

Yairi, E. & Ambrose, N.G. (1992). Onset of stuttering in preschool children: Selected factors. *Journal of Speech, Language, and Hearing Research*, 35(4), 782-788. doi:10.1044/jshr.3504.782

Yairi, E. & Ambrose, N.G. (1999). Early childhood stuttering: Persistency and recovery rates. *Journal of Speech Language and Hearing Research*, 42(5), 1097-1112.

Yairi, E. & Ambrose, N. (2013). Epidemiology of stuttering: 21st century advances. *Journal of Fluency Disorders*, 38(2), 66-87.

Yairi, E. & Seery, C.H. (2014). *Stuttering: Foundations and Clinical Applications*: Pearson Allyn & Bacon.

13 Toward Food Sovereignty and Security for People Living with Swallowing Disabilities in Globally Vulnerable Environments

Mershen Pillay

Key information for local and national policy and lawmakers

The purpose of this chapter is to provide information for various stakeholders involved in the health care, education, and employment of people living with dysphagia (swallowing disabilities). Dysphagia refers to difficulty with swallowing (eating and drinking) due to motor and/or sensory deficits. Dysphagia may occur at birth, affect the elderly, or impact anyone affected by communicable illnesses such as COVID-19 and HIV/AIDS or the following non-communicable illnesses:

- Neurological disease such as head injury, stroke, motor neuron disease, Parkinson's, or dementia
- Diseases/trauma to the body such as head and neck cancers (tongue, nose, or larynx), cleft lip and palate
- Mental illness
- Work-related injuries, especially exposure to chemicals in the workplace
- Side effects of medications
- Age-related effects

Child health issues that may also involve dysphagia include: cerebral palsy, autistic spectrum disorder, cleft palate, intrauterine exposure to HIV/AIDS, or alcohol and drug effects. Information provided in this chapter should (a) increase the visibility of people with swallowing disabilities and (b) highlight the unique services needed within the framework of food sovereignty, defined as the transformation of food systems that address people's rights to healthy and culturally appropriate foods, along with the ability to decide how food is produced and distributed.

Governments should respect people's right to adequate, available, accessible, culturally acceptable (sustainable, *author's own words*) and nutritious food (International Planning Committee, 2009). It is also essential that all projects and plans developed

be sustainable to improve people's lives while conserving natural resources despite demands for food, water, education, health and related economic and other needs (United Nations, 2015). The World Bank (World Bank, 1986) and the FAO (1996) definition of food security is when all people, at all times, have physical, economic and social access to sufficient, safe and nutritious food to meet their dietary needs and food preferences for an active and healthy life (FAO, 1996). Practically, this places the onus on the poor to solve their hunger by earning more to buy or grow food.

Unsurprisingly, those with disabilities are more food insecure than their counterparts (Friedman, 2021), a vulnerability more relevant to people living with swallowing disabilities (dysphagia) (Quarmby & Pillay, 2019). In richer, relatively well-cared-for populations, food tends to be available. However, underserved populations, who are frequently characterized by impoverishment, experience a precarious relationship with food and nutrition. In these economically-vulnerable contexts, people living with disabilities are at risk of losing their food security.

Globally, the COVID-19 pandemic left those with disabilities without a voice and exceptionally low purchasing power for sufficient, safe, and nutritious foods (Food and Agricultural Organization of the United Nations [FAO], International Fund for Agricultural Development [IFAD], United Nations International Children's Emergency Fund (UNICEF), World Food Programme (WFP) and World Health Organization (WHO), 2020) Can healthcare policymakers (and associated services) ignore or work around the precarious reality of impoverishment for people living with disabilities? This chapter is about making visible the food sovereignty and security available for people living with swallowing disabilities.

The incidence and prevalence of dysphagia

Globally dysphagia affects around 600 million people (Steele et al., 2015). People living with swallowing disabilities constitute a significant percentage of the 690 million people (8.9%) who are hungry (FAO, IFAD, UNICEF, WFP, & WHO, 2020).

The impact of dysphagia

Choking to death among dysphagic or older adults is uncommon (Hanley, 2018; Taniguchi et al., 2020). Fifty-one percent of individuals experience aspiration that occurs when foods or liquids go down the wrong way into the airways, often without any obvious signs like coughing (Garon, Sierzant, & Ormiston, 2009). This causes critical health-related events such as aspiration-related pneumonias and choking.

Activities of daily living and livelihoods

Dysphagia impacts on everyday living since mealtimes play a central role in social lives, cultural celebrations, and connecting loved ones. The sensory aspects of swallowing are closely connected to smell and taste. Head and neck cancer or COVID-19 survivors experience difficulties with smell and/or taste (Vergara et al., 2021). The most common causes of sensory disturbances are nasal and sinus diseases, upper respiratory infections,

and head trauma, while the cause of taste deficiencies may consist of oral infections. Human swallowing abilities depend on sensory feedback.

Globally, many individuals with disabilities live in the Majority World's low-middle income countries across Africa, Asia, and Latin America (WHO, 2011). Minority World, high-income countries show disproportionately higher food insecurity rates amongst people living with disabilities (Cipriano-Crespo et al., 2020; Coleman-Jensen et al., 2017; Loopstra et al., 2020; Schwartz, Buliung, & Wilson, 2019) and may include the indigenous peoples such as the First Nations in Canada (Richmond et al., 2020), Aboriginal Australians (Spurway & Soldatic, 2016), and Māori in New Zealand (McKerchar, 2020). Others who may be affected are Black and other racial minorities (Morales, Morales, & Beltran, 2020), foreign-born/migrants with disabilities (up to 43.2%) (Altman, Heflin & Patnaik, 2020), women (Schwartz et al., 2019), and transgender and gender diverse populations (Russomanno & Jabson Tree, 2020).

Key information for health professionals, social workers, community leaders, and educational practitioners

The purpose of this section is to improve understanding and support facilitated by key service providers in governmental and non-governmental health, educational, social, and occupational sectors. Providers include educators, community healthcare workers, and caregivers such as family members or primary caregivers of persons of all ages with disabilities in the local (community, regional); national level (country), the international level (e.g., humanitarian aid), and health service provision by WHO, UNICEF, and other international organizations. When managed by dysphagia practitioners, health risks decrease (Beom, et al., 2015; Kraaijenga et al., 2015; Ortega, et al., 2016; Speyer, et al., 2010; Suntrup et al., 2015). However, services for people with swallowing disabilities are limited for Majority World countries (Pillay, Tiwari, Kathard, & Chikte, 2020; Pillay, 2013; Wylie et al., 2013) and other low-middle income contexts (Chen, Kent, & Cui, 2021). Global workforce deficits means that dysphagia services must be offered at primary healthcare level and need to be taken to communities (Cieza et al., 2020). This works well with the adage that food/eating is everyone's business. Community health workers, medical, nursing, rehabilitation and other healthcare professionals, caregivers, school educators, and employers of people with special needs all need to know about swallowing disabilities. They need to understand how to position a person as well as how to produce and prepare foods, adapt/modify and classify food textures, and manage risks associated with eating and drinking, including choking hazards. To address the food needs of populations with a swallowing disorder, the International Federation of Red Cross and Red Crescent Societies' Global Food Security and Assessment Guidelines (Food Security Cluster 2010) provide useful resources to enable the mapping of food security at an individual and national level.

THRIVE: Tackling hunger by research and innovation in vulnerable environments

This section is based on a framework called Tackling Hunger with Research & Innovation in Vulnerable Environments (THRIVE) which was developed about 10 years ago (Pillay

& Kathard, 2018). It was consolidated via the South African University of KwaZulu-Natal with its tradition of over 30 years of community-based speech therapy/rehabilitation (Jager, 1994). THRIVE was developed to reposition swallowing and feeding in a way that promotes transformative practitioners who are concerned with the food security and the sovereignty or control by their patients (Pillay, 2013; Pillay & Kathard, 2018). THRIVE consists of four core interventions:

- Food production
- Food preparation
- Food/diet texture classification
- Mealtime risk management and primary care

How to identify people with swallowing disabilities within food security and sovereignty

THRIVE consists of several tools, including swallowing safety identification and food security checklists. Non-medical individuals such as family or caregivers, including community caregivers or generic community health workers, may identify (screen) for swallowing safety in underserved populations. As such, selected tools and guidelines account for the knowledge/skills of a range of caregivers.

It is important to consider that oral trials (e.g., water swallow trials) must be done by a dysphagia practitioner or a medical/healthcare professional (nurse, other

Table 13.1 Swallowing and eating screening tools.

<p>For non-medical personnel</p> <p><i>For infants and children</i></p> <ul style="list-style-type: none"> • The Feeding Matters Infant and Child Feeding Questionnaire © (Silverman et al., 2020): • The above tool and others such as the PEDI-EAT-10 and ChOMPS are available at https://www.feedingflock.com/tools <p><i>For adults</i></p> <ul style="list-style-type: none"> • Eating Assessment Tool (EAT-10) (Nestlé Health Science, 2021): Available in many languages, including all UN official languages (e.g., Spanish, Italian, Portuguese, , Swedish, Turkish, Greek, Dutch, and French). <p>For trained medical/health care personnel</p> <p><i>For neonates/infants/children</i></p> <ul style="list-style-type: none"> • Neonatal Feeding Assessment Scale (NFAS) (Viviers, 2019) • Neonatal Eating Assessment Tool for breast-feeding and bottle-feeding (Feeding Flock, 2019) <p><i>For adults</i></p> <ul style="list-style-type: none"> • Gugging Swallow Screener [GUSS] (Trapl et al., 2007): Available in many languages, including all of the UN's official languages (except Arabic), with a recent application in Egypt. The Gugging Swallowing Screen can also be accessed at Wordpress.com (2017). • Toronto Bedside Swallowing Screening Test (TOR-BSST) (Martino et al., 2009): French, Spanish, Italian, Chinese, German. With Portuguese and Thai translations in preparation.

rehabilitation personnel, medical doctor, speech and language therapist, or clinical associates) who is cross-trained, competent in dysphagia screening, and able to clinically manage penetration or aspiration events. See Table 13.1 for screening tools. These tools should be used within a train-the-trainer format, which is a framework for training people such as community caregivers or peer professionals so that they can train other people. Suggested tools are considered in relation to the United Nations (UN) official languages for Arabic, Chinese, English, French, Russian, and Spanish.

The impact of dysphagia/swallowing disabilities

Dysphagia is associated with poorer health outcomes. As stated above, acute and chronic dysphagia can result in pneumonia, malnutrition and even death. Alternative feeding modalities may be considered such as tube feeding (e.g., nasogastric tube or a percutaneous endoscopic gastrostomy tube) or intravenous (parenteral) nutrition. People may need to eat texture-modified diets (Cichero et al., 2017), often with a good measure of success. Social, psychological and citizenship issues are some of the broader impacts beyond the bodily processes affected. For example, mental health and quality of life are of concern (Kim, Park, Park, & Kim, 2020). People living in already vulnerable environments are likely to face difficulty with a swallowing disability (Pillay, 2013; Quarmby & Pillay, 2019, Karani & Pillay, 2020). Identifying difficulty with swallowing is important. Without this support, individuals may find it difficult to adapt methods of management and caring to improve health outcomes.

The importance of the identification of people with dysphagia

Identifying difficulty with swallowing is important for many reasons. However, two key reasons for this identification must be highlighted. Firstly, identification will lead to the improvement and the knowledge of local and regional governments for the development of services. Secondly, it is important in order to ensure that an individual is managed correctly by amending the textures of foods, changing physical position, considering alternative feeding methods, and routines that lead to improved health outcomes. Ultimately, people who are identified as living with a swallowing disability will become more visible within country health profiles and more easily identified for their associated food insecurity and reduced food sovereignty. Food sovereignty is defined as the right for individuals to access healthy and culturally-appropriate food produced through ecologically sound and sustainable methods.

What to do after identification

In immediate risk management, the guidelines in Table 13.2 address important management of mealtime choking or aspiration risks (primary preventative). Examples of the correct approach to swallowing difficulties are to ensure that the individual is fully awake and alert, is positioned in a manner that allows safe swallowing, ensuring that the mouth area is free of other foods, and consideration of the appropriate textures to assure safe swallowing abilities.

For example, it is important to support nutrition and hydration abilities, taking into account the individual's dietary preferences. In addition, optimal support must be considered with a plan to improve swallowing abilities. Details about safe swallowing/mealtime guidelines are presented in Table 13.2, along with direct basic and advanced life support safety management strategies. This is best managed by a trained healthcare worker. In preparation for emergencies (choking), consider learning basic life supports to manage choking (British Red Cross, 2021; Global First Aid Reference Centre Platform, 2021).

It is also important to use the country's medical/healthcare pathways to manage the level of risk identified via the swallowing screening. For example, if a person in a rural community is identified with a choking event at home, then it is expected that whatever usual route is used should be engaged to escalate this community case to the relevant healthcare facility/service, such as a clinic or a hospital emergency service.

In short-term management, food sovereignty and security risk must be escalated to provider/producer level. Social, governmental, non-governmental, and aid agencies offer useful resources (Alliance for Food Sovereignty in Africa, 2021; Humanitarian Response, 2021; Indigenous Food Systems Network, 2021; La Via Campesina, 2021; Navdanya, 2016; United Nations, 2021; World Food Program, 2021; and World Vision, 2021). For long-term management, it is important to work within a framework that addresses the impact of colonization (Pillay & Kathard, 2015).

Colonization has played a role in many countries (Food Empowerment, 2021). For example, Spaniards who entered Mesoamerica found crops such as beans, pumpkins, chillies, avocados, elderberries, guavas, papayas, tomatoes, cocoa, cotton, tobacco, henequen, indigo, maguey, corn, and cassava (Armstrong & Shenk, 1982). However, these foods were not consistent with the foods that they were familiar with or had eaten and were absent in their native country. Lands were replanted with foods that the colonists were familiar with and desired. Therefore, it is important to work with people living with swallowing disabilities at a micro-level and at the macro-level, such as food production via home gardens. This means shifting dysphagia practice within a community-based rehabilitation framework (CBR Matrix, 2021).

How to help and support people with swallowing disabilities and food insecurity with reduced sovereignty

Map the impact of dysphagia on the person/family's lives and collaboratively develop aspects of THRIVE:

- Food production
- Food preparation
- Food/diet texture classification
- Mealtime risks management and primary care

There is no single solution or textbook response to any of the aspects of THRIVE.

Table 13.2 Safe swallowing/mealtime guidelines.

	Desirable	If not possible then consider
Body position	Sit upright. If in a chair, then make sure your feet are on the ground and your bottom is against the back of the chair.	If sitting upright is not possible then ensure your upper body is elevated at least 45 degree or consider tilting (or lying) on the unaffected/stronger side (if relevant).
	<ul style="list-style-type: none"> · There is no one/universal safe position for swallowing. It is dependent on many factors. · It is generally considered unsafe to eat or drink when lying flat on a surface like a bed. · Keep the same position for at least half an hour after eating/drinking. 	
Head/neck posture	Your neck should be in a neutral position and when you swallow you should tuck your chin toward your chest as far as possible.	Consider sitting forward/tilting your top half of your body forward to avoid foods rushing toward your airways.
	It is considered least safe to eat/drink with your head tilted backwards.	
Pace	Eat slowly and especially drink small amounts of liquids.	<i>For carers:</i> Only present/make small amounts of food available per bite/mouthful, then wait before offering another amount of food.
Talking/distractions	No talking when eating or drinking.	Eat in a quiet place or face one other person only.
Food textures/liquid thicknesses	Eat/drink only what is safest for you to swallow (as prescribed by your healthcare worker).	Ask your healthcare worker to consider the International Dysphagia Diet Standardization Initiative (IDDSI) https://iddsi.org/Framework . See especially the testing methods used to classify food textures and the thickness of liquids.
	Avoid: <ul style="list-style-type: none"> • mixed textures of foods like thin liquid soups with vegetables/meat floating in it • foods that break up and stick onto surfaces like popcorn and some beans with skins • fruit/vegetables with skins, like peas, or seeds, like tomatoes • stringy or 'leafy' foods like spinach, lettuce • sticky foods like toffee • hard foods like nuts, seeds • foods that change textures like ice-cream or wafers that melt 	
Use of feeding instruments	Avoid using straws or spouted cups unless asked to do so by a dysphagia-trained healthcare professional	
Mouth check	Always look around your mouth (use a mirror if necessary) and make sure there are no foods in your cheeks or under your tongue, anywhere in your mouth	

Solutions should be based on the needs of the individual with the swallowing disability and the knowledge of their retained abilities as well as their disability. It is important to include consideration of the family and caregivers as well as governments and NGOs in the field. THRIVE is part of a bigger movement that positions swallowing disabilities within a framework of equity and population-based strategies (Pillay & Kathard, 2018; Department of Health and Rehabilitation Sciences, 2021).

Key Dos and Don'ts

Initially, as choking and aspiration risks are common, it is important to establish a clear healthcare pathway from home/community to contextually relevant, available medical and rehabilitation services. In the case of an immediate risk, it may be useful to ensure that the person's mouth is clear by removing any food/object that are obstructing the airway, as far as possible. Methods like the Heimlich manoeuvre should be taught, as appropriate.

Dysphagia practices should not be imported from well-resourced contexts and made to fit elsewhere. For example, richer/Minority World citizens may have access to dysphagia texture-modified foods whereas Majority World citizens (including the impoverished in, e.g., Europe, North America, and Australasia) may not have access to even commercial food thickeners. Consider alternative thickeners, such as agar, potato starch, and other solutions developed to meet IDDSI levels. Naturally thick items can also be considered, such as yogurt, applesauce, cream soups and puddings.

Practitioners should consider talking about food production for homes/families, not only for the person living with the swallowing disorder, such as suggestions for a home garden. There are also indigenous, culturally relevant foods that are dysphagia-friendly foods which maintain a consistent texture and content when eaten or cooked (e.g., sweet potatoes, taros, and yams).

Food preparation methods should be considered when prescribing diet textural modifications. For example, if local, indigenous thickeners are used, then test the ease-of-use and economic value of simple food preparation methods like using forks to whisk (and aerate) foods to IDDSI level 4 (pureed/extremely thick) foods/liquids (de Villiers et al., 2019). The International Dysphagia Diet Standardization Initiative (IDDSI) is a global standard with terminology and definitions to describe texture-modified foods and thickened liquids used for individuals with dysphagia of all ages, in all care settings, and for all cultures.

It is important to invest in methods for the food to act as a dysphagia therapeutic tool. Where there are too few dysphagia service providers then it makes sense to develop foods that improve the swallow when eaten. For example, exploit the therapeutic potential of thermal (hot/cold) or chemical (sour boluses) properties. Transitional foods that are crispy/crunchy (food textural acoustics) may contain useful sensory properties to enhance swallowing/motor responses (Karani & Pillay, 2021).

Information for professionals working with people living with swallowing disabilities

The purpose of this section is to provide a brief update of current knowledge trends, and to provide links to useful resources for professionals working with un(der)served people living with swallowing disabilities.

Updates on dysphagia assessments and interventions

Three core issues are worth highlighting specifically for their relevance to Majority World contexts, especially for those affected by colonial processes:

- Contextualization
- Culture
- Community

Contextualization of dysphagia standards/practices: Dysphagia practitioners focused on Majority World un(der)served populations should critically reconsider their clinical reasoning as contextually responsive practices (Pillay & Pillay, 2021). This means accounting for the experiences of vulnerable and impoverished people, multilingual populations and the unique needs of marginalized, un(der)served people from First Nations/indigenous, Black and Ethnic Minorities or migrant populations (Pillay, 2013, Pillay & Kathard, 2018). Generally accepted (technical) dysphagia practice standards (e.g., instrumental diagnostic assessments) should be part of the plan when possible for un(der)served populations

Culture and swallowing and dysphagia clinical practices: Food, eating and mealtimes are intimately connected to culture (Riquelme, 2004). Interventions should account for class, gender, age, and a variety of other cultural factors. These cultural factors should affect how the deliver of biomedical-based rehabilitation practices (e.g., exercises, texture modified diets, safe swallowing strategies, see Table 13.2) should be considered alongside socio-cultural and political strategies like food sovereignty and security intervention.

Community-based dysphagia rehabilitation: Taking its cue from the WHO's Community Based Rehabilitation (CBR) matrix (WHO, 2010, p.67), dysphagia services should shift beyond hospital and clinical walls to homes and populations by working with families, local practitioners and community leaders.

Resources to inspire thinking/doing relevant work in un(der)served populations can be found in Table 13.3.

Discussion

This chapter has presented the causes of dysphagia and approaches when working with individuals with this disorder. As presented here, it is important to consider foods, position, and other factors when working with this population. The development of services that are equitable and which meet the needs of underserved populations is essential. This requires that practitioners, as well as having the necessary medical and therapeutic skills, can interpret the knowledge that they have about their clients' culture.

Table 13.3 Useful dysphagia, food sovereignty and food security practice/knowledge resources.

Dysphagia (general resources)	Dysphagia Research Society	https://www.dysphagiaresearch.org/
	ASHA paediatric dysphagia guidelines	https://www2.asha.org/PRPSpecificTopic.aspx?folderid=8589934965&section=Resources
	ASHA adult dysphagia guidelines	https://www.asha.org/practice-portal/clinical-topics/adult-dysphagia/
Dysphagia Screening Tools (see Table 13.1)	EAT-10	Belafsky, P.C., Mouadeb, D.A., Rees, C.J., Pryor, J.C., Postma, G.N., Allen, J., & Leonard, R.J. (2008). Validity and reliability of the Eating Assessment Tool (EAT-10). <i>The Annals of Otolaryngology, Rhinology, and Laryngology</i> , 117(12), 919–924. https://doi.org/10.1177/000348940811701210 Cordier, R., Joosten, A., Clavé, P., Schindler, A., Bülow, M., Demir, N., Arslan, S.S., & Speyer, R. (2017). Evaluating the psychometric properties of the Eating Assessment Tool (EAT-10) using Rasch Analysis. <i>Dysphagia</i> , 32(2), 250–260. doi: 10.1007/s00455-016-9754-2. Epub 2016 Nov 21. PMID: 27873090 Hansen, T. & Kjaersgaard, A. (2020). Item analysis of the Eating Assessment Tool (EAT-10) by the Rasch model: A secondary analysis of cross-sectional survey data obtained among community-dwelling elders. <i>Health and Quality of Life Outcomes</i> , 18(1), 139. doi: 10.1186/s12955-020-01384-2. PMID: 32404203; PMCID: PMC7222581
	Swallowing Disturbance Questionnaire	Cohen, J.T. & Manor, Y. (2011). Swallowing Disturbance Questionnaire for detecting dysphagia. <i>Laryngoscope</i> , 121(7), 1383–1387. https://doi.org/10.1002/lary.21839
	South African Dysphagia Screening Tool	Ostrowsky, C. & Seedat, J. (2016). The South African Dysphagia Screening Tool (SADS): A screening tool for a developing context. <i>South African Journal of Communication Disorders</i> , 63(1), 9 pages. doi: https://doi.org/10.4102/sajcd.v63i1.117
Texture Modified Foods	List of foods (including risky foods)	Hemsley, B., Steel, J., Sheppard, J.J., Malandraki, G.A., Bryant, L., & Balandin, S. (2019). Dying for a meal: An integrative review of characteristics of choking incidents and recommendations to prevent fatal and nonfatal choking across populations. <i>American Journal of Speech-Language Pathology</i> , 28(3), 1283–1297. https://doi.org/10.1044/2018_AJSLP-18-0150
	International Dysphagia Diet Standardization Initiative (IDDSI) www.iddsi.org	Cichero, J.A., Steele, C., Duivesteyn, J., Clavé, P., Chen, J., Kayashita, J., Dantas, R., Lecko, C., Speyer, R., Lam, P., & Murray, J. (2013). The need for international terminology and definitions for texture-modified foods and thickened liquids used in dysphagia management: Foundations of a global initiative. <i>Curr Phys Med Rehabil Rep</i> ;1(4):280–291. doi: 10.1007/s40141-013-0024-z. PMID: 24392282; PMCID: PMC3873065.

Food Sovereignty and Food Security	EPIC – Equitable Population-based Innovations for Communication (and swallowing)	http://www.dhrs.uct.ac.za/dhrs/divisions/csd/epic/team <i>includes examples of THRIVE and contact details of people working in the field</i>
		Borras, A.M. & Mohamed, F.A. (2020). Health inequities and the shifting paradigms of food security, food insecurity, and food sovereignty. <i>International Journal of Health Services: Planning, Administration, Evaluation</i> , 50(3), 299–313. https://doi.org/10.1177/0020731420913184 International Planning Committee. (2009). Final Declaration. People's Food Sovereignty Forum. Rome, Italy. Available at: http://www.foodsovereignty.org/Resources/Archive/Forum.aspx (15 April 2013).

Acknowledgements: Dr Mieke Moerman (IALP Dysphagia Sub-Committee Chair) and Dr Oshrat Sella (Member: Dysphagia sub-committee).

References

- Alliance for Food Sovereignty in Africa. (2021). Available at <https://afsafrica.org/>
- Altman, C.E., Heflin, C.M., & Patnaik, H.A. (2020). Disability, food insecurity by nativity, citizenship, and duration. *SSM: Population Health*, 10. doi:10.1016/j.ssmph.2020.100550
- Armstrong, R. & Shenk, J. (1982). *El Salvador, the Face of Revolution*, 2nd ed. Boston: South End Press.
- Beom, J., Oh, B.M., Choi, K.H., et al. (2015). Effect of electrical stimulation of the suprahyoid muscles in brain-injured patients with dysphagia. *Dysphagia*, 30, 423–429. <https://doi.org/10.1007/s00455-015-9617-2>
- British Red Cross. (2021). Learn first aid for someone who is choking. Available at <https://www.redcross.org.uk/first-aid/learn-first-aid/choking>
- CBR Matrix. (2021). Available at https://www.who.int/disabilities/cbr/cbr_matrix_11.10.pdf
- Charlton, K.E. (2016). Food security, food systems and food sovereignty in the 21st century: A new paradigm required to meet Sustainable Development Goals. *Nutrition and Dietetics*, 73(1), 3–12.
- Chen, S., Kent, B., & Cui, Y. (2021). Interventions to prevent aspiration in older adults with dysphagia living in nursing homes: A scoping review. *BMC Geriatrics*, 21, 429. Available at <https://doi.org/10.1186/s12877-021-02366-9>
- Cichero, J.A.Y., Lam, P., Steele, C.M., et al. (2017). Development of international terminology and definitions for texture-modified foods and thickened fluids used in dysphagia management: The IDDSI Framework. *Dysphagia*, 32, 293–314. Available at <https://doi.org/10.1007/s00455-016-9758-y>
- Cieza, A., Kamenov, K., Chatterji, S., Causey, K., Hanson, S.W., & Vos, T. (2020). Global estimates of the need for rehabilitation based on the Global Burden of Disease Study 2019: A systematic analysis. *The Lancet*, 396(10267), 2006–2017. Available at [https://doi.org/10.1016/S0140-6736\(20\)32340-0](https://doi.org/10.1016/S0140-6736(20)32340-0)
- Cipriano-Crespo, C., Rodríguez-Hernández, M., Cantero-Garrito, P., & Mariano-Juárez, L. (2020). Eating experiences of people with disabilities: A qualitative study in Spain. *Healthcare*, 8(4), 512. Available at <http://dx.doi.org/10.3390/healthcare8040512>.

- Coleman-Jensen, A., Rabbitt, M.P., Gregory, C.A., & Singh, A. (2017). *Household Food Security in the United States in 2016* (No. ERR-237). U.S. Department of Agriculture, Economic Research Service, Washington, DC <https://www.ers.usda.gov/webdocs/publications/84973/err-237.pdf?v=42979>, Accessed date: Apr 16, 2018.
- Department of Health and Rehabilitation Sciences. (2021). The Epic Project: University of Cape Town. Available at <http://www.dhrs.uct.ac.za/dhrs/divisions/csd/epic/team>
- de Villiers, M., Moodley, L., Pillay, M., & Hanson, B. (2019) The impact of modification techniques on the rheological properties of dysphagia foods and liquids. *Journal of Texture Studies*, 51(1), 154–168. <https://doi.org/10.1111/jtxs.12476>
- FAO, IFAD, UNICEF, WFP, and WHO. (2020). *The State of Food Security and Nutrition in the World 2020. Transforming food systems for affordable healthy diets*. Rome: FAO. Available at <https://doi.org/10.4060/ca9692en>
- Feeding Flock. (2019). Our assessment tools. Available at <https://www.feedingflock.com/tools>
- Food Empowerment Project. (2021). Colonization, food, and the practice of eating. Available at <https://foodispower.org/our-food-choices/colonization-food-and-the-practice-of-eating/>
- Food Security Cluster. (2010). IFRC: Global Food Security Assessment Guidelines - A Step-by-Step Guide for National Societies. Available at <https://fscluster.org/document/ifrc-global-food-security-assessment>
- Friedman, C. (2021). Food insecurity of people with disabilities who were Medicare beneficiaries during the covid-19 pandemic. *Disability And Health Journal*. doi: 10.1016/j.dhjo.2021.101166
- Garon, B.R., Sierzant, T., & Ormiston, C. (2009). Silent aspiration: Results of 2,000 video fluoroscopic evaluations. *Journal of Neuroscience Nursing*, 41(4), 178-185. Available at <https://doi.org/10.1097/JNN.0b013e3181aaaade>
- Global First Aid Reference Centre Platform. (2021). Available at <https://www.globalfirstaidcentre.org/>
- Hanley, M.J. (2018). Exploring the social context of choking and its implications for care. PhD thesis, University of Tasmania, Australia. Retrieved from: <https://eprints.utas.edu.au/30162/>
- Humanitarian Response. (2021). Available at <https://www.humanitarianresponse.info/en/coordination/clusters/food-security>
- Indigenous Food Systems Network. (2021). Available at <https://indigenousfoodsystems.org/>
- International Planning Committee. (2009) Final Declaration. People's Food Sovereignty Forum. Rome, Italy. Available at: <http://www.foodsovereignty.org/Resources/Archive/Forum.aspx> (15 April 2013)
- Jager, G. (1994). Community based education in speech pathology and audiology at the University of Durban-Westville. *South African Journal of Communication Disorders*, 41(1), 93–102. doi: <https://doi.org/10.4102/sajcd.v41i1.260>
- Karani, T.F. & Pillay, M. (2021). It's crunch time: Exploring the sensibility of food textural acoustics for individuals with dysphagia. *The South African Journal of Communication Disorders = Die Suid-Afrikaanse tydskrif vir Kommunikasiefwykings*, 68(1), e1–e12. <https://doi.org/10.4102/sajcd.v68i1.806>
- Kim, D.Y., Park, H.S., Park, S.W., & Kim, J. (2020). The impact of dysphagia on quality of life in stroke patients. *Medicine*, 99(34), p e21795. doi: 10.1097/MD.00000000000021795
- Kraaijenga, S.A.C., van der Molen, L., Jacobi, I., et al. (2015). Prospective clinical study on long-term swallowing function and voice quality in advanced head and neck cancer patients treated with concurrent chemoradiotherapy and preventive swallowing exercises. *European Archives of Otorhinolaryngology*, 272, 3521–3531. <https://doi.org/10.1007/s00405-014-3379-6>
- La Via Campesina. (2021). Available at <https://viacampesina.org/en>
- Loopstra, R., Reeves, A., & Stuckler, D. (2015). Rising food insecurity in Europe. *Lancet*, 385(9982), 2041. Available at [https://doi.org/10.1016/S0140-6736\(15\)60983-7](https://doi.org/10.1016/S0140-6736(15)60983-7)

- Martino, R., Silver, F., Teasell, R., Bayley, M., Nicholson, G., Streiner, D.L., & Diamant, N.E. (2009). The Toronto Bedside Swallowing Screening Test (TOR-BSST): Development and validation of a dysphagia screening tool for patients with stroke. *Stroke*, 40(2), 555–561. doi: 10.1161/STROKEAHA.107.510370. Epub 2008 Dec 12. PMID: 19074483
- McKerchar, C. (2020). An outbreak of hunger: The spread of food insecurity on a time of Covid-19. In: Child Poverty Action Group, *Aotearoa, land of the long wide bare cupboard/Food insecurity in New Zealand*. Retrieved on 29 August 2021. Available at <https://www.cpag.org.nz/assets/06062020%20CPAG%20Food%20Insecurity%20IV%20-%20FINAL.pdf>
- Morales, D.X., Morales, S.A., & Beltran, T.F. (2021). Racial/ethnic disparities in household food insecurity during the COVID-19 pandemic: A nationally representative study. *Journal of Racial and Ethnic Health Disparities*, 8(5), 1300–1314. Advance online publication. <https://doi.org/10.1007/s40615-020-00892-7>
- Navdanya. (2016). Available at <https://www.navdanya.org/site/>.
- Nestlé Health Science. (2021) AT-10: A swallowing screening tool. Available at <https://www.nestlehealthscience.com/health-management/gastro-intestinal/dysphagia/eat-10>
- Ortega, O., Rofes, L., Martin, A., et al. (2016). A comparative study between two sensory stimulation strategies after two weeks treatment on older patients with oropharyngeal dysphagia. *Dysphagia*, 31, 706–716. Available at <https://doi.org/10.1007/s00455-016-9736-4>
- Pillay, M. (2013). Can the subaltern speak? Visibility of international migrants with communicative and swallowing disabilities in the World Report on Disability. *International Journal of Speech-Language Pathology*, (15)1, 79–83.
- Pillay, M. & Kathard, H. (2015). Decolonizing health professionals' education: Audiology & Speech Therapy in South Africa. *African Journal of Rhetoric*, 7, 193–227. Available at <https://journals.co.za/doi/10.10520/EJC172807>
- Pillay, M. & Kathard, H. (2018). Renewing our cultural borderlands: Equitable Population Innovations for Communication (EPIC). *Topics in Language Disorders*, 38(2), 151–168. doi: 10.1097/tld.0000000000000151
- Pillay, T. & Pillay, M. (2021). Contextualising clinical reasoning within the clinical swallow evaluation: A scoping review and expert consultation. *South African Journal of Communication Disorders*, 68(1), e1–e12. doi: <https://doi.org/10.4102/sajcd.v68i1.832>
- Pillay, M., Tiwari, R., Kathard, H., & Chikte, U. (2020). Sustainable workforce: South African Audiologists and Speech Therapists. *Human Resources for Health*, 18(1), 47. Available at <https://doi.org/10.1186/s12960-020-00488-6>
- Quarmby, C.A. & Pillay, M. (2019). The intersection of disability and food security: Perspectives of health and humanitarian aid workers. *African Journal of Disability*, 7, e322. doi: 10.4102/ajod.v7i0.322. African Journal of Disability. 8.
- Richmond, C., Steckley, M., Neufeld, H., Kerr, R.B., Wilson, K., & Dokis, B. (2020). First Nations food environments: Exploring the role of place, income, and social connection. *Current Developments in Nutrition*, 4(8), 108. Available at <https://doi.org/10.1093/cdn/nzaa108>.
- Riquelme, L.F. (2004). Cultural competence in dysphagia. *The ASHA Leader*, 9(7). <https://doi.org/10.1044/leader.FTR5.09072004.8>
- Russomanno, J. & Jabson Tree, J.M. (2020). Food insecurity and food pantry use among transgender and gender non-conforming people in the Southeast United States. *BMC Public Health*, 20, 590. Available at <https://doi.org/10.1186/s12889-020-08684-8>
- Schwartz, N., Buliung, R., & Wilson, K. (2019). Disability and food access and insecurity: A scoping review of the literature. *Health Place*, 57, 107–121. doi: 10.1016/j.healthplace.2019.03.011. Epub 2019 Apr 24. PMID: 31026771

- Silverman, A.H., Kristoffer, B.S., Linn, C., et al. (2020). Psychometric properties of the Infant and Child Feeding Questionnaire. *Journal of Pediatrics*, 223, 81-86. doi: 10.jpeds.2020.04.040.
- Speyer, R., Baijens, L., Heijnen, M., et al. (2010). Effects of therapy in oropharyngeal dysphagia by Speech and Language Therapists: A systematic review. *Dysphagia*, 25, 40-65. <https://doi.org/10.1007/s00455-009-9239-7>
- Spurway, K. & Soldatic, K. (2016). "Life just keeps throwing lemons": The lived experience of food insecurity among aboriginal people with disabilities in the West Kimberley. *Local Environment*, 21(9), 1118-1131. Available at <https://doi.org/10.1080/13549839.2015.1073235>
- Steele, C.M., Alsanei, W.A., Ayanikalath, S., Barbon, C.E., Chen, J., Cichero, J.A., Coutts, K., Dantas, R.O., Duivesteyn, J., Giosa, L., Hanson, B., Lam, P., Lecko, C., Leigh, C., Nagy, A., Namasivayam, A.M., Nascimento, W.V., Odendaal, I., Smith, C.H., & Wang, H. (2015). The influence of food texture and liquid consistency modification on swallowing physiology and function: A systematic review. *Dysphagia*, 30(1), 2-26. Available at <https://doi.org/10.1007/s00455-014-9578-x>
- Suntrup, S., Marian, T., Schröder, J.B., et al. (2015). Electrical pharyngeal stimulation for dysphagia treatment in tracheotomized stroke patients: A randomized controlled trial. *Intensive Care Medicine*, 41, 1629-1637. <https://doi.org/10.1007/s00134-015-3897-8>
- Taniguchi, Y., Iwagami, M., Sakata, N., Watanabe, T., Abe, K., & Tamiya, N. (2020). Epidemiology of food choking deaths in Japan: Time trends and regional variations. *Journal of Epidemiology*, 31(5), 356-360. Available at <https://doi.org/10.2188/jea.JE20200057>
- Trapl, M., Enderle, P., Nowotny, M., Teuschl, Y., Matz, K., Dachenhausen, A., & Brainin, M. (2007). Dysphagia bedside screening for acute-stroke patients: The Gugging Swallowing Screen. *Stroke*, 38, 2948-2952.
- United Nations (2015). Sustainable Development Goals: 17 Goals to transform our world. <https://www.un.org/sustainabledevelopment/sustainable-development-goals/>
- United Nations. (2021). Creative Community Outreach Initiative (CCOI). Available at <https://www.un.org/en/collection/29/7832>
- Vergara, J., Lirani-Silva, C., Brodsky, M.B., Miles, A., Clavé, P., Nascimento, W., & Mourão, L.F. (2021). Potential influence of olfactory, gustatory, and pharyngolaryngeal sensory dysfunctions on swallowing physiology in COVID-19. *Otolaryngology-Head and Neck Surgery*, 164(6), 1134-1135. Available at <https://doi.org/10.1177/0194599820972680>
- Viviers, M., Kritzinger, A., & Graham, M. (2019). Reliability and validity of the neonatal feeding assessment scale (NFAS) for the early identification of dysphagia in moderate to late preterm neonates. *African Health Sciences*, 19(3), 2718-2727. Available at <https://doi.org/10.4314/ahs.v19i3.47>
- Wordpress.com. (2017). The Gugging Swallowing Screen. Available at https://gussgroupinternational.files.wordpress.com/2017/01/guss_english_mai2017.pdf
- World Bank. (1986). *Poverty and Hunger: Issues and Options for Food Security in Developing Countries*. Washington, DC: World Bank.
- World Food Program (2021). Available at <https://www.wfp.org/>
- World Health Organisation (2011). World Report on Disability. Available at file:///C:/Users/sandr/Dropbox/PC/Downloads/WHO_NMH_VIP_11.01_eng.pdf
- World Health Organisation (2020). The state of food security and nutrition in the world. Available at <https://www.who.int/publications/m/item/state-of-food-security-and-nutrition-in-the-world-2020>
- World Vision (2021). Available at <https://www.worldvision.org/>
- Wylie, K., McAllister, L., Davidson, B., & Marshall, J. (2013). Changing practice: Implications of the World Report on Disability for responding to communication disability in underserved populations. *International Journal of Speech-Language Pathology*, 15, 1-13.