cases of dysphagia, a patient can be placed on an NPO (nothing by mouth) diet. This means that it is unsafe for the patient to take any foods or liquids orally, as they are at a high risk for aspiration. Instead, patients can receive an NG (nasogastric) or G (gastric) tube to satisfy proper hydration and nutrition needs. This is a tube that is passed either through the nose and down through the nasopharynx and esophagus into the stomach or is directly inserted into the abdomen and into the stomach in order to deliver nutrition to the patient (Groher & Crary, 2016).

In addition to diet modifications, SLPs use compensatory strategies to help aid with the treatment of dysphagia (“ASHA: Adult Dysphagia: Treatment”, n.d.). These strategies aim to strengthen and improve a patient’s swallowing mechanism. Evidence-based compensatory strategies include the Mendelsohn Maneuver, Effortful Swallow, Tongue-hold Maneuver, and postural adjustments (Groher & Crary, 2016).

The Mendelsohn Maneuver is a compensatory strategy used for patients who demonstrate bolus transfer difficulties (Groher & Crary, 2016). It is designed to elevate the larynx and open the esophagus by having the patient touch their Adam’s apple or voice box with their fingertips. They are instructed to feel their voice box lift up and fall

when they swallow. Next, they are asked to “hold” their swallow when their Adam’s apple is elevated for a few seconds before completing the swallow. The patient should repeat this exercise 5-10 times daily or as instructed by the clinician (Groher & Crary, 2016).

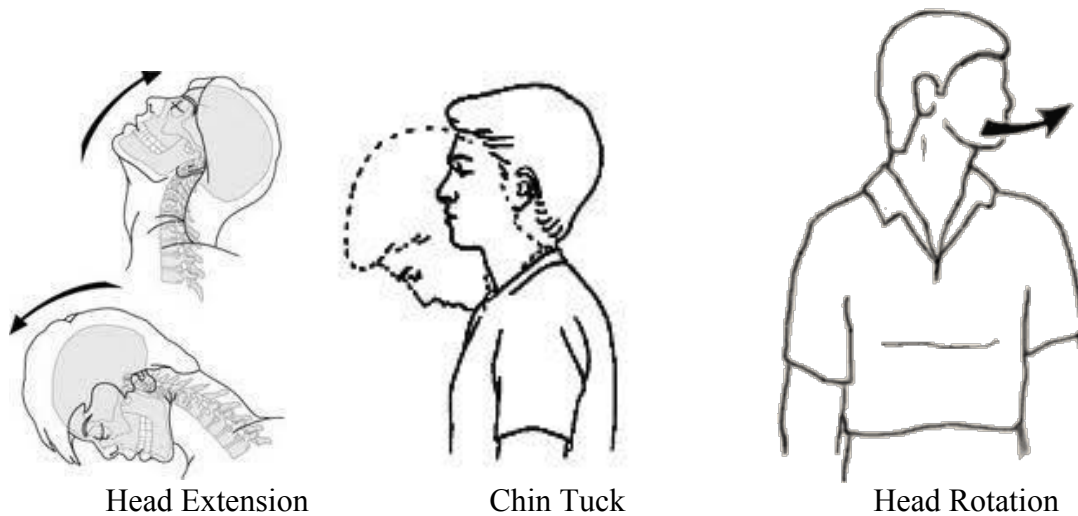
The Effortful Swallow is a compensatory strategy designed to improve airway protection and reduce residue in the larynx (Groher & Crary, 2016). The patient is instructed to pretend to swallow something large, like a grape or big capsule, without any liquid. The premise of this exercise is that the motor neurons recruited for the swallow will increase the demand on the muscles involved, and thus begin to train and strengthen the muscles involved in increasing airway closure, the duration of hyoid excursion, tongue-palate pressure, and the duration of pharyngo-esophageal sphincter (PES) opening (Groher & Crary, 2016).

The Tongue-Hold Maneuver is a compensatory strategy aimed at supporting patients with reduced anterior movement of the posterior pharyngeal wall (Groher & Crary, 2016). This maneuver teaches patients to increase movement of the posterior pharyngeal wall to compensate for a reduction in tongue base-pharyngeal wall contact by having the patient place the anterior tip of their tongue between their lips or teeth. Next, the patient is instructed to hold their tongue between their lips/teeth while producing a dry swallow. This maneuver increases anterior movements of the posterior pharyngeal wall during swallowing which encourages movement of the bolus.

Postural adjustments of the head are compensatory strategies a patient can use to help redirect the position of the bolus in the oral cavity and pharynx. The “Head Extension” is a postural adjustment in which the patient raises their chin, allowing the



oropharynx to widen. This movement is designed to help move the bolus from the mouth into the pharynx when oral or lingual deficits are present. The “Chin Tuck” is when the patient is instructed to tuck their chin in towards their neck/chest in order to improve airway protection during the swallow. Lastly, the “Head Rotation” is a postural adjustment used in cases where there are hemilateral impairments. The patient is asked to turn their head toward the weaker side during the swallow. As the result, this rotation causes a narrowing or closing off of the swallowing tract on the side toward which the head is turned (Groher & Crary, 2016). SLPs use compensatory strategies in their standard care in addition to diet modification in order to help make improvements for their patient’s swallowing mechanism. Below in Figure 2 are images to help depict the postural adjustments.



*Figure 2:* Representations of postural adjustments such as the head extension, (“Contact Sports and Head Injuries”, n.d.) chin tuck, (“Stretching Exercises for Chronic Neck Pain”, n.d.) and head rotation (“Stretching Exercises for Women”, n.d.).

Ashford et al. (2009) conducted an evidence-based systematic review on dysphagia behavioral treatments. They found that compensatory strategies like the Mendelsohn Maneuver, Effortful Swallow, and Postural Adjustments have “physiological

evidence to support the existing hypotheses regarding the role of each intervention in treating specific aspects of dysphagia” (Ashford et al., 2009).

Dysphagia can be classified into different severities (O’Neil, Purdy, Falk, and Gallo, 1999). For simplicity reasons, the present study refers to dysphagia as being classified into three broad categories: mild, moderate and severe. The table below describes these three distinct categories adapted from “The Dysphagia Outcome and Severity Scale” (O’Neil, 1999).

Table 1

Recommendations for Dysphagia Severity

Severity of Dysphagia	Description
Mild	<p>Patient needs distant supervision. Patient may need one diet consistency restricted for either liquids or solids.</p> <p>Examples of solids would be: meats and vegetables are cooked until soft, and are not tough or stringy.</p> <p>Examples of liquids would be thickening liquids to a consistency similar to nectar.</p>
Moderate	<p>Patient needs total assistance, supervision, or strategies. Two or more diet consistencies may be restricted.</p> <p>Examples of solids would be: meats chopped or ground, vegetables are of one consistency (baked potato, soufflé) or are mashed with a fork.</p> <p>Examples of liquids would be thickening liquids to a consistency similar to honey (mild-moderate) or pudding (moderate-severe).</p>

Severe

NPO. Patient is unable to tolerate any diet safely. NG or G tube would be other alternatives to feeding.

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### **Need for External Support for Low Middle Income Countries**

Developed countries, such as the U.S., have standards of care (as outlined above for dysphagia) for service provision. Many professionals have the desire to improve healthcare services in low and middle income countries, and Malawi is no exception. In a study of understanding the barriers to setting up healthcare in resource-limited settings, Agyeman-Duah et al. (2014) found that Malawi is “hampered by a chronic lack of resources, severe human resource deficiencies, and inadequate material resources essential for healthcare” (Agyeman-Duah, 2014). Prior to the study conducted by Agyeman-Duah et al., (2014) at the Medical Department, Kamuzu Central Hospital in Lilongwe, the management and medical staff expressed concerns that they were not performing up to expectations of a leading referral hospital, as well as meeting standards for teaching medical interns and clinical officers (Agyeman-Duah et al., 2014). In their study, Agyeman-Duah and colleagues reported that “staff performance, patient focus, shortage of drugs, long waiting times, whom-you-know service, and poor amenities in the department” as areas in which they thought were problematic in the department. Currently there are many NGOs in Malawi that are aimed to help. The Council for Non Governmental Organisations in Malawi (CONGOMA) aims to “provide a sharing and reflection platform for NGOs to influence governance and development processed in Malawi and enhance their operating environment” (“CONGOMA: Vision & Mission”, 2000). The CONGOMA’s website provides an updated list of running NGOs in the

country. (Refer to Appendix G for a list of NGOs that can tailor to the aid patients with feeding and swallowing disorders or to the education of healthcare providers).

## **Conclusion**

There are currently no studies focusing on feeding and swallowing disorders in Malawi. Survey and interview responses of this pilot study provide a baseline of the current treatment strategies used for feeding and swallowing disorders in Malawi. It also provides a descriptive analysis pertaining to the patterns and themes in the delivery of patient care, within the social context of the country.

The aim of this research was to collect information from Rehabilitation Technicians and other service providers in Malawi, regarding the provision of services to patients or clients who have feeding and/or swallowing problems. A survey was administered to capture respondents' occupation and demographic information, personal opinions and experiences regarding dysphagia and feeding/swallowing, and the current knowledge and practices surrounding the management of feeding and swallowing disorders in Malawi.

Results of this survey provide insight into the types of providers who encounter feeding/swallowing disorders, the frequency with which the different phases of dysphagia were observed, providers' views on their role/responsibilities towards treating feeding/swallowing disorders, confidence in their ability to treat and manage feeding/swallowing disorders, the difficulties they encounter, the current resources and support available, and how environmental factors such as the community, religion, and family members affect service provision.

The aims of this study were to expand our understanding of current management and treatment of feeding/swallowing disorders in Malawi and to educate other healthcare providers about the current needs in this specific field.

## Method

### Ethics

Prior to the initiation of this study, approval from Arizona State University's Institutional Review Board and the National Health Sciences Research Committee in Malawi were obtained. (See Appendices A and B). Participants provided informed consent before taking part in the study. (See Appendix C).

### Procedure

**Study Setting.** This study was conducted in Blantyre, Malawi. Malawi is a landlocked country located on the southeastern region of the African continent. Data collection occurred at Queen Elizabeth Central Hospital, as well as in rural communities near Blantyre, such as Zomba. Below in Figure 3 is a geographical map of Malawi.

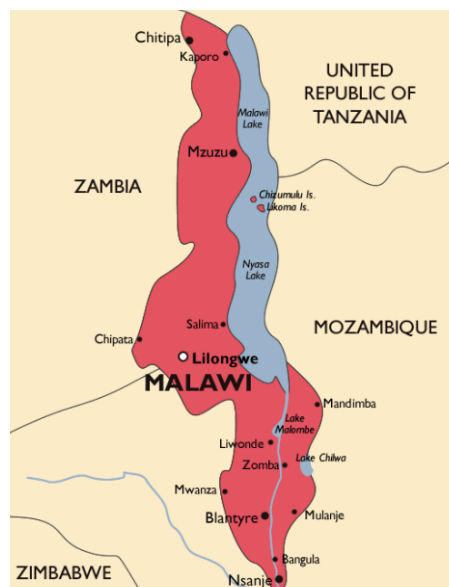


Figure 3: Map of Malawi (red) in south east Africa, highlighting areas of data collection in Blantyre and Zomba (“Fit for Travel”, n.d.).

**Participants.** There were a total of 5 participants in this study. Inclusion criteria included experience in assessing and treating patients with feeding or swallowing difficulties as well as proficiency reading/writing/speaking English (and their native language). This was confirmed by self-report. Participants were recruited by word of mouth, and referrals from other participants. Recruitment flyers were left at Queen Elizabeth Central Hospital in Blantyre to recruit more respondents. (Appendix D). The setting varied by respondent, with three participants completing the survey and interview in a quiet room. One participant was administered the survey and interview at her front desk in the children’s ward of the hospital. Another participant was administered the survey and interview in a public setting (during an outreach clinic). Table 2 below shows the participant demographics in this study

Table 2

Participant Demographics					
Participant	Gender	Age	Occupation	Time in Occupation	Years Spent Training for Profession
A	Male	35	Otolaryngologist (ENT)	4 years	3 years
B	Male	26	Rehabilitation Technician	3 years	3 years
C	Female	29	Audiology Technician (former nurse)	5 months	1 year
D	Female	48	Nurse Midwife Technician	20 + years	3 years
E	Male	24	Registered Nurse/Manager of Nutrition Ward	1 year	4 years

***Participant A.*** Participant A, a 35-year-old male, was working as an Otolaryngologist (ENT) at Queen Elizabeth Central Hospital in Blantyre, Malawi. He has been working in this field for four years and reports schooling took him 3 years before receiving his diploma as an ENT. Participant A described his job responsibilities as “doing surgeries” such as adenoidectomies, tonsillectomies, thyroidectomies, as well as performing foreign body removals, counseling of patients, hearing aid programming, and ear wax removals. At the time of the study, Participant A estimated 10 clients on his caseload with mild dysphagia, 11 clients with moderate dysphagia, and 7 clients with severe dysphagia. He reported that most of his clients have difficulties in the oral preparatory, pharyngeal, and esophageal phases of the swallow. He did not report ever seeing a client experience difficulty in the oral transit phase of the swallow.

***Participant B.*** Participant B, a 26-year-old male, was working as a Rehabilitation Technician focusing on treating speech and language disorders at Able Kids in Blantyre, Malawi. He has been working in this field for three years and reports schooling took him 3 years before receiving his diploma. Participant B described his job responsibilities as doing assessments, creating reports and therapy goals, conferring with school teachers and parents, conducting school visits, home visits, doing therapy, and speaking with medical professionals. At the time of the study, Participant B reported that of his clients with feeding and swallowing difficulties, most of his clients have mild dysphagia, some have moderate dysphagia, and none of his clients have severe dysphagia.

***Participant C.*** Participant C, a 29-year-old female, was working as an Audiology Technician at Queen Elizabeth Central Hospital in Blantyre, Malawi but had previously

worked as nurse at the same hospital. She had been working in this field for 5 months and reported schooling took her 1 year before receiving her diploma. Participant C described her job responsibilities as taking a client history, examining the patient, addressing areas of concerns, and treating the client's current ailments. At the time of the study, Participant C estimated 10 clients on her caseload with mild dysphagia, 15 clients with moderate dysphagia, and 5 clients with severe dysphagia. She reported that most of her clients have difficulties in all phases of the swallow. Participant C did not complete all components of the survey.

***Participant D.*** Participant D, a 48-year-old female, was working as a Midwife Nurse Technician at the Mlambale Hospital in Blantyre, Malawi. She had been working in this field for over 20 years. Participant D described her job responsibilities as gathering reports from managing staff, preparing the ward, instructing clients to make their beds, administering medicines, initiating rounds, taking blood samples, fulfilling doctors' orders, writing down drug orders in the records books, bringing drug orders to the pharmacy, checking blood sugars for those clients with diabetes, and writing reports about her patients at the end of the day. Participant D reported that most of her clients had difficulties in the all phases of the swallow and reported frequently seeing clients with mild, moderate, and severe dysphagia.

***Participant E.*** Participant E, a 24-year-old male, was working as a manager in the Nutritional Ward at Queen Elizabeth Central Hospital in Blantyre, Malawi. He had been working in this field for four years and reported schooling as a Registered Nurse took him 4 years before receiving his diploma. Participant E described his job responsibilities as overseeing the ward, management of the patients, management of the people,



collecting and checking inventory, and making sure orders are done properly. Participant E reported prioritizing his main focus on his patients. He worked with children ages 6 months to 17 years in the ward. At the time of the study, Participant E estimated 19 clients on his current caseload with feeding or swallowing problems. Of these 19, he estimates 5 of the patients have cerebral palsy. He reported that most of his clients have difficulties in the oral preparatory phase, oral transit phase, pharyngeal stage, and reported that it is difficult for him to know whether or not a client is experiencing difficulties during the esophageal phase of the swallow.

**General Design.** The study included two-parts: a written survey completed by the participant, and an interview between the participant and investigator. The survey was composed of six parts, described in the table below.

Table 3

Survey Outline		
Section	Format	Description
Part 1	Fill-In	Demographic information on participants.
Part 2	Fill-In	Current caseload, types of dysphagia patients seen, basic understanding of feeding/swallowing difficulties.
Part 3	Likert Scale	Participants indicated their opinion on proposed statements.
Part 4	Likert Scale	Participant indicated their experiences/perspectives on proposed statements.

Part 5	Free Response/Interview	Knowledge of dysphagia treatment across severities.
Part 6	Check-Box	Participants indicated what areas they would like more information/training in.

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Total time spent on the study was approximately one hour per participant. The experimenter provided each participant an informed consent form, and a copy of the approval forms from Arizona State University’s Institutional Review Board and the National Health Sciences Research Committee in Malawi. Additionally, the experimenter explained that the purpose of this study was for partial fulfillment of a Masters student thesis, and that there would be no incentive in choosing to participate. Participants were handed a laminated copy of the survey and an EXPO marker to record their answers. In section 5 of the survey, participants could decide whether to write out responses to proposed questions, or were allowed to verbally answer the questions while being audio recorded. Throughout the study, participants were encouraged to ask clarifying questions, and could decide to withdraw during the study at any time.

**Data Analysis**

Responses collected from Part 3 and Part 4 of the survey were collapsed and analyzed into six different categories: Perception of Job Responsibilities, Confidence in Treatment Abilities, Difficulties Encountered, Availability and Adequacy of Resources and Support, Health Provider’s Concern for Client, and Community, Family, and Others’ Influence. Participants were asked to rate on a Likert scale (Strongly Disagree, Disagree, Neutral, Agree, or Strongly Agree) or (Never, Almost Never, Sometimes, Very Often, or Almost Always) to statements pertaining to the six categories above. Results were

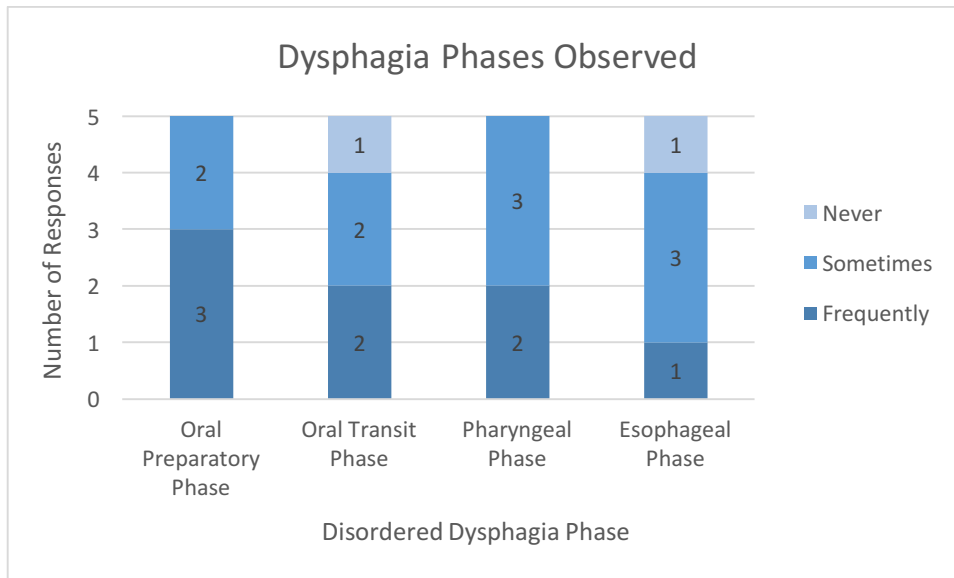
calculated by frequency of responses in each Likert scale rating and categories which showed common themes, were then converted into proportions.

Part 5 of the survey was the interview/free response portion. Participants responded to several questions pertaining to their knowledge and practice of treating feeding/swallowing disorders. Responses were reviewed and analyzed on an individual basis due to diverse answers. Answers were scored as correct or incorrect according to the professional judgement of two US graduate student clinicians with graduate level coursework in swallowing disorders, and Malawian culture. Inter-rater reliability of responses was above 95%.

## **Results**

### **Caseload Observations**

In the survey, participants were asked to indicate the how often they encountered each disordered phase(s) of the swallow (frequently, sometimes or never). Three out of the five participants listed the oral preparatory phase as the most frequently observed phase. Three out of five participants also listed the pharyngeal and esophageal phases of the swallow as a common area of difficulty observed. Figure 4 below depicts the frequency at which each phase was reported.



*Figure 4:* Frequency of times respondents reported observing different disordered phases of the swallow.

Participants of this survey encountered patients experiencing difficulties in all phases of the swallow, the most common being the oral preparatory phase of the swallow. Respondents mentioned that common medical diagnoses or concerns they encounter when patients exhibit swallowing difficulties are: tonsillitis, thyroidectomies, fever, weight loss, lung infections, speaking difficulties, dehydration, malnutrition, Cerebral Palsy, pneumonia, chronic coughing, and aspiration. Symptoms that patients present with that led participants to believe they have dysphagia are: vomiting, coughing, choking, crying, drooling, weight loss, minimal bolus control in the oral cavity, inability to keep the mouth closed, history of lung infections, as well as patients' self-reports of painful swallowing.

## Opinion and Personal Experience Ratings

**Perception of responsibility.** Participants were asked to indicate on a Likert Scale their opinions on the below statements. Tables 4a, 4b, 4c, and 4d correspond to the five participants' responses to each of the four questions in this category.

1. It is my responsibility to help children and adults who have swallowing and/or feeding problems manage their eating.

Table 4a

Responsibility to Help Clients Manage Eating					
Likert Rating:	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Frequency Count:			1	1	3

2. It is my responsibility to obtain training necessary to achieve competency in dysphagia intervention.

Table 4b

Responsibility to Obtain Training					
Likert Rating	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Frequency Count			1		4

3. Managing feeding and swallowing problems should be a part of my job.

Table 4c

Managing Feeding/Swallowing should be a part of my Job					
Likert Rating	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Frequency Count		1		1	3

4. I am interested in increasing my knowledge in the area of dysphagia intervention.

Table 4d

Desire to Increase Knowledge					
Likert Rating	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Frequency Count			1	1	3

Below in Figure 5 is a combination of all participants' responses to questions addressing perceived responsibility.

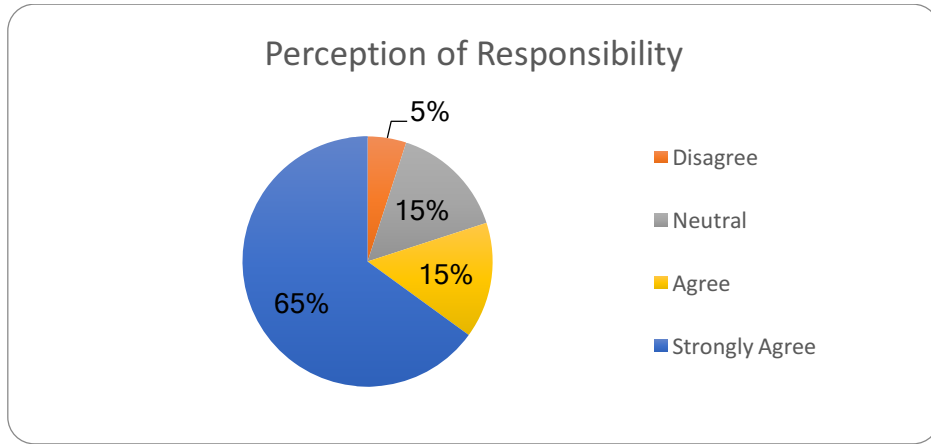


Figure 5: Proportion of times respondents selected each category on the Likert scale, for questions addressing perceived responsibility.

There were no responses given for the Likert scale rating *Strongly Disagree*.

Overall, participants reported a strong feeling of responsibility toward managing swallowing concerns in their patients.

**Confidence in treatment abilities.** Participants were asked to indicate on a Likert Scale their opinions on the below statements:

1. I feel confident in my ability to provide dysphagia intervention to children with swallowing and/or feeding disorders.

2. I feel confident in my ability to provide dysphagia intervention to adults with swallowing and/or feeding disorders.

Results are shown for each participant, to show the difference between the confidence levels of each respondent. Responses were given a numerical value (*Strongly Disagree:1, Disagree:2, Neutral: 3, Agree: 4, and Strongly Agree:5*). Response values for the above two statements were averaged to create a confidence rating per participant. The results are below in Table 5.

Table 5

Average Perceived Confidence Ratings in Treatment Abilities	
Participant	Average Confidence Rating (1-5 scale)
Midwife Nurse	5
Otolaryngologist (ENT)	4.5
Audiology Technician	3
RN/Manager of Nutrition Ward	3
Rehabilitation Technician	2

Confidence in treatment abilities varied across the different occupations surveyed. Those whose job descriptions/responsibilities include direct treatment of feeding/swallowing disorders did not necessarily report a higher confidence rating. The only participant who differentiated his treatment confidence when serving children and adults was the Otolaryngologist. The ENT reported he felt more confident in his treatment abilities pertaining to children than adults. All other participants in this study gave equal confidence ratings for the treatment of children and adults.

**Difficulties encountered.** Participants were asked to indicate on a Likert Scale their opinions on the below statements. Tables 6a, 6b, 6c, and 6d correspond to the five participants' responses to each of the four questions in this category.

1. When working with your clients who have feeding or swallowing problems how often have you had difficulties preparing liquids and food the “correct” way.

Table 6a

Difficulty Preparing Liquids and Foods					
Likert Rating	Never	Almost Never	Sometimes	Very Often	Almost Always
Frequency Count	1	1	2		1

2. When working with your clients who have feeding or swallowing problems how often have you had difficulties feeding the client because you don't know how best to prepare the liquid/food.

Table 6b

Difficulty Feeding Clients					
Likert Rating	Never	Almost Never	Sometimes	Very Often	Almost Always
Frequency Count	2	2	1		

3. When working with your clients who have feeding or swallowing problems how often have you had difficulties feeding the client because they refuse to eat the foods or liquids you recommend.



Table 6c

Clients Refuse Foods of Liquids					
Likert Rating	Never	Almost Never	Sometimes	Very Often	Almost Always
Frequency Count			2	2	1

- When working with your clients who have feeding or swallowing problems how often have you had difficulties feeding the client because other family members or service providers have different opinions about feeding the client.

Table 6d

Differing Opinions					
Likert Rating	Never	Almost Never	Sometimes	Very Often	Almost Always
Frequency Count	1	1	2	1	

Responses fluctuated across the spectrum, with the most frequent response given as “Sometimes” encountering difficulties. No single difficulty stood out as a common problem for the participants taking the survey.

**Availability of resources and support.** Participants were asked to indicate on a Likert Scale their opinions on the below statements. Tables 7a, and 7b correspond to the five participants’ responses to the two questions in this category.

- Due to a patient’s/client’s feeding and swallowing difficulties how often have you found it hard to get help from others.

Table 7a

Difficulty Getting Help					
Likert Rating	Never	Almost Never	Sometimes	Very Often	Almost Always
Frequency Count	2	1	2		

2. Due to a patient's/client's feeding and swallowing difficulties how often have you found it hard to provide services to the client and the client's family.

Table 7b

Difficulty Providing Services					
Likert Rating	Never	Almost Never	Sometimes	Very Often	Almost Always
Frequency Count			3	2	

Participants felt they sometimes encountered difficulties with the availability of resources and support. More specifically, participants felt that it was “harder” to provide services to the client and the client's family, and found it “easier” to get help from others.

**Adequacy of resources and support.** Participants were asked to indicate on a Likert Scale their opinions on the below statements. Tables 8a, 8b, and 8c correspond to the five participants' responses to each of the three questions in this category.

1. I have adequate tools and resources to provide intervention to patients who have feeding or swallowing problems.

Table 8a

Adequate Tools and Resources					
Likert Rating	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Frequency Count	3	2			

2. I have adequate time to provide dysphagia intervention to patients with feeding or swallowing problems.

Table 8b

Adequate Time					
Likert Rating	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Frequency Count	2	1		1	1

3. My supervisor and colleagues support my efforts to provide dysphagia intervention.

Table 8c

Support for Providing Dysphagia Intervention					
Likert Rating	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Frequency Count				2	2

Participant C omitted one answer from this category. A breakdown of the combined results in this category is below in Figure 6.

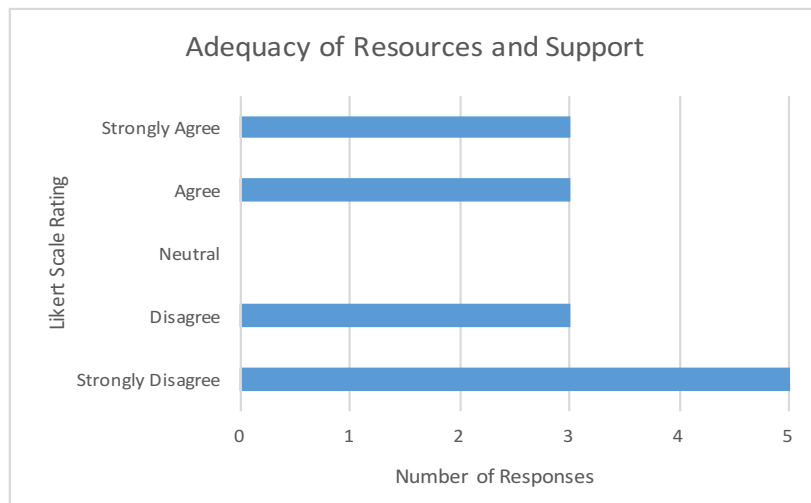


Figure 6: Frequency of times respondents selected each category on the Likert scale, for questions addressing adequacy of resources and support.

The data above shows a bimodal response. Participants felt they did not have the adequate tools and resources to provide intervention, but felt they did have support from their supervisors and colleagues to provide dysphagia intervention. Generally, participants did not agree or disagree with having adequate time to provide services to those with feeding or swallowing problems.

**Health provider’s concern for client.** Participants were asked to indicate on a Likert Scale their opinions on the below statements. Tables 9a, 9b, 9c, 9d, 9e, and 9f correspond to the five participants’ responses to each of the six questions in this category.

1. Due to a patient’s/client’s feeding and swallowing difficulties how often have you worried about your client’s general health.

Table 9a

Worried About Client’s General Health					
Likert Rating	Never	Almost Never	Sometimes	Very Often	Almost Always
Frequency Count				3	2

2. Due to a patient’s/client’s feeding and swallowing difficulties how often have you worried your client is not receiving adequate nutrition or hydration.

Table 9b

Worried About Nutrition and Hydration					
Likert Rating	Never	Almost Never	Sometimes	Very Often	Almost Always
Frequency Count				2	3

3. Due to a patient’s/client’s feeding and swallowing difficulties how often have you worried about your client’s breathing.

Table 9c

Worried About Client's Breathing					
Likert Rating	Never	Almost Never	Sometimes	Very Often	Almost Always
Frequency Count			1	2	2

4. Due to a patient's/client's feeding and swallowing difficulties how often have you worried that your client will choke while eating or drinking.

Table 9d

Worried About Choking					
Likert Rating	Never	Almost Never	Sometimes	Very Often	Almost Always
Frequency Count	1				4

5. Due to a patient's/client's feeding and swallowing difficulties how often have you worried that your client will develop pneumonia.

Table 9e

Worried About Developing Pneumonia					
Likert Rating	Never	Almost Never	Sometimes	Very Often	Almost Always
Frequency Count	1				4

6. Due to a patient's/client's feeding and swallowing difficulties how often have you worried that you aren't doing enough for your client.

Table 9f

Worried You Aren't Doing Enough					
Likert Rating	Never	Almost Never	Sometimes	Very Often	Almost Always
Frequency Count	1		2	1	1

A breakdown of the combined results in this category is below in Figure 7.

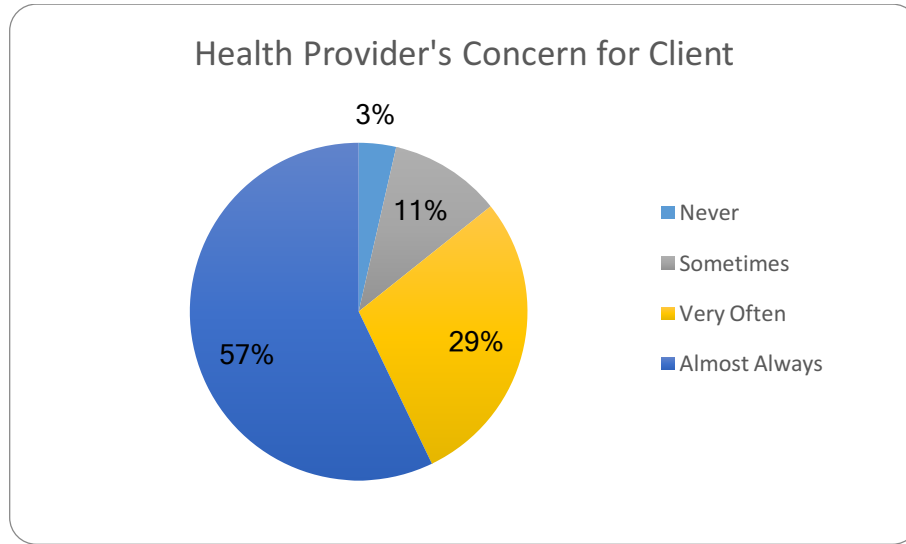


Figure 7: Proportion of times respondents selected each category on the Likert scale, for questions addressing health providers' concern for their clients.

There were no responses given for the Likert scale rating *Almost Never*. Overall, participants identified as having a strong concern for their clients.

**Community, family, and others' influence.** Participants were asked to indicate on a Likert Scale their opinions on the below statements. Tables 10a, 10b and 10c correspond to the five participants' responses to each of the three questions in this category.

1. Due to a patient's/client's feeding and swallowing difficulties how often have you worried about how others will react towards your client.

Table 10a

Reactions Towards Clients					
Likert Rating	Never	Almost Never	Sometimes	Very Often	Almost Always
Frequency Count	1		1	2	1

2. Due to a patient's/client's feeding and swallowing difficulties how often have you worried about how your client's feeding/swallowing affects their immediate family/community members.

Table 10b

Family/Community Stipulations					
Likert Rating	Never	Almost Never	Sometimes	Very Often	Almost Always
Frequency Count			1	2	2

3. Due to a patient's/client's feeding and swallowing difficulties how often have you worried about your client receiving adequate help and support from family members.

Table 10c

Client Receiving Help/Support from Family					
Likert Rating	Never	Almost Never	Sometimes	Very Often	Almost Always
Frequency Count			1	1	3

A breakdown of the combined results in this category is below in Figure 8.

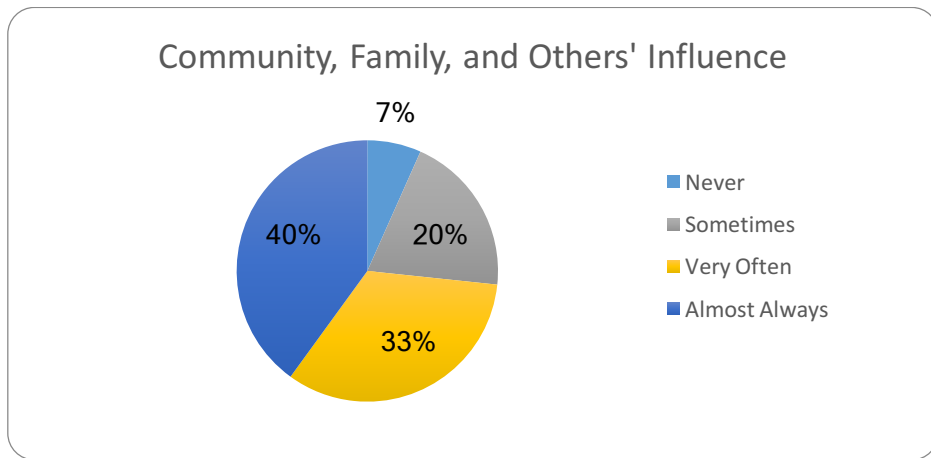


Figure 8: Proportion of times respondents selected each category on the Likert scale, for questions addressing community, family and others' influence on clients.

There were no responses given for the Likert scale rating *Almost Never*. Overall, participants worried about how their patients' community and family members will respond to the diagnosis of a feeding/swallowing disorder.

**Participant Knowledge of Clinical Practice Standards**

Participants were asked to provide their perception of swallowing capabilities across the different severities of dysphagia and their recommendation for treatment. Four out of the five total participants took part in this section of the study. Below is a table providing the number of accurate of responses as well as notable quotes during the interview. (Refer to Appendix F for US standard recommendations).

Table 11

**Participants' Treatment Recommendations for Mild, Moderate, and Severe Dysphagia**

Severity of Dysphagia	Swallowing Capabilities and Recommendations Meeting US Standards	Notable Quotes from Participants
Mild	Zero out of 4 Total Responses  (0/4)	<p>“The patient can withstand the pain and the food can pass through without any problem.”</p> <p>“The first stages of the swallow are adequate and the swallowing reflex will take care of the rest.”</p>
Moderate	Zero out of 4 Total Responses  (0/4)	<p>“Dysphagia is not all that severe, [the patient] can allow some food to pass.”</p> <p>“Moderate dysphagia clients will often be able to keep liquids in mouth and push it back to trigger a swallow.”</p>



Severe

Two out of 4 Total  
Responses  
  
(2/4)

“Swallowing is a reflexive ability [therefore food can pass].”

“They have restrictions, [it’s] difficult for fluids to come in, they just keep the food in their mouth and cannot swallow.”

“If they cannot eat/drink, there is not much to do, they will go[gestures about dying].”

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Upon reviewing participants’ responses regarding treatment of mild, moderate, and severe dysphagia, participants’ perceived confidence in treatment abilities was examined. The chart below depicts the degree to which the participants’ responses meet U.S. standards for treatment of mild, moderate, and severe dysphagia as compared to their perceived confidence in treatment abilities.

Table 12

Participant Treatment (Tx) Recommendations Compared to Confidence in Treatment Abilities

Participant	Proportion of Responses Meeting U.S. Standards for Tx in Mild, Moderate, Severe Dysphagia	Confidence in Tx Abilities (1-5 rating scale)
Nurse Midwife	1/3	5
Otolaryngologist (ENT)	0/3	4.5
RN/Manager of Nutritional Ward	1/3	3
Rehabilitation Technician	0/3	2

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Table displaying accuracy of treatment recommendations according to US standards, and perceived confidence in treatment abilities according to Likert scale ratings (one indicating low confidence, five indicating high confidence).

Confidence in treatment abilities did not correspond to knowledge of US treatment standards. The most confident participant gave only one treatment recommendation that meets US standards, and the second most confident participant gave zero treatment recommendations that align with US standards.

Additionally, during the free response/interview portion, participants were also asked what other strategies they use to help promote safe swallowing for their patients, where they seek additional resources for help treating feeding/swallowing disorders, and what cross-cultural challenges they have encountered while providing for their patients.

### **Other Strategies**

The four participants who took part in this portion of the interview mentioned various strategies they use to help promote safe swallowing for their patients. Most of these recommendations catered to their clients receiving proper nutrition and hydration needs. The ENT recommended that patients receive nutritious foods, are positioned correctly during instances of eating and drinking, and that some patients should receive an NG tube. The Rehabilitation Technician recommended that the patient sit upright and be alert when eating/drinking. The nurse midwife technician made similar recommendations as the ENT, stating that patients could receive an NG tube and should be fed nutritious foods. The manager of the nutrition ward emphasized the importance of making sure patients receive food containing properties of the 6 different food groups (dairy, grains, fruits, vegetables, sugars, and protein), and that you should feed the patient small bites when they are alert.

Overall, respondents recommended that patients should take small sips/bites when eating or drinking and to do so when alert, or sitting upright as other strategies to use when aiding a patient with feeding or swallowing concerns.

### **Seeking Additional Resources**

When asked where participants go in order to seek additional resources, almost all participants referred to one another as additional resources to use when they encounter feeding/swallowing disorders. Additionally, the Moyo Palliative Care Centre was recommended by the nurse midwife technician where children can be provided chiponde (a nutritious paste) according to their height and weight measurements. The Nutrition Manager referenced UNICEF (United Nations International Children's Emergency Fund) as a resource to obtain supplies, but notes that there is limited support for clients who have difficulties swallowing.

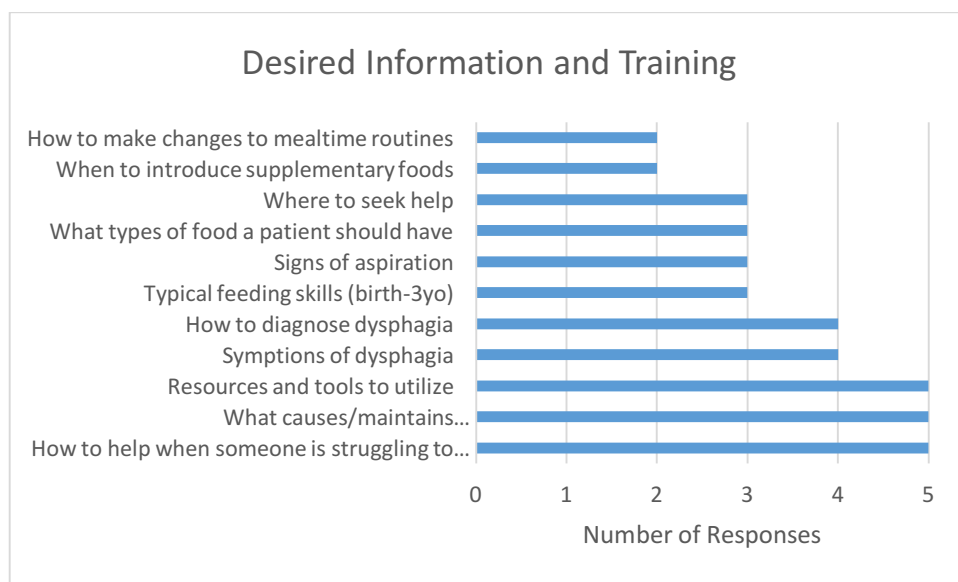
### **Cross-Cultural Challenges**

Participants listed some cross-cultural challenges they have encountered when providing services to their clients. The ENT referenced how some patients are not allowed to eat certain foods during specific religious holidays or periods of time (specifically Jewish holidays in which individuals are restricted from eating pork). The rehabilitation technician noted that some cultures are sensitive to how you approach a client if you are of the opposite sex (specifically if a male health provider were to touch a female client, she may feel uncomfortable). He says that this can make physical prompting difficult especially in cases of Cerebral Palsy. The nurse midwife expressed how some of her patients cannot cope with a dysphagia or feeding/swallowing diagnosis because they don't have enough food, or that they are unable to find food. Lastly, the

manager of the nutrition ward explained that there are “misconceptions or misunderstandings of the changes to swallowing. [There is a] lack of knowledge, and [clients] are unable to understand [the dietary changes needed to be made].” He mentions that community acceptance can be an issue for some patients with feeding/swallowing disorders. Additionally, there are sometimes different beliefs for why a child may exhibit a feeding/swallowing problem. “[Parents/caregivers] do not understand the pathology [which] leads to the mismanagements of the child. [The child may then] go to see a witch doctor.”

### **Inquiry for More Information**

At the end of the survey, respondents indicated whether or not they would like to receive more training or more information in various areas surrounding feeding and swallowing disorders. Below in Figure 9 is a graph depicting all areas of interest to the respondents. Two of the participants wrote in the survey that they would like further information for caregivers on “how to best take care of their children” and “other tools used for feeding of the patients and types of food and frequency of meals.”



*Figure 9:* Number of respondents who selected each category of information and training.

All participants wanted more information in resources and tools utilize, information on what causes and maintains feeding/swallowing disorders, and how to intervene when someone is experiencing swallowing difficulties.

### **Discussion**

This is the first known study of the treatment of feeding/swallowing disorders in Malawi. The survey gathered information on *who* treats feeding/swallowing disorders, their *experiences and opinions* regarding feeding/swallowing disorders, and their *knowledge* of diagnosis, treatment, and management of feeding/swallowing disorders in Malawi. The aim of this study was to provide a general baseline in hopes for promoting future research and support pertaining to those individuals with feeding and swallowing disorders in Malawi.

### **The Who**

Results of this study indicate that providers from various healthcare domains encounter and treat feeding/swallowing disorders. These occupations include but are not limited to, Otolaryngologists, Rehabilitation Technicians, Nurses, and even Audiologists. In western medicine, speech language pathologists are professionals who have specific training in the diagnosis, treatment, and intervention of feeding and swallowing disorders. Malawi currently does not have an education program dedicated to the speech language pathology profession, therefore many different occupations see and treat these types of patients. Malawi has the Clinical Rehabilitation Officer program, which was designed to provide healthcare professionals with a general training in rehabilitation/therapy. This program includes basic instruction for physical, occupational, and speech-language

therapy (Fielder, 2013). One of the participants from this study (Participant B) completed this program. He notes that most of his colleagues chose to pursue physical therapy upon completion of their degree. He further elaborated that he too, wanted to pursue physical therapy but was “coerced” by a New Zealand SLP to become a “speech pathologist” as there were so few in the country. Participant B credits most of his speech-language knowledge to his New Zealand mentor’s instruction and not the Clinical Rehabilitation Officer program in Malawi.

**Caseload.** From the five participants in this study, the most frequently reported disordered phase of the swallow was the oral preparatory phase. During this phase, the patient takes in the liquid or solid food and manipulates it into a bolus (Groher & Crary, 2016). This is the most visible phase of the swallow, and one that a trained healthcare provider can diagnose at a bedside swallow examination. Other phases of the swallow sometimes cannot be diagnosed at a bedside swallow exam due to the inability to see the anatomy and physiology of the swallow. In the United States, SLPs can use several exams in order to see these phases of the swallow, such as a MBS or FEES examination in order to accurately diagnose which phase of the swallow is disordered (“ASHA: Adult Dysphagia: Assessment”, n.d.). Participants in this study mentioned the use of a bedside swallow examination of their clients with swallowing difficulties, however, none of the participants referenced formal evaluations similar to a MBS/FEES. Therefore, even though the most frequently reported disordered phase of the swallow was the oral preparatory phase, other phases of the swallow may be equally as common, but are not diagnosed due to a lack of medical equipment and formal diagnostic and evaluative tools.

## **Experiences and Opinions**

Results of the participants' experiences and opinions show some general trends as well as some diverse viewpoints pertaining to their perceived responsibility, the adequacy and availability of resources and support, the difficulties they encounter, their general concern for their client as well as their clients' families/community, and their perceived confidence in treatment abilities.

**Perceived responsibility.** Overall, participants reported a strong sense of responsibility toward managing swallowing concerns in their patients. They felt strongly towards helping children and adults manage their eating, obtaining the training necessary to achieve competency in swallowing intervention, increasing their knowledge of feeding and swallowing disorders, as well as a strong sense that they should be providing services for these patients on their caseload. These results show that there are many different health care providers in Malawi who feel a professional responsibility and obligation towards diagnosing, treating, and managing patients with feeding or swallowing concerns.

**Availability of resources and support.** Participants did not indicate a strong agreement or disagreement towards their opinions regarding availability of resources. Generally, respondents felt they sometimes found it hard to get help from others, and sometimes found it hard to provide adequate services to the client and their families. This is interesting to note, since three out of five of the participants later indicated that they would like more information on where they can seek help in section 6 of the study.

When specifically asked where they go to seek additional resources or support, almost all respondents referenced one another. Meaning, that they would refer the client to the ENT, the Rehabilitation Technician, or to another department within a formal hospital setting. Additionally, one participant made reference to Moyo Palliative Care Centre, and another participant referenced UNICEF as outside organizations they could use for additional support. The Moyo Palliative Care Centre is an NGO based in Salima, Malawi where individuals who are suffering from HIV/AIDs, cancer, or other life-limiting illnesses can seek holistic palliative care (“Ndi Moyo – The Place Giving Life”, n.d).

There are many organizations that are designed to help provide resources, tools, and support to medical professionals, and those in medical need in Malawi. (Refer to Appendix G for a list of known NGOs in Malawi). The fact that only two of these organizations were mentioned by the participants in this study could mean that these organizations are not well known, are not advertised, or that they are not used due to confounding variables such as excessive travel, or costs. It could also indicate that these NGOs do not actually perform the services they aim to provide, or they only provide services when in country, or that they may not be training any healthcare workers in Malawi.

**Adequacy of resources and support.** Generally speaking, participants of this study had opposing viewpoints in the adequacy of resources and support. They felt they did not have adequate resources and tools to provide intervention, but they did feel they had adequate support from supervisors and/or colleagues. Participants had mixed reviews across the Likert scale as to whether they felt they had adequate time to provide feeding



and swallowing intervention. When asked if participants would like more information on resources and tools to utilize, all five participants indicated that they were interested.

**Difficulties encountered.** Responses towards participants' perceptions regarding the difficulties they encounter varied across the spectrum. Generally, participants felt that they sometimes had difficulties preparing liquids and foods correctly, that they sometimes experienced difficulties feeding the client because they refused to eat the recommended diet, and sometimes encountered difficulties because other family members or service providers held different or conflicting opinions about treatment. The nurse midwife recalled experiencing difficulties when providing diet recommendations to some families. She stated, "that some of her patients cannot cope with dysphagia or a feeding/swallowing difficulty because they do not have access to enough food at home or in their community, and that they may be unable to find food within their community." Another participant mentioned that very impoverished families may not be able to have the means to make nsima, due to a shortage. He stated, "If you don't have nsima for the day, then you haven't eaten at all." Nsima is a cooked ground white maize flour and is a staple in the country. It is a food that could be used as a treatment recommendation for mild and moderate dysphagia. This is because you can alter the consistency of nsima, and nsima is a very compactable food, similar to mashed potatoes. Responses to the proposed statements about diet modifications were not heavily weighed to either side of the Likert scale. This could be due to the fact that participants had little variation in diet modifications for their treatment recommendations of mild, moderate, and severe dysphagia and that a family's financial status may prevent them from following diet recommendations.

**Concern for clients and their family/community.** Participants showed a high concern for their patient's well-being, as well as a high concern for how the patient's family and community will cope with the patient's diagnosis of a feeding or swallowing disorder. Participants were concerned for their patients' general health, whether or not they were receiving adequate nutrition and hydration needs, whether or not they would choke/aspirate on liquids or food at home, their respiration capabilities, if they would develop pneumonia, and even felt that they, as healthcare providers, were not doing enough for their clients. Participants also expressed concern over how other individuals will react towards their clients with feeding/swallowing difficulties, and how these difficulties will affect their role and relationships within the family/community, and the amount of support they receive from their family and the community (Stone-MacDonald, & Butera, 2014). This corresponds to the concerns in which those with disabilities pose to their community as outlined in Stone-MacDonald and Butera's study in Malawi.

**Cross cultural challenges.** Taking cultural considerations into one's practice is an important factor in providing healthcare services. In the US, it is within an SLP's scope of practice to account for cross-cultural considerations ("ASHA: Scope of Practice in Speech-Language Pathology", n.d.). This is outlined in ASHA's code of ethics. For the purpose of future research, and any external service provision in Malawi, it is important for healthcare providers to learn of cross-cultural differences in order for them to be accounted for in service provision. A key factor in the progression of treatment of feeding/swallowing disorders is complying to the diet modification of the healthcare provider. If the caregivers or community members cannot comply to the

recommendations made for the patient, the patient could sustain a disabled swallow and suffer the social/emotional consequences of the community.

Three of the five participants described cross-cultural challenges they have encountered in their practice. The ENT noted that a patient's religion can have a direct effect on the treatment of those individuals with feeding or swallowing disorders. He stated that for individuals who abstain from eating particular foods (i.e. Jewish individuals abstain from pork) can make treatment recommendations harder, or that it is a factor to think about when making recommendations to the client. The Rehabilitation Technician noted that he had come across clients who felt uncomfortable about a health care provider of the opposite sex physically touching them. This is the case even for physical prompting, such as placing hands on an individual's chin to provide additional support while swallowing. Lastly the RN and manager of the nutritional ward mentioned the common belief that illness can be caused by witchcraft. As described by Simwaka, (2007) the Malawian Theory of Illness can be attributed to three different influences a God, ancestors, or witchcraft. Participant E of this study, mentioned that this is a common cultural belief he encounters when treating patients. He stated, "[Parents/caregivers] do not understand the pathology [which] leads to the mismanagement for the child. [The child may then] see a witch doctor [instead of seeking help from the formal healthcare system]." Peltzer and Simwaka (1997) claims that some individuals seeking help from healthcare providers don't necessarily care which sector they receive treatment from (formal or informal sector), but that other factors will influence their choice, such as access, transportation, and costs. Additionally, if the patient is not improving with care at one sector, they may seek help from the other sector (Simwaka, 2007). When providing

evaluations, assessments, and treatment for feeding and swallowing disorders it is important to consider all of the cross-cultural implications and how they will affect an individual's recommendations, service provision, and plan of care (“ASHA: Preferred Practice Patterns for the Profession of Speech-Language Pathology”, 2004).

**Perceived confidence in treatment abilities.** Confidence in one's ability to provide dysphagia treatment for adults and children varied within the different disciplines surveyed. The Nurse Midwife (Participant D) reported the strongest confidence. Of the five respondents, she has the most experience in her professional field, with over 20 years of experience. The next most confident participant was the Otolaryngologist, with 4 years of experience in his profession. All other participants had 3 years or less spent in their current occupation. Surprisingly, the least confident participant was the rehabilitation technician who had direct training from a New Zealand speech-language pathologist. It is noted from other sections of the study, that high confidence in treatment abilities did not correspond to high knowledge of “accurate” treatment of feeding and swallowing disorders, according to US standards.

### **Knowledge**

The four participants who completed section 5 of the study provided their current treatment recommendation for mild, moderate, and severe dysphagia. None of the participants gave treatment recommendations for mild and moderate dysphagia that would meet the minimum standard of care established in the US, and only two participants provided treatment recommendations for severe dysphagia that would meet US standards.

In western practices, individuals with mild dysphagia are recommended to have one or more diet consistency changes. This could be thickening liquids to a nectar-thick consistency, or softening solid foods (O'Neil et al., 1999). General safety precautions such as being alert, eating small bites, and drinking small sips in an upright position should be enforced. Participants in this study identified patients as being able to safely swallow all liquids and foods, without any diet consistency changes.

In moderate dysphagia, patients need supervision, diet consistency modifications, and compensatory strategies. Diet modifications can vary from recommending honey-thick to nectar-thick liquid consistencies. Meats should be ground or chopped, and vegetables should be pureed into one consistency (e.g. mashed potatoes) (O'Neil et al., 1999).

Compensatory strategies such as the Mendelsohn or Tongue-Hold Maneuver should be introduced to the patient in addition to following safe swallowing precautions (Groher & Crary, 2016). Incorporating compensatory strategies allows the patient to work on strengthening their muscles necessary for swallowing. Participants in this study indicated that there was no need for diet consistency modifications, and one participant made reference to the notion that patients will be able to manipulate the bolus to trigger a “swallow reflex.” This is an alarming statement as swallowing is not solely an involuntary skill. “Eating and swallowing are complex behaviors involving both volitional and reflexive activities of more than 30 nerves and muscles.” (Matsuo, & Palmer, 2008). Therefore, a patient will not be able to eat or drink safely if relying only on the reflexive skills of the swallowing mechanism.

In severe dysphagia, patients cannot safely swallow any liquids or foods. In their case, an NG or G tube may be needed to fulfill nutritional needs. To moisten the palate, and maintain oral hygiene, the patient requires supervision, for example, the SLP can feed the patient ice chips or given a dampened sponge to suck on (O'Neil, 1999). Two of the participants identified that patients should be recommended a NG or G tube in order to meet proper hydration and nutritional needs, whereas the other participants felt that patients could still swallow safely.

In addition to providing treatment recommendations for mild, moderate and severe dysphagia, respondents were asked to list any other strategies they use in their treatment. In this section of the survey, all participants referenced "other strategies" to be making sure that food is nutritious and that their patients maintain proper hydration. Respondents were able to distinguish between feeding/swallowing disorders and malnutrition, but noted that a feeding/swallowing disorder could lead to greater health risks, and maintaining proper nutrition/hydration was a high priority in their treatment recommendations.

The four participants who took part in this section of the survey were the ENT, Rehabilitation Technician, Nurse Midwife, and RN/Manager of the Nutrition Ward. The fact that most participants' treatment recommendations were inadequate is a concern, as most participants rated themselves as having relatively high confidence in their treatment capabilities. Confidence in treatment abilities did not correspond to knowledge of treatment standards. Reasons for inaccurate knowledge responses could be a lack of specific education of the treatment of feeding/swallowing disorders, a lack of tools and

resources in order to create diet modifications, as well as a lack of medical equipment and technology in order to properly diagnose a feeding/swallowing disorder.

**Compensatory strategies.** Since none of the participants mentioned the use of compensatory strategies such as the Tongue-hold Maneuver, Mendelsohn, Effortful Swallow, or Postural Adjustments it may be assumed that there is no knowledge of these evidenced-based practices. However, two participants did make reference to making sure the patients were alert, and sitting upright when eating or drinking. All participants identified that bite sizes should be the size of a teaspoon instead of a tablespoon. This indicates that most of the participants in this study are aware of the general safe swallow precautions to take with patients who present with feeding/swallowing difficulties.

### **Inquiry for More Information**

At the end of the study, participants were asked to indicate what areas in which they would like more information or training. All participants indicated they would like more information on the resources and tools they can utilize, and training on what causes/maintains feeding and swallowing disorders, as well as how they can help when someone is struggling to swallow. Most participants (4 out of 5) desired more information on the symptoms of dysphagia, and how one can diagnose a swallowing disorder. Three participants wished to know where they can seek help, what types of foods patients should receive, the signs of aspiration, and how typical feeding skills develop. Two participants wanted more information on how to make changes to mealtime routines, and when to introduce supplementary foods to patients.

Additionally, participants were allowed to write in any topic they wanted more training or information on. One participant wanted to know how to best take care of

children with feeding and swallowing difficulties, and another participant wanted more training or information on other tools used for the feeding of patients, the frequency at which patients should be fed, and what types of foods these patients should be given.

Given this information, the healthcare providers in this study wanted to know more about the basics of feeding/swallowing disorders. This suggests that their formal education or professional training may be lacking this specific information. Concurrently, because all respondents across the different professional disciplines in the study inquired for more basic knowledge, it may also suggest that these medical professionals are not able to consult with one another when evaluating or treating feeding/swallowing disorders.

### **Limitations**

Recruiting participants proved difficult for this study. Hypotheses for this include a lack of coordination across service providers, a lack of a professional organizational structure (which could have led to the potential identification of new participants), a lack of personal gain from participating, the dissemination of announcements, time, and English speaking/reading/writing proficiency. Two more potential participants were identified but declined to respond.

Additionally, no traditional healers were identified to participate in the study. This eliminated the experiences, viewpoints, and knowledge of the informal healthcare branch in Malawi (Fisher et al., 2017). Results of this study could have yielded different trends if there was inclusion of healthcare providers from the informal branch.

The medical terminology, “dysphagia” proved to be confusing for some participants, as several of them asked the investigator to clarify or define the term. It was



explained as a feeding/swallowing difficulty. This could have been due to language barriers, or perhaps there is a different medical term used for feeding/swallowing disorders in Malawi. Or feeding/swallowing difficulties are not provided a medical terminology in their formal education.

Another limitation to this study was the format of Section 2 of the survey. Section 2 asked respondents to identify the number of current patients with different disordered phases of the swallow on their caseload. This section proved hard for participants to complete, and interpret what the section was designed to collect. Most participants choose not to complete this section, therefore a comprehensive and detailed account of the number of patients a participant encountered on their caseload was not discovered.

While in country, an investigator worked alongside Participant B providing professional speech-language pathology evaluation and treatment recommendations for his current caseload. Prior to Participant B's involvement in the study, the experimenter gave many resources to the participant which covered broad topics encompassing the scope of practice for speech-language pathologists. Given this information, Participant B may have been inclined to rate himself lower when filling out the Likert scale pertaining to his perceived confidence in his treatment abilities.

### **Future Studies**

This descriptive study provides healthcare professionals foundational information pertaining to the management of feeding and swallowing disorders in Malawi. Results from this study indicate that Malawian healthcare providers need more education about the diagnosis, evaluation, assessment, and treatment of feeding and swallowing disorders, as their current formal education trainings seem to be lacking the basic anatomy and

physiology of the swallowing mechanism, diet modifications recommendations, and compensatory strategies used in intervention.

Education or intervention training of feeding and swallowing disorders needs to account for cultural considerations such as how disabilities are viewed in the community, and the common Malawian belief that an illness can be due to witchcraft, ancestors, or evil spirits. Service providers from this study also mentioned the importance of taking into account each patient's own personal considerations, such as religious beliefs that impact diet, physical touch of a member of the opposite sex, and current financial stability of the patient.

This study also shows that healthcare providers are not aware of, or do not access nearby non-governmental organizations as an additional resource or form of professional support. An investigation as to why this is could greatly impact the future quality of care for individuals in Malawi with feeding or swallowing disorders.

Ideally, creating a culturally sensitive and sustainable program targeting the education of service providers who see and treat feeding and swallowing disorders would be most beneficial. Malawian healthcare providers have expressed a strong desire to learn more about dysphagia, and expressed interest in receiving further trainings and support in providing interventions for those with feeding and swallowing disorders. Providing healthcare providers with educational handouts concerning general anatomy and physiology of the swallow, the different disordered phases of the swallow, as well as different swallowing compensatory strategies (such as the effortful swallow, tongue-hold maneuver, postural adjustments, etc.) can be a start. Malawian healthcare providers can incorporate use of compensatory strategies in their service provision for clients with

swallowing difficulties immediately after having gained knowledge and explanation of them. Incorporating the use of compensatory strategies does not impact healthcare providers, or facilities (hospitals, clinics, foundations, etc.) financially, as use of these strategies does not require additional tools, resources, or infrastructure.

In order to create sustainable programs, coordination and collaboration with local and active NGOs should be considered. There are many NGOs in Malawi that are designed to increase support for medical professionals, as well as create greater access to nutrition (refer to Appendix G). From this survey, healthcare providers were concerned that clients were not receiving adequate nutrition and hydration needs as a result of their feeding or swallowing disorder. Project Peanut Butter, an NGO in Malawi, is a program where a peanut butter paste is made for consumption as a means to receive nutrition. This paste would make for an excellent diet modification recommendation for an individual with dysphagia, as the bolus of peanut butter is compact, aiding in an easier swallow. This is just one example of many NGOs in Malawi that could aid in the creation of programs designed to increase education for healthcare providers in Malawi.

### **What Was Learned**

The results of this pilot study provide insight into the various types of providers who see and treat feeding/swallowing disorders, their opinions and experiences regarding service provision, and their treatment knowledge of dysphagia. This study also dives into topics of cross-cultural implications, challenges faced, and what future research is needed in the management of feeding and swallowing disorders in Malawi.

Overall, Malawian healthcare providers who see and treat individuals with feeding/swallowing disorders feel a high personal obligation and responsibility to provide

services to these individuals and show high concern for how their clients are perceived by family and community members.

Currently, there isn't a concrete distinction between treatment recommendations for mild and moderate dysphagia, and no knowledge of compensatory strategies to use in intervention. There is a high desire for healthcare providers to seek out more information and training pertaining to the management of feeding and swallowing disorders.

Future research or resources need to be tailored towards increasing general evaluation, diagnosis, and treatment knowledge of feeding and swallowing disorders that takes into account cross-cultural considerations and the lack of medical diagnostic equipment. Knowledge of unused and nearby resources need to be advertised and brought to the attention of healthcare providers so they know where and how they can seek additional support when necessary in order to provide comprehensive services to their patients. Utilizing nutritionists, or creating a nutrition education program would also be beneficial to healthcare providers treating individuals with feeding and swallowing disorders. Although this study did not go into depth about how patients are meeting these needs, respondents frequently stressed the importance of addressing nutrition and hydration in their service provision.

The hope of this study is to provide a baseline for future research or creation of culturally sensitive and sustainable programs catering to the service provision of feeding and swallowing disorders.

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APPENDIX A

ARIZONA STATE UNIVERSITY APPROVAL FORM



Dear Tamiko Azuma:

On 3/31/2017 the ASU IRB reviewed the following protocol:

Type of Review:	Initial Study
Title:	Survey of Feeding and Swallowing Intervention Practices by Service Providers in Malawi
Investigator:	Tamiko Azuma
IRB ID:	STUDY00006076
Funding:	None
Grant Title:	None
Grant ID:	None
Documents Reviewed:	<ul style="list-style-type: none"><li>• Helms Tillery CV, Category: Vitaes/resumes of study team;</li><li>• Recruitment Flyer, Category: Recruitment Materials;</li><li>• Survey, Category: Measures (Survey questions/Interview questions /interview guides/focus group questions);</li><li>• Malawi Consent_03.31.2017.pdf, Category: Consent Form;</li><li>• Malawi_IRB Protocol_03.31.2017.docx, Category: IRB Protocol;</li><li>• Dysphagia Study Proposal, Category: Other (to reflect anything not captured above);</li><li>• Azuma_CV, Category: Vitaes/resumes of study team;</li></ul>

The IRB determined that the protocol is considered exempt pursuant to Federal Regulations 45CFR46 (2) Tests, surveys, interviews, or observation on 3/31/2017.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL (HRP-103).

Sincerely,

IRB Administrator

cc: Christie Larson

Christie Larson  
Tamiko Azuma  
Augusta Helms Tillery

APPENDIX B

NHSRC MALAWI APPROVAL FORM

Telephone: + 265 789 400  
Facsimile: + 265 789 431

All Communications should be addressed to:

The Secretary for Health and Population



In reply please quote No.

MINISTRY OF HEALTH AND POPULATION

P.O. BOX 30377  
LILONGWE 3  
MALAWI

15<sup>th</sup> May, 2017

Christie Larson  
Arizona State University/QECH  
Blantyre

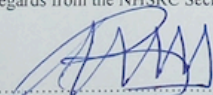
Dear Madam,

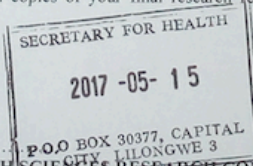
**RE: PROTOCOL # 17/05/1767: SURVEY OF FEEDING AND SWALLOWING PREPARATION AND INTERVENTION PRACTICES BY SERVICE PROVIDERS IN MALAWI**

Thank you for the above titled proposal that you submitted to the National Health Sciences Research Committee (NHSRC) for review. Please be advised that the NHSRC has **reviewed** and **approved** your application to conduct the above titled study.

- **APPROVAL NUMBER** : 1767
- The above details should be used on all correspondences, consent forms and documents as appropriate.
- **APPROVAL DATE** : 15/05/2017
- **EXPIRATION DATE**  
This approval expires on **14/05/2018**. After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the NHSRC Secretariat should be submitted one month before the expiration date for continuing review.
- **SERIOUS ADVERSE EVENT REPORTING**: All serious problems having to do with subject safety must be reported to the NHSRC within 10 working days using standard forms obtainable from the NHSRC Secretariat.
- **MODIFICATIONS**: Prior NHSRC approval using forms obtainable from the NHSRC Secretariat is required before implementing any changes in the protocol (including changes in the consent documents). You may not use any other consent documents besides those approved by the NHSRC.
- **TERMINATION OF STUDY**: On termination of a study, a report has to be submitted to the NHSRC using standard forms obtainable from the NHSRC Secretariat.
- **QUESTIONS**: Please contact the NHSRC on phone number +265 888 344 443 or by email on [mohdocentre@gmail.com](mailto:mohdocentre@gmail.com).
- **OTHER**: Please be reminded to send in copies of your final research results for our records (Health Research Database).

Kind regards from the NHSRC Secretariat.

  
For: CHAIRPERSON, NATIONAL HEALTH SCIENCES RESEARCH COMMITTEE  
Promoting Ethical Conduct of Research<sup>1</sup>



Executive Committee: *Dr B. Chilima (Chairperson), Dr B. Ngwira (Vice-Chairperson)*  
Registered with the USA Office for Human Research Protections (OHRP) as an International IRBIRB  
Number IRB00003905 FWA00005976

APPENDIX C  
INFORMED CONSENT FORM

## **Consent Form: Social Behavioral**

***Title of research study:*** Survey of Feeding and Swallowing Intervention Practices by Service Providers in Malawi

***Investigators:*** Tamiko Azuma, Ph.D., Kate Helms Tillery, Ph. D., CT Larson, B.S.

### ***Why am I being invited to take part in a research study?***

We invite you to take part in a research study because you provide services to patients or clients who may have feeding or swallowing problems. As part of this study, you will be asked questions about your experiences with and perspectives on management of feeding or swallowing problems in your clients.

### ***Why is this research being done?***

***The purposes of this research are to gain a better understanding of 1) current practices used to manage feeding and swallowing problems in Malawi and 2) additional information, training, or resources service providers need to serve patients who have feeding or swallowing problems.***

### ***How long will the research last?***

We expect that you will spend about 1 hour answering survey questions.

### ***How many people will be studied?***

We expect about 100 people will participate in this study.

### ***What happens if I say yes, I want to be in this research?***

You are free to decide whether you wish to participate in this study. If you agree to participate, you will be asked questions about the provision of services to patients who have feeding and/or swallowing problems. You may decline to answer any of the questions. We are also asking your permission to audio record the interview. Only the research team will have access to the recordings. The recordings will be deleted immediately after being transcribed and any published quotes will be anonymous. To protect your identity, please refrain from using names or other identifying information during the interview. Let me know if, at any time, you do not want to be recorded and we will stop. It will take approximately one hour to complete the entire session.

### ***What happens if I say yes, but I change my mind later?***

You can leave the study at any time. Withdrawing from the study will not be held against you in any way.

***Will being in this study help me in any way?***

We cannot promise any direct benefits to you from your taking part in this research. However, possible future benefits may include improvement in the training, information, or resources for managing feeding or swallowing disorders in Malawi.

***What happens to the information collected for the research?***

The results of this study may be used in reports, presentations or publications. Although job title and facility may be specified, your name will not be included. In order to maintain confidentiality of participant records, a unique identification code will be used to identify each participant. All data will be stored either as paper documents in a locked file cabinet (accessed only by the investigators), or as electronic files on secure password protected digital media. The data will be retained until data analysis is complete and then will be destroyed.

***Who can I talk to?***

If you have questions, concerns, or complaints, talk to the research team at

- ***Tamiko Azuma, Ph.D. Principal Investigator, 480-965-9455, tamiko.azuma@asu.edu***
- ***Kate Helms Tillery, Ph.D., CCC-SLP, Co-Investigator, 480- 727-4511, ahelms@asu.edu***
- ***CT Larson, B.S., Co-Investigator, 408-768-3854, ctlarson@asu.edu***

This research has been reviewed and approved by the Social Behavioral Institutional Review Board (IRB) at Arizona State University (ASU) and by the National Health Sciences Research Committee of the Malawi Ministry of Health.

You may talk to the ASU IRB at (480) 965-6788 or by email at [research.integrity@asu.edu](mailto:research.integrity@asu.edu) if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research participant.
- You want to get information or provide input about this research.

If you choose to participate in this study, please tell the researcher now. Your verbal agreement indicates your consent to participate in the study.

APPENDIX D  
RECRUITMENT FLYER



## FEEDING AND SWALLOWING SURVEY

I am a graduate student under the direction of Professors Kate Helms Tillery and Tamiko Azuma in the Department of Speech and Hearing Science at Arizona State University in the U.S.

I am conducting a research study to learn more about the experiences of Rehabilitation Technicians and other service providers who encounter patients with feeding and swallowing problems in their jobs.

I am recruiting Rehabilitation Technicians to participate in a survey which will take approximately 1 hour.

Your participation in this study is voluntary. If you have any questions concerning the study, please contact me at:

Email: [ctlarson0629@gmail.com](mailto:ctlarson0629@gmail.com)

WhatsApp: +1 408 768 3854

Your help and willingness to participate in this survey is truly appreciated.

Thank you!

Arizona State University Research Team

Tamiko Azuma, Ph.D.

Kate Helms Tillery, Ph.D. CCC-SLP

CT Larson, B.S.

APPENDIX E

FULL SURVEY

## Survey Questions

In order to learn about how we can assist service providers in Malawi, we are collecting information about your experience with patients who have feeding or swallowing problems, also referred to as dysphagia. Please answer the questions to the best of your ability. There are no right or wrong answers; we will not judge your answers as correct or incorrect. If there is a question that is unclear or difficult to understand, mark it with an X, and I will explain it.

### Part 1:

Research ID #: \_\_\_\_\_ Age: \_\_\_\_\_ Gender:

Occupation: \_\_\_\_\_

Number of years in the occupation: \_\_\_\_\_ Number of years of school:

Final degree: \_\_\_\_\_

Current employment setting: \_\_\_\_\_ Native Language: \_\_\_\_\_

Languages Spoken: \_\_\_\_\_

Please describe your job responsibilities:

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### Part 2:

Please answer the following questions to the best of your ability.

1. **Please estimate how many clients on your current caseload have a feeding or swallowing problem** \_\_\_\_\_
  
2. **Please indicate how often you see problems in the following areas** (circle the relevant word or write the number of clients in the blank)
  - a. **Oral preparatory phase:** (Keeping food in the mouth, sucking or nursing, chewing food, and manipulating the food into a bolus, in preparation to swallow).

Frequently	Sometimes	Never	# of
clients: _____			
  
  - b. **Oral transit phase:** (Moving the food toward the back of the mouth)

Frequently	Sometimes	Never	# of
clients: _____			

c. **Pharyngeal phase:** (Initiating the swallow)  
Frequently                      Sometimes                      Never                      # of  
clients: \_\_\_\_\_

d. **Esophageal phase:** (Movement of the food from the esophagus toward the stomach)  
Frequently                      Sometimes                      Never                      # of  
clients: \_\_\_\_\_

3. **What signs or symptoms lead you to believe the patients have feeding or swallowing problems?**

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4. **How often do you see mild, moderate, or severe dysphagia? Please indicate # of clients if possible**

a. **Mild:**                      Frequently                      Sometimes                      Never  
# of clients: \_\_\_\_\_

b. **Moderate:**                      Frequently                      Sometimes                      Never  
# of clients: \_\_\_\_\_

c. **Severe:**                      Frequently                      Sometimes                      Never  
# of clients: \_\_\_\_\_

5. **What other medical concerns do these patients have?**

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6. **What resources and tools do you currently use to help patients with feeding or swallowing disorders?**

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**7. How important is treating dysphagia or feeding/swallowing disorders to you?**

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**8. How are you currently counseling dysphagia or feeding/swallowing disordered patients?**

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**Part 3:**

Please circle one of the five available options indicating your opinion to the proposed statement.

**1. It is my responsibility to help children and adults who have swallowing and/or feedings problems manage their eating and drinking.**

Strongly Disagree Disagree Disagree Neutral  
Agree Strongly Agree

**2. It is my responsibility to obtain training necessary to achieve competency in dysphagia intervention**

Strongly Disagree Disagree Neutral  
Agree Strongly Agree

**3. Managing feeding and swallowing problems should be part of my job.**

Strongly Disagree Disagree Neutral  
Agree Strongly Agree

**4. I should not be responsible for helping patients manage their feeding or swallowing problem.**

Strongly Disagree Disagree Neutral  
Agree Strongly Agree

**5. I have adequate tools and resources to provide intervention to patients who have feeding or swallowing problems.**

- |  |                   |                            |          |         |
|--|-------------------|----------------------------|----------|---------|
|  | Strongly<br>Agree | Disagree<br>Strongly Agree | Disagree | Neutral |
|--|-------------------|----------------------------|----------|---------|
- 6. I have adequate time to provide dysphasia intervention to patients with feeding or swallowing problems.**
- |  |                   |                            |          |         |
|--|-------------------|----------------------------|----------|---------|
|  | Strongly<br>Agree | Disagree<br>Strongly Agree | Disagree | Neutral |
|--|-------------------|----------------------------|----------|---------|
- 7. Dysphagia intervention should be avoided if the client is at risk of choking.**
- |  |                   |                            |          |         |
|--|-------------------|----------------------------|----------|---------|
|  | Strongly<br>Agree | Disagree<br>Strongly Agree | Disagree | Neutral |
|--|-------------------|----------------------------|----------|---------|
- 8. I am interested in increasing my knowledge in the area of dysphagia intervention.**
- |  |                   |                            |          |         |
|--|-------------------|----------------------------|----------|---------|
|  | Strongly<br>Agree | Disagree<br>Strongly Agree | Disagree | Neutral |
|--|-------------------|----------------------------|----------|---------|
- 9. My supervisor and colleagues support my efforts to provide dysphagia intervention.**
- |  |                   |                            |          |         |
|--|-------------------|----------------------------|----------|---------|
|  | Strongly<br>Agree | Disagree<br>Strongly Agree | Disagree | Neutral |
|--|-------------------|----------------------------|----------|---------|
- 10. I feel confident in my ability to provide dysphagia intervention to children with swallowing and/or feeding disorders.**
- |  |                   |                            |          |         |
|--|-------------------|----------------------------|----------|---------|
|  | Strongly<br>Agree | Disagree<br>Strongly Agree | Disagree | Neutral |
|--|-------------------|----------------------------|----------|---------|
- 11. I feel confident in my ability to provide dysphagia intervention to adults with swallowing and/or feeding disorders.**
- |  |                   |                            |          |         |
|--|-------------------|----------------------------|----------|---------|
|  | Strongly<br>Agree | Disagree<br>Strongly Agree | Disagree | Neutral |
|--|-------------------|----------------------------|----------|---------|

**Part 4:**

For each question, please circle the word that most accurately describes your experience or perspective.

**Due to a patient's/client's feeding and swallowing difficulties how often have you...**

- 1. Found it hard to get help from others**

Never	Almost Never	Sometimes	Very Often	Almost
Always				
  
- 2. Found it hard to provide services to the client and the client's family**

	Never	Almost Never	Sometimes	Very Often	Almost
Always					
<b>3. Worried about your client's general health</b>					
Always	Never	Almost Never	Sometimes	Very Often	Almost
<b>4. Worried your client is not receiving adequate nutrition or hydration</b>					
Always	Never	Almost Never	Sometimes	Very Often	Almost
<b>5. Worried about how others will react towards your client</b>					
Always	Never	Almost Never	Sometimes	Very Often	Almost
<b>6. Worried about your client's breathing</b>					
Always	Never	Almost Never	Sometimes	Very Often	Almost
<b>7. Worried that your client will choke while eating or drinking</b>					
Always	Never	Almost Never	Sometimes	Very Often	Almost
<b>8. Worried that your client will develop pneumonia</b>					
Always	Never	Almost Never	Sometimes	Very Often	Almost
<b>9. Worried that you aren't doing enough for your client</b>					
Always	Never	Almost Never	Sometimes	Very Often	Almost
<b>10. Worried about how your client's feeding/swallowing affects their immediate family/community members</b>					
Always	Never	Almost Never	Sometimes	Very Often	Almost
<b>11. Worried about your client receiving adequate help and support from family members</b>					
Always	Never	Almost Never	Sometimes	Very Often	Almost

**When working with your clients who have feeding or swallowing problems how often have you...**

- 1. Had difficulties preparing liquids and foods the "correct" way**

Never      Almost Never      Sometimes      Very Often      Almost  
Always

**2. Had difficulties feeding the client because you don't know how best to prepare the liquid/food**

Never      Almost Never      Sometimes      Very Often      Almost  
Always

**3. Had difficulties feeding the client because they refuse to eat the foods or liquids that you recommend**

Never      Almost Never      Sometimes      Very Often      Almost  
Always

**4. Had difficulties feeding the client because other family members or service providers have different opinions about feeding the client**

Never      Almost Never      Sometimes      Very Often      Almost  
Always

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**Part 5:**

To the best of your knowledge, please reply to the following questions.

**Severe Dysphagia**

**1. If you have (or have had) a patient with severe dysphagia on your caseload, what types of liquids has this patient received?**

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**2. Do you believe that this patient can safely swallow liquids?**

**a. Circle one:** Yes      No

**b. Please explain:**

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**c. If yes, how should the liquids be prepared?**

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d. If no, what other means are available to provide this patient with adequate hydration?

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e. Please add your comments below:

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3. If you have (or have had) a patient with severe dysphagia on your caseload, what types of food has this patient received?

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4. Do you believe that this patient can safely swallow food?

a. Circle one: Yes      No

b. Please explain:

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c. If yes, how should the food be prepared?

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d. If no, what other means are available to provide this patient with adequate nutrition?

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e. Please add your comments below:

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**Moderate Dysphagia**

5. If you have (or have had) a patient with moderate dysphagia on your caseload, what types of liquids has this patient received?

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6. Do you believe that this patient can safely swallow liquids?

- a. Circle one: Yes    No
- b. Please explain:

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c. If yes, how should the liquids be prepared?

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d. If no, what other means are available to provide this patient with adequate hydration?

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e. Please add your comments below:

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7. If you have (or have had) a patient with moderate dysphagia on your caseload, what types of food has this patient received?

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8. Do you believe that this patient can safely swallow food?

a. Circle one: Yes      No

b. Please explain:

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c. If yes, how should the food be prepared?

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d. If no, what other means are available to provide this patient with adequate nutrition?

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e. Please add your comments below:

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**Mild Dysphagia**

**9. If you have (or have had) a patient with mild dysphagia on your caseload, what types of liquids has this patient received?**

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**10. Do you believe that this patient can safely swallow liquids?**

**a. Circle one: Yes      No**

**b. Please explain:**

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**c. If yes, how should the liquids be prepared?**

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**d. If no, what other means are available to provide this patient with adequate hydration?**

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**e. Please add your comments below:**

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**11. If you have (or have had) a patient with mild dysphagia on your caseload, what types of food has this patient received?**

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**12. Do you believe that this patient can safely swallow food?**

**a. Circle one: Yes      No**

**b. Please explain:**

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**c. If yes, how should the food be prepared?**

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**d. If no, what other means are available to provide this patient with adequate nutrition?**

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**e. Please add your comments below:**

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**1. What are some effects of aspiration and what are the primary concerns if your patient is aspirating?**

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2. **What strategies have you used to facilitate safe swallowing for your patients?**

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3. **Do your patients independently follow safe feeding and swallowing practices?**

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4. **Please give an example of a food that is safe to eat for a patient with severe dysphagia.**

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5. **Please give an example of a food that is NOT safe to eat for a patient with severe dysphagia.**

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6. **What modifications should be made to liquids given to patients with dysphagia?**

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7. **How large should a single bite be? (tablespoon, teaspoon, etc)**

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8. **Where and how do you seek additional resources to help you treat feeding and swallowing disorders?**

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9. **What cross cultural challenges have you encompassed in your service provision?**

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**Part 6:**

Please check the areas in which you would like more information or training.

- How typical feeding skills and abilities of a child (birth-3) evolve.
- When to introduce supplementary foods to children.
- How to help a child/adult when he/she is struggling to swallow.
- Symptoms of dysphagia, or a feeding/swallowing disorder.
- Signs of aspiration.
- How to diagnose dysphagia, or a feeding/swallowing disorder.
- What causes or maintains feeding/swallowing challenges.
- How to make changes to mealtime routines, and feeding routines.
- What types of food should a patient have.
- Where to seek help.
- Resources and tools to utilize.
- Other?

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Thank you for participating in this survey! It is greatly appreciated.

APPENDIX F

US STANDARDS FOR DYSPHAGIA TREATMENT



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Full per-oral nutrition (P.O): Normal diet

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Level 7: Normal in all situations

- Normal diet
- No strategies or extra time needed

Level 6: Within functional limits/modified independence

- Normal diet, functional swallow
- Patient may have mild oral or pharyngeal delay, retention or trace epiglottal undercoating but independently and spontaneously compensates/clears
- May need extra time for meal
- Have no aspiration or penetration across consistencies

Full P.O: Modified diet and/or independence

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Level 5: Mild dysphagia: Distant supervision, may need one diet consistency restricted

- May exhibit one or more of the following
  - Aspiration of thin liquids only but with strong reflexive cough to clear completely
  - Airway penetration midway to cords with one or more consistency or to cords with one consistency but clears spontaneously
  - Retention in pharynx that is cleared spontaneously
  - Mild oral dysphagia with reduced mastication and/or oral retention that is cleared spontaneously

Level 4: Mild-moderate dysphagia: Intermittent supervision/cueing, one or two consistencies restricted

- May exhibit one or more of the following
  - Retention in pharynx cleared with cue
  - Retention in the oral cavity that is cleared with cue
  - Aspiration with one consistency, with weak or no reflexive cough
    - Or airway penetration to the level of the vocal cords with cough with two consistencies
    - Or airway penetration to the level of the vocal cords without cough with one consistency

Level 3: Moderate dysphagia: Total assist, supervision, or strategies, two or more diet consistencies restricted

- May exhibit one or more of the following
  - Moderate retention in pharynx, cleared with cue
  - Moderate retention in oral cavity, cleared with cue
  - Airway penetration to the level of the vocal cords without cough with two or more consistencies
    - Or aspiration with two consistencies, with weak or no reflexive cough
    - Or aspiration with one consistency, no cough and airway penetration to cords with one, no cough

Nonoral nutrition necessary

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Level 2: Moderately severe dysphagia: Maximum assistance or use of strategies with partial P.O. only (tolerates at least one consistency safely with total use of strategies)

- May exhibit one or more of the following
  - Severe retention in pharynx, unable to clear or needs multiple cues
  - Severe oral stage bolus loss or retention, unable to clear or needs multiple cues
  - Aspiration with two or more consistencies, no reflexive cough, weak volitional cough
    - Or aspiration with one or more consistency, no cough and airway penetration to cords with one or more consistency, no cough

Level 1: Severe dysphagia: NPO: Unable to tolerate any P.O. safely

- May exhibit one or more of the following
    - Severe retention in pharynx, unable to clear
    - Severe oral stage bolus loss or retention, unable to clear
    - Silent aspiration with two or more consistencies, nonfunctional volitional cough
    - Or unable to achieve swallow
- 

Falk, J., Gallo, L., O'Neil, K.H., & Purdy, M.H. (1999). The Dysphagia Outcome and Severity Scale. *Dysphagia*, 14, 139-145.

APPENDIX G

LIST OF KNOWN NON-GOVERNMENTAL ORGANIZATIONS IN MALAWI  
CATERING TO HEALTH OR EDUCATION

<b>Organization</b>	<b>Location (If Known)</b>
African Development & Education Foundation (ADEF)	Blantyre
Association of Early Childhood Development in Malawi	Blantyre, Limbe
Baobab Health	Blantyre, Lilongwe
Bedir Education & Medical Trust	Blantyre
CARE Malawi	Lilongwe
Centre for Human Rights and Rehabilitation	Lilongwe
Forum for the Development of Youth with Disabilities	Blantyre
Healing Every Nation	Blantyre
John Hopkins University Centre for Communication Programs	N/A
John Snow Research & Training Institute	N/A
Lifeline Malawi	Lilongwe
Malawi Health Equity Network	Lilongwe
Management Sciences for Health	N/A
NDI Moyo Palliative Care Trust	Salima
Pakachere Institute of Health Development Communication	Blantyre
Parent and Child Health Initiative	Lilongwe
Partners in Health	Neno District
Partners in Hope	Lilongwe
Programme For Appropriate Technology in Health (PATH)	N/A
Project Peanut Butter	N/A
Rainbow Child Development Center	N/A
Research for Equity and Community Health Trust	Lilongwe
Teethsavers International Inc.	N/A
The Salvation Army	12 epicenter locations in country
United Nations International Children's Emergency Fund (UNICEF)	Lilongwe