

Original Paper

A Pilot Study of the Rehabilitation Services Provided for Patients with Dysphagia in Medical Settings in Jordan

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Abstract

Services provided for dysphagia conditions are poorly investigated in Jordan. The aim of this study was to explore the rehabilitation services provided to patients with dysphagia in medical settings in Jordan. Data were collected from public and private hospitals, hearing and speech centres, and rehabilitation centres located in Amman province. Thirty-eight participants (16 patients and 22 professionals from various disciplines) were interviewed. There was limited knowledge about dysphagia among healthcare professionals. The provision of rehabilitation services was minimal and secondary to the provision of medical services. Clinical pathways and guidelines need to be devised to organize the work of professionals involved in the management of dysphagia.

Keywords

Dysphagia, occupational therapists, speech pathologists, rehabilitation services

1. Introduction

Over 6 million Americans suffer from dysphagia (American Speech-Language-Hearing Association (ASHA), n.d.d, n.d.c). One in 17 people will develop some form of dysphagia in their lifetime (The Agency for Health Care Policy and Research (AHCPR), 2005). 50% Americans over 60 will experience dysphagia at some point after that age. It is estimated that up to 75% of nursing home

residents experience some degree of dysphagia (AHCPR, 2005).

Patients with multiple neuropathy critical illness and who are admitted in the intensive care unit (ICU) frequently have some form of dysphagia. Many factors can contribute to the development of dysphagia such as age, Chronic Obstructive Pulmonary Disease (COPD), mechanical ventilation, tracheal tubes, and in some instances of non-use behaviours (Ponfick Linden & Nowak, 2015). The prevalence of dysphagia in neurological diseases such as Parkinson's disease and Amyotrophic lateral sclerosis (ALS) runs as high as 90% (Troche et al., 2010). Dysphagia is also a very common post-stroke symptom; in their study, Ho, Liu and Huang (2014) found that over half of the rehabilitation unit stroke patients had dysphagia.

The significance of investigating dysphagia stems from the fact that it is associated with several complications such as aspiration pneumonia, malnutrition, and increased length of hospitalization (Ho et al., 2014; ASHA, n.d.c). Dysphagia can cause choking, bronchospasm, an increased infection rate, dehydration and weight loss (ASHA, n.d.d). In head and neck cancer patients, dysphagia can also lead to poor wound healing and reduced tolerance to medical treatments (Gaziano, 2002). Furthermore, dysphagia is known to have various debilitating side-effects on the health and quality of life of patients (Swan, Speyer, Heijnen, Wagg, & Cordier, 2015). Dysphagia has negative psychological side effects such as depression and anxiety (Zhang, Huang, Wu, Chen, & Huang, 2014). This, in part, is due to the fact that oral food intake is one of the pleasures human beings experience (Kringelbach, 2015).

Signs used for the identification, evaluation and treatment of dysphagia are variable as their representation varies from a patient to another (Kruger, 2014). This in turn, adds the complexity of the rehabilitation of dysphagia due to the variation in the application of the procedures of assessment and intervention especially in Jordanian medical institutions. In fact, and as an example of this variability, Cray and Carnaby (2014) report that the frequency of coughing/dysphagia incidences increase following a clinician's decision concerning the timing of introduction of oral intake, and the texture material and the size of bolus, which varies from clinician to clinician.

Langmore and Pisegna (2015) report that the rehabilitation of dysphagia is challenging due to lack of consensus concerning the criteria that constitutes a healthy swallow, and the criteria used to measure its improvement (Langmore & Pisegna, 2015). Such criteria could be related to minimized complications such as decreased recurrences of aspiration, patient's satisfaction, the pressure generated on the pharyngeal walls while swallowing, the strength of the swallow by measuring the strength of the tongue during the process, the endurance of the patient over various textures, and/or the speed of the onset of the swallow (Langmore & Pisegna, 2015).

1.1 Dysphagia Rehabilitation: Common Approaches/Manoeuvres

Methods used for the assessment and evaluation of dysphagia are multiple. There are clinical non-instrumental assessment approaches such as cervical auscultation, meal observation, orofacial examination and the instrumental assessment approaches that rely on the use of instruments assessment tools such as Fibreoptic Endoscopic Evaluation of Swallowing (FEES) and modified barium swallow

tests (ASHA, n.d.d). However, in their study, Kjaersgaard, Nielsen and Sjølund (2014) found that both instrumental and non-instrumental approaches of evaluation are equally effective in making a decision concerning the initiation of oral intake, and reducing the risk of aspiration pneumonia for the initiation oral intake (Kjaersgaard et al., 2014; Kjaersgaard, Nielsen, & Sjølund, 2015).

One of the most common rehabilitation methods for the management of dysphagia is Exercise-based therapies (Crary & Carnaby, 2014). Also, Transcutaneous Electrical Stimulation (TES) contributes to exercise-based dysphagia rehabilitation in adults (Crary & Carnaby, 2014). Also, one of the compensatory techniques is the intraoral stimulation using the tactile, temperature and variation in size and texture of food. For example, H ägg and Tibbling (2015) found in their study of 31 stroke patients a significant improvement in the activity of the four facial quadrants, in the swallowing capacity, and in lip force following the application of the intraoral stimulation even in cases of long-standing post-stroke dysfunction.

For the effects of the swallowing training to be effective, Zhang et al. (2014) found that the earlier the identification and the initiation of the management starts, the better it is in counteracting the negative effects of anxiety and depression. In addition, in their study Murray Miller, Doeltgen and Scholten (2014) found that the management of dysphagia and its side effects should be directed at counteracting the dehydration by the incorporation of protocols for the provision and monitoring of consumption of liquids, by offering more fluid via thickened-food or free water protocols or by routine use of non-oral supplementary routes.

1.2 Recent Investigations

Crary and Carnaby (2014), in their review, report the presence of a rising acknowledgement of the complexity of dysphagia and which resulted into a shift in its common rehabilitation practices (Crary & Carnaby, 2014). Recently, there is a growing awareness for the need for designing integrative and comprehensive rehabilitative programmes for dysphagia management instead of relying on techniques centred on a single practice, e.g. oral-motor exercises (Crary & Carnaby, 2014). There is a shift in the trend of managing dysphagia from solely relying on exercise therapy to the use of adjunctive methods, particularly the Transcutaneous Electrical Stimulation (TES) (Crary & Carnaby, 2014). Also, the current practices focus on the incorporation of documentation of physiological changes as a method of evaluation of dysphagia and monitoring the progress brought forth by exercise therapy (Crary & Carnaby, 2014).

There are multiple exercise based rehabilitative techniques/manoeuvres employed for the management of dysphagia such as the effortful swallow, the masako, the super-supraglottic exercise, and the McNeill dysphagia treatment protocol (Langmore & Pisegna, 2015). However, such procedures lack the sufficient evidence that supports their utility due to scarcity of research studies (Crary & Carnaby, 2014; Langmore & Pisegna, 2015) (Table 1 summarizes examples of some studies and their limitations). Even when the effects of such techniques are researched, generally their effects are limited to short term outcomes (Langmore & Pisegna, 2015).

A number of studies have been conducted to investigate the efficacy of various dysphagia rehabilitation techniques with good but inclusive results. For example, in a pilot study, Cheng Chan, Wong and Cheung (2015) investigated the utility of repetitive transcranial magnetic stimulation (rTMS) in the rehabilitation of dysphagia and found positive effects on swallowing functions and on quality of life. On a sample of 4 subjects, Cheng et al. (2015) investigated the short run effects of the rTMS by measuring and comparing the evaluating results of Videofluoroscopic Swallowing Study (VFSS), swallowing-related quality of life questionnaire, and the tongue pressure assessment three times: at baseline, at one week, and one month after its application.

Troche et al. (2010) have investigated the effectiveness of the Expiratory Muscle Strength Training (EMST) in patients with Parkinson's disease. There were significant results for the use of such technique on the quality of life and the function of the Upper Esophageal Sphincter (UES) of the patents.

Shaker et al. (2002) conducted a Randomized Control Trial (RCT) on 27 patients where the effects of the Suprahyoid muscle strengthening exercise [Shaker head lift] was investigated in 11 patients [exercise group] against 7 patients [Sham group]. Subjects of this study were having multiple conditions such as brainstem stroke, myocardial revascularization, and pharyngeal radiation. Though the study found significant results of the employment of the Shaker head lift exercise on swallowing function.

The study conducted by Hägg and Tibbling (2015) conducted a study on 31 stroke patients to investigate the benefits of intraoral stimulation with stroke patients. The study provided significant results in facial activity and lip force brought forth by the application of intraoral stimulation.

The rehabilitative approaches for intervention of dysphagia need to be further evaluated and researched due to methodological limitations associated with the sample size, research design, and inclusion criteria of participants (Crary & Carnaby, 2014). Such methodological limitations may limit the generalization of the results of studies that yield the evidence concerning the utility of common techniques for the management of dysphagia (Langmore & Pisegna, 2015).

In Jordan, research regarding dysphagia in general and the efficacy of the rehabilitative techniques in particular is scarce. As such, professional practices in dysphagia assessment and rehabilitation is generally are generally not well support by research investigations other than those conducted in the Western countries.

Table 1. Studies Investigating Effects of Assessment and Intervention Manoeuvres Used in Dysphagia Rehabilitation

Manoeuvre/ Approach/ Technique	Number (n) & Design	Population	Initiation & Duration of intervention	Significance	Study
Facial-Oral Tract Therapy (FOOT)	RCT n=119 Mean age= 60 years	Acquired brain injury including stroke, subarachnoid haemorrhage,	Initiation since onset: - 112 included within 90 days after injury - 2 patients within 180 days - 5 within more than 360 days	No significant difference between both approaches: In the number of patients with pneumonia before or after oral initiation. No significant difference in the effectiveness of both approaches for: - Evaluation for eligibility for oral intake - Reducing the risk of aspiration pneumonia	Kjaersgaard et al. (2015) & Kjaersgaard et al. (2014)
Fibreoptic Endoscopic Evaluation of Swallowing (FEES)	- (n= 62) FOOT (control group) - (n=57) FEES (intervention group)	traumatic brain injury and anoxia, & other neurological disorders			
Intraoral stimulation	Prospective study n= 31 - (n=11)Group 1 (median age= 71 years) - (n=20)Group 2 (median age= 61 years)	Stroke	Initiation since onset: - Group 1 started 5 weeks after their stroke - Group 2 started 57 weeks after stroke Progress measured: - At baseline - End of treatment (After a three-months) - Follow-up (at least after one year)	Improvement was significant in both groups between the (baseline and follow up, and baseline and end of treatment (P < 0.001) in: - All four facial quadrants demonstrated by scores of facial activity test (FAT) - Swallowing capacity demonstrated by scores of swallowing capacity test (SCT) - Lip force demonstrated but score of lip force test (LF) Not significant in both groups between end of treatment and follow up)	Häg g and Tibbling (2015)
repetitive Transcranial Magnetic Stimulation (rTMS)	RCT n=4 Mean age = 71 (2 women and 2 men) - (n=2) EMST - (n= 2) Sham group	Chronic dysphagia after stroke	Initiation since onset: - 2 years after onset Frequency & durations of intervention: - 10 sessions of 5 Hz active stimulation (intervention group) - 10 sessions of sham stimulation (control group). - 10 sessions for 2 weeks , each session was 30 min, 3000 pulses 5 Hz rTMS/session Progress measured: - After 1 week - And after 1 month	(Significance NA) however it stated that rTMS improves: - Swallowing functions - Quality of life	Cheng et al. (2015)
Expiratory Muscle Strength Training (EMST)	RCT n= 60 (n=30) EMST (mean age=66.7) (n= 30) Sham group (mean age=68.5)	Idiopathic Parkinson's disease	Initiation since onset: - NS Frequency & durations of intervention: - 4 weeks, 5 days per week, for 20 minutes per day (Sham & EMST groups) Progress measured: - After 2 nd visit (2 nd week) - And after 4 weeks	Significant in: - Quality of life (p =0.007) Significant in (Pre & post): - UES opening (p = 0.007) - UES closure (p = 0.007) - UEs widest (p = 0.007) - Penetration- aspiration score (p=0.021)	Troche et al. (2010)
Suprahyoid muscle strengthening exercise [Shaker head lift]	RCT n=27 Median age=72 years (n=11) Intervention (n=7) Sham	Multiple conditions (CVA, carotid endarterectomy, brainstem stroke, Myocardial revascularization, Pharyngeal radiation)	Initiation since onset: - NS Frequency & durations of intervention: - 3 times per day for 6 weeks Progress measured: - At baseline - After 6 weeks	Significant in (between groups): - Functional Outcome Assessment of Swallowing (FOAMS) (P= 0.01) Significant in (Pre & post): - Anteroposterior diameter of the UES opening (P =0.01) - Anterior laryngeal excursion (P=0.01) - FOAMS (P=0.01)	Shaker et al. (2002)

Note. n= number, UES= Upper Esophageal Sphincter, FOAMS= Functional Outcome Assessment Measurements of Swallowing, NA= Not Applicable as not provided by the source.

1.3 Research Aim and Objectives

This paper represents the findings of pilot study that aims to explore the nature of rehabilitation services provided to patients with dysphagia in medical settings in Jordan. This paper reports the findings which incorporated qualitative research methodologies.

2. Methods

2.1 Design

Information regarding the current practices in dysphagia assessment and rehabilitation is far from sufficient on. That is, the knowledge about rehabilitation services provided in medical institutions in Jordan is scarce and this gathering information through specifically designed exploratory questionnaires and personal interviews a suitable design to underpin this research study, and as an approach for data analysis.

2.2 Sample and Recruitment

The sample constituted 38 participants (22 males, 16 females). They are 16 patients (9 males, 7 females) with dysphagia and 22 professionals (13 males, 9 females) (i.e., 2 physicians, 16 nurses, and 4 speech pathologists in terms of discipline). The average experience of professionals was 11.4 years (range 1-36 years). Table 2 demonstrates the demographics of both the patients and the professionals, while Table 3 presents the experience and the specialization of the professionals.

Table 2. Demographics of Participants

	Patients (n=16)	Professionals (n=22)	TOTAL (n=38)
Age (mean)	48.5 yrs	33 yrs	39.9 yrs
Age range	18-93 yrs	23-53 yrs	18-93 yrs
Gender male (%)	9 (41%)	13 (59%)	22
Gender female (%)	7(43.8%)	9 (56.2%)	16

Note. n= number, yrs= years

Table 3. The Specializations and Experiences of Professionals

	Number (n)	Unit/department	Average experience (yrs)	Range of experience (yrs)
Nurses	16	Endoscopy unit, General surgery, Intensive Care Unit (ICU), Internal medicine unit, otorhinolaryngology unit (ENT), Paediatrics unit, rehabilitation Centre	10.3	1-28
Physicians	2	Gastroenterology (GI) unit, Cardiac & Internal medicine Unit	25.5	15-36

SLPs	4	Rehabilitation department or speech and hearing centre	8	7-9
Total/ overall	22	-	11.4	1-36

Note. n= number, yrs= years, SLPs= Speech Language Pathologists

Data were collected from various medical institutions: 3 public hospitals, two private hospitals, one private hearing and speech centre, one public centre, and one public rehabilitation and reform centre, all of which were located in Amman province. Amman is the capital of Jordan where most health-related services are concentrated.

Professionals who had a certificate of experience in dysphagia or self-reported exposure to dysphagia conditions were included in the current study. It should be noted here that dysphagia practice in Jordan is still in its developing stage. Additionally, none of the medical institutions contain a specialized department or a unit to evaluate or manage dysphagia. Thus, departments where dysphagia patients were located such as the ICU, the Internal medicine Unit, and the Otorhinolaryngology (ENT) Unit were targeted.

2.3 Data Collection

The semi-structured interview was selected as the method of data collection to allow for in-depth data to be gathered (Ritchie & Lewis, 2007). A crude interview guide was used and included questions that served as pointers only, and were typically followed by prompts, such as *Can you elaborate on that? Or give an example from your own experience?* Table 4 demonstrates the main topic that was explored: “Rehabilitative services provided”, and some examples of questions pertinent to each topic.

Table 4. Examples of Questions from the Topic Guide

Topic	Questions (Patients)	Questions (Professionals)
Rehabilitative services provided	<ul style="list-style-type: none"> – Were there any tests provided to you to evaluate and manage dysphagia? – Who are the professionals involved in the management of dysphagia? 	<ul style="list-style-type: none"> – How are patients with dysphagia identified? – Are there any clinical pathways or guidelines that govern the provision of dysphagia rehabilitation services? – What are the rehabilitation services provided for dysphagia? – Who are the professionals that are mainly involved in the management of dysphagia? What is the role of each one of them?

2.4 Ethical Issues

Ethical approval to pursue this study was granted from the Institutional Review Board at the [concealed for blinded review].

2.5 Data Analysis

After data collection, data was organized under a set of codes where data scripts that share the same topic or keywords were aligned under each code. After that, the codes were grouped into themes where the coded data that share the same meaning were grouped together under the same theme. MAXQDA11 software was used to assist the tabulation of data under a set of codes and themes. Finally, from the constructed themes which are the basis for the creation of interrelations and explanations.

3. Findings

The data analysis revealed five main themes: The subjects understanding of the primary conditions where dysphagia presents as secondary symptom, the symptoms of concern used to identify dysphagia, the professionals involved in the management in dysphagia, the rehabilitative services provided, and level of knowledge about dysphagia. Those are presented in Figure 1 and will be further discussed in the subsequent subsections.

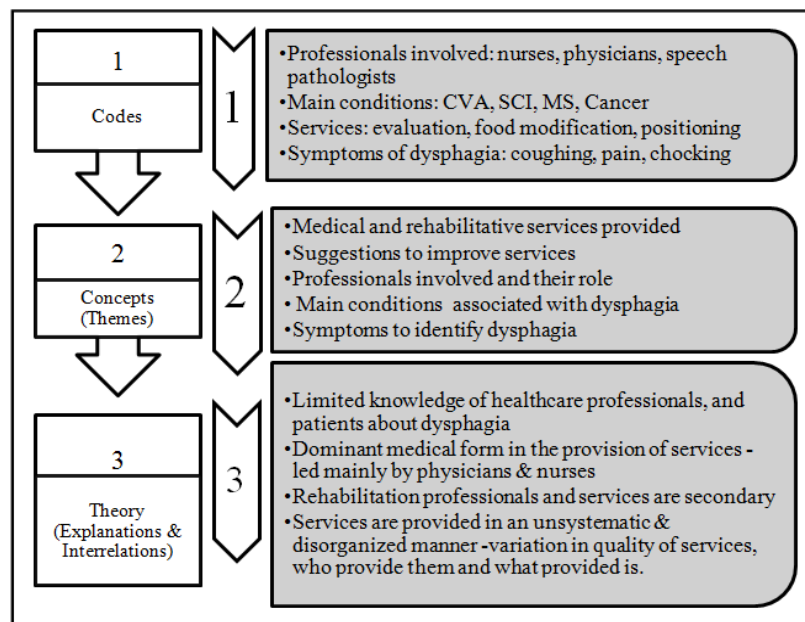


Figure 1. The Main Emergent Themes of Data Analysis

3.1 Dysphagia: The Primary Conditions

Based on the findings of this study, dysphagia presented as an associated symptom with other primary conditions which are presented in Table 5. Cerebrovascular Accident (CVA) was the most neuromuscular conditions reported by participants to result in dysphagia. For the GI tract disorders, the Gastroesophageal Reflux Disease (GERD) was the most common disorder resulting in dysphagia as

reported by participants. Table 5 summarizes the main findings concerning the main conditions that caused dysphagia and their percentages.

Table 5. Primary Conditions Where Dysphagia Presents as Secondary Symptom

Genre/ Main department	N & (%) Genre	Main condition	n & (%) Patients	n & (%) Professionals	n & (%) Total
Neuromuscular diseases	24 (63.2%)	CVA	7 (43.8%)	14 (63.6%)	21 (55.3%)
		CP	1 (6.3%)	3 (13.6%)	4 (10.5%)
		Sclerosis (Amyotrophic lateral, Multiple)	0 (0%)	3 (13.6%)	3 (7.9%)
		Meningitis	1 (6.3%)	1 (4.5%)	2 (5.3%)
		Myasthenia gravis	0 (0%)	2 (9.1%)	2 (5.3%)
		Brain Haemorrhage	1 (6.3%)	1 (4.5%)	2 (5.3%)
		Not specified	0 (0%)	1 (4.5%)	1 (2.6%)
		GI unit	13 (34.2%)	GERD reflux	1 (6.3%)
GI tract infections	0 (0%)	2 (9.1%)		2 (5.3%)	
Esophageal Motility Disorders	0 (0%)	2 (9.1%)		2 (5.3%)	
Other	0 (0%)	9 (40.9%)		9 (23.7%)	
Cancer	12 (31.6%)	Not specified		1 (6.3%)	11 (50%)
Cardiopulmonary diseases	7 (18.4%)	-	4 (25%)	3 (13.6%)	7 (18.4%)
ENT unit	7 (18.4%)	Not specified	1 (6.3%)	6 (27.3%)	7 (18.4%)
Psychogenic	6 (15.8%)	-	1 (6.3%)	5 (22.7%)	6 (15.8%)
Internal medicine unit	5 (13.2%)	Not specified	1(6.3%)	4 (18.2%)	6 (13.2%)
RTAs & TBIs	4 (10.5%)	-	1 (6.3%)	3 (13.6%)	4 (10.5%)
SCIs	3 (7.9%)	-	2 (12.5%)	1 (4.5%)	3 (7.9%)
ICU	2 (5.3%)	Not specified	0 (0%)	2 (9.1%)	2 (5.3%)
ASD	1 (2.6%)	-	0 (0%)	1 (4.5%)	1 (2.6%)

Note. ASD=Autism Spectrum Disorder, CVA= Cerebrovascular Accident, CP=Cerebral palsy, GI=Gastro-Intestinal, ICU= Intensive Care Unit, RTAs=Road Traffic Accidents, TBIs= Traumatic Brain Injuries, SCI=Spinal Cord Injuries

3.2 Symptoms of Dysphagia

The findings of this research showed that there are specific differential signs that the patients/their family members and the professionals depend on to identify dysphagia conditions which are presented in Table 6.

Table 6. Main Symptoms Used to Identify the Presence of Dysphagia

Complaint/observation	n & (%)	n & (%)	n & (%)
	Patients	Professionals	Total
Pain & difficulty while swallowing	9 (56.3%)	11 (50%)	20 (52.6%)
Aspiration & Coughing	9 (56.3%)	6 (27.3%)	15 (39.5%)
Total avoidance of eating and/or drinking	5 (31.3%)	2 (9.1%)	7 (18.4%)
Aspirations Pneumonia & high body temperature	0 (0%)	5 (22.7%)	5 (13.2%)
Absence of gag reflex	0 (0%)	5(22.7%)	5 (13.2%)
Only eating/drinking a specific sort of food	4 (25%)	0 (0%)	4 (10.5%)
Chocking /difficulty breathing while eating	1 (6.3%)	3 (13.6%)	4 (10.5%)
Eating/drinking a small portion	3 (18.8%)	0 (0%)	3 (7.9%)
Constipation and abdominal pain	2 (12.5%)	0 (0%)	2 (5.3%)
Effortful & prolonged eating and/or drinking (takes time)	1 (6.3%)	1 (4.5%)	2 (5.3%)
Vomiting	2 (12.5%)	0 (0%)	2 (5.3%)
Loss of weight	0 (0%)	1 (4.5%)	1 (2.6%)

An interesting finding was that though some complaints were reported by the patients and their families as a sign of dysphagia, those complaints were not reported to be of concern for the identification of dysphagia by professionals. Those complaints were avoidance of a specific sort of food/drinks or, only eating/drinking a specific sort of food/drinks, eating/drinking a small portion, constipation and abdominal pain, and vomiting (Table 6).

Another interesting finding was that about (22.7%) of professionals reported that the examination of the gag reflex is an important procedure for the identification of dysphagia. However, several research studies are raising doubts regarding the clinical relevancy of this for the identification of dysphagia such as the study conducted by Leder (1996). This finding will be further discussed in subsequent sections.

3.3 Professionals Involved in the Management of Dysphagia

The main professionals involved in the management of dysphagia in Jordan as reported by participants respectively were the physicians, nurses, nutritionists, speech pathologists, occupational therapists, and (Table 7 summarizes the results). It should be noted here that some professionals who are involved in the overall management of dysphagia patient (physicians, nurses, physiotherapists, and psychiatrists), were viewed by the participants as specifically involved with the management of the dysphagia condition.

Table 7. Professionals Involved in Dysphagia Management in Jordan

Professional	n & (%)	n & (%)	n & (%)
	Patients	Professionals	Total
Physicians	8 (50%)	22 (100%)	30 (78.9%)
Nurses	2 (12.5%)	14 (63.6%)	16 (42.1%)
Nutritionists	2 (12.5%)	10 (45.5%)	12 (31.6%)
Speech pathologists	0 (0%)	3 (13.6%)	3 (7.9%)
Occupational therapists	0 (0%)	3 (13.6%)	3 (7.9%)
Physiotherapists	0 (0%)	2 (9.1%)	2 (5.3%)
Psychiatrists	0 (0%)	1 (4.5%)	1 (2.6%)

Note. n= Number

The medical staffs (physicians and nurses) were viewed as dominant in the provision of services for dysphagia patients. The main role of physicians, who were the main professionals involved in the management of dysphagia, as reported by participants, was directed at performing the instrumental and non-instrumental evaluation (26.3%), educating the patients and their family members about dysphagia and its management (21.1%), diagnosis, performing referrals to other services (18.4%), applying feeding tubes (15.8%), prescribing medications (15.8%), and giving instructions and recommendations to other professionals (nurses, nutritionists and speech pathologists) (13.2%). Physicians were the first encounter in the process of the management of dysphagia, as nurses reported:

“If the patient had a complaint of a difficulty in swallowing, we report that to the physician. It requires first a medical procedure undertaken by physicians” [Pro.II, nurse]

The main role of nurses was directed at applying the instructions of the physician concerning the texture and the type of food to be provided to patients (13.2%), and grading the texture of food/drinks, the speed of feeding and the size of bolus while feeding the patients (15.8%). Performing oral motor exercises and Thermal Tactile Oral Stimulation (TTOS) was reported by (5.3%) to be equally the role of occupational therapists and nurses, while positioning was mainly performed by nurses and speech pathologists as reported by (2.6%) of participants.

The main role of nutritionist as reported by (23.7%) of participants was directed at evaluating the dietary needs of patients and designing dietary programmes suitable for each patient's condition. However, the role of nutritionists was not always evident in all institutions which required nurses to do it, as reported by some nurses:

“Because we don't have a nutritionist who can follow up each case, we try to do that and give instructions to family members concerning what to do” [Pro.II, nurse].

Table 8 summarizes the role of professionals as reported by participants.

Table 8. Role of Professionals in Dysphagia Management

Role	Physicians	Nurses	Nutritionists	SLPs	OTRs	PTs	Psychiatrists	Total
Non-instrumental & Instrumental Evaluation	10 (26.3%)*	3 (7.9%)	0 (0%)	3 (7.9%)	0 (0%)	0 (0%)	0 (0%)	16 (42.1%)
Education & counselling (the family and the patients)	8 (21.1%)*	3 (7.9%)	2 (5.3%)	1 (2.6%)	0 (0%)	0 (0%)	1 (2.6%)	15 (39.5%)
Referrals to other services	7 (18.4%)*	1 (2.6%)	0 (0%)	1 (2.6%)	0 (0%)	0 (0%)	0 (0%)	9 (23.7%)
Diagnosis	7 (18.4%)*	0 (0%)	0 (0%)	1 (2.6%)	0 (0%)	0 (0%)	0 (0%)	8 (21.1%)
Applying the orders of the physician concerning the texture and type of food	0 (0%)	5 (13.2%)*	3 (7.9%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	8 (21.1%)
Applying feeding tubes	6 (15.8%)*	2 (5.3%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	8 (21.1%)
Gradation in the texture of food/drinks while feeding the patient	0 (0%)	6 (15.8%)*	0 (0%)	2 (5.3%)	0 (0%)	0 (0%)	0 (0%)	8 (21.1%)
Designing a dietary programme suitable for the patient's condition	0 (0%)	0 (0%)	9 (23.7%)*	0 (0%)	0 (0%)	0 (0%)	0 (0%)	6 (15.8%)
Prescribing medication	6 (15.8%)*	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	6 (15.8%)
Directing other specialists concerning the texture of food to be given	5 (13.2%)*	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	5 (13.2%)
Oral motor exercises & TTOS	0 (0%)	2 (5.3%)*	0 (0%)	0 (0%)	2 (5.3%)*	1 (2.6%)	0 (0%)	5 (13.2%)
Positioning	0 (0%)	1 (2.6%)*	0 (0%)	1 (2.6%)*	0 (0%)	0 (0%)	0 (0%)	2 (5.3%)

Note. *= Highest percentage, SLPs= speech pathologists, OTs= Occupational therapists, PTs= Physiotherapist

Participants reported that professional involved in the management of dysphagia conditions were not working as a team but rather their efforts were dispersed and disorganized. There were referrals between departments and between various disciplines, however several professionals did not know the role of other professionals. Some participants even thought that the management of dysphagia is exclusive to speech pathologists:

“The evaluation [[instrumental and non-instrumental]] is only performed by speech pathologists and sometimes nurses may help” [Pro. 6, speech pathologist].

“A rehabilitative team does not exist, departments work in isolation of each other” [Pro.21, nurse].

“There is neither a specialized team nor a specialized department for the management of

dysphagia” [Pro.22, nurse].

Participants suggested a need to renovate the system to become more responsive to the needs of patients suffering from dysphagia. This could be by encouraging professionals to work as part of a multidisciplinary team, and by stressing the importance of communication among them. Another suggestion was the establishment of an integrative computerized system specialized for showing all the procedures and services that each patient with dysphagia has undergone, in order to prevent overlap in services, and to ameliorate communication among professionals involved:

“I wish that there was much more cooperation with physicians and that we can see more patients, and that the evaluation become performed by both parties [physicians and speech pathologists]. The situation may become better if the system is computerized. By pressing a button, I can acquire all the necessary information about the patient” [Pro.10, speech pathologist].

“There is not an integral, well-defined system or guideline that shows how to proceed with the patient. There is a need for something comprehensive and integral, as the situation now requires the patient to receive the required services in different departments in order to be treated” [Pro.14, nurse].

3.4 Services Provided for Patients with Dysphagia

Table 9 summarizes the services provided for patients with dysphagia, the most common provided service as reported by professionals was the application of feeding tubes as reported by 71.7% of participants. This supports the assumption that the management of dysphagia does not take into account possible rehabilitation, but a medical procedure.

Though education of the patients and the family about dysphagia and how to manage it was the main service reported (56.3%), only 18.2% of the professionals reported that they provide such a service. This maybe attributed, in part, to the misconception that medical intervention is the sole appropriate intervention for dysphagia clients, or that professionals may not have viewed that education was part of their role but rather as an extra task that is not within their scope of practice.

The evaluative services included instrumental and non-instrumental methods. The most instrumental methods used for the evaluation of dysphagia were reported to be fluoroscopy (42.1%), followed by endoscopy (28.9%), then modified barium swallow (MBS) (7.9%), and finally the esophageal manometry (5.3%). None of the patients or their family members reported to receive any of these services. This could be due to their lack of knowledge about those methods; thus, patients may have been subjected to those procedures without knowing their purpose.

The rehabilitative services for the treatment of dysphagia were mainly focused on positioning (34.2%), swallowing manoeuvres, oral motor exercises, and TTOS (13.2%). Electrical stimulation was not reported by any of the participants to be used in dysphagia the management. This could be attributed to the lack of the knowledge of professionals about other non-conventional methods used in the management of dysphagia.

Table 9. Services Provided for Patients with Dysphagia

Genre	Service	n & (%)	n & (%)	n & (%)
		Patients	Professionals	Total
Medical services	Feeding tubes	7 (43.8%)	20(90.9%)	27 (71.7%)
	Medications & supplements	3 (18.8%)	0 (0%)	3 (7.9%)
Dietary services	Feeding, designing a dietary programme, & Gradation in the texture& type of food	7 (43.8%)	19 (86.4%)	26 (68.4%)
Evaluative services	Instrumental evaluation: Fluoroscopy	0 (0%)	16 (72.7%)	16 (42.1%)
	Instrumental evaluation: Endoscopy	0 (0%)	11 (50%)	11 (28.9%)
	Case history & Non-instrumental evaluation (e.g.: bedside evaluation)	0 (0%)	10 (45.5%)	10 (26.3%)
	Instrumental evaluation: MBS	0 (0%)	3 (13.6%)	3 (7.9%)
	Instrumental evaluation: Esophageal manometry	0 (0%)	2 (9.1%)	2 (5.3%)
Rehabilitative services	Rehabilitative services: Positioning	5 (31.3%)	8 (36.4%)	13 (34.2%)
	Rehabilitative services: Swallowing manoeuvres, Oral motor exercises & TTOS	1 (6.3%)	4 (18.2%)	5 (13.2%)
	Rehabilitative services: Adaptive tools	0 (0%)	1 (4.5%)	1 (2.6%)
Education	Education	9 (56.3%)	4(18.2%)	13 (34.2%)

3.5 Knowledge and Experience about Dysphagia

Several participants reported that there was a lack of interest, knowledge and/or experience among professionals about dysphagia:

“Knowledge about this area [[dysphagia]] is still limited, and there is lack of awareness about this topic on the medical and rehabilitative levels. In Jordan, there are no specialized courses about this topic. Knowledge about it is gained through experience. This area is not getting the required and sufficient amount of interest and care” [Pro.12, speech pathologist].

“Researcher: do you perform bedside evaluation to identify dysphagia?”, “Pro.21: Sorry but I do not have any experience in that regard” [Pro.21, nurse].

“Researcher: what are the gaps in dysphagia management?”, “Pro.14: there is a gap because no one is interested in this area” [Pro.14, nurse].

There is a need to equip the professionals with the necessary knowledge and training required to manage dysphagia cases.

“for example, a professional who is working in the cerebral palsy department, needs to take a course in dysphagia to know about it, who can suffer from it, and what procedures need to be followed” [Pro.12, speech pathologist].

The patients and their family members had little knowledge about dysphagia. This was because professionals did not assume an active role in educating patients and their families about the management of this condition, probably, because they themselves lacked that knowledge.

“I do not have any information about dysphagia except from you [[referring to the researcher]]” [Pt. 9].

“We often hear about clients who acquire aspiration pneumonia because they were not aware that they had dysphagia. Such cases are self-referred or referred by their caregivers. If a patient and his/her family did not have the awareness and knowledge about dysphagia complications, the patient will have aspiration” [Pro.5, nurse].

The lack of knowledge about dysphagia and ways of its management obliged some patients and their families to develop strategies to encounter dysphagia that do not involve any professional. They mainly acquire such strategies through trial and error and what works best and sometimes by referring to internet resources.

“no one told me what exactly to do! I surfed the internet looking for dietary websites which define the sort of diet that suits my condition, and to get acquainted with other people who have similar conditions” [Pt.11]

4. Discussion

4.1 Services Provided

Some professionals and patients and their care givers stated that feeding tubes are sought as the first and preferred form of intervention for dysphagia as it is easy to administer and requires less time in terms of management follow up. Mitchell, Kiely and Lipsitz (1998) stated that feeding tubes may contribute to patients' death by complications related to infections that it may contribute to; therefore, this should be taken in consideration that it does not help all patients with dysphagia. There is a need to invest in the provision of rehabilitative integrative services to guarantee that services provided for the management of dysphagia are comprehensive and carefully chosen.

The assessment of dysphagia condition was based on the use of instrumental and non-instrumental methods. Videofluoroscopy was one of the most common methods used by professionals for the evaluation of dysphagia. However, several methods for evaluation and intervention were not used by professionals. One example is the use of the TES although several investigations show that it possesses potential benefits if used as part of the exercise-based dysphagia rehabilitation (Crary & Carnaby, 2014). Other methods of intervention such as the use of adaptive equipment such as adaptive cups and spoons and esophageal manometry were not common. This could be partly attributed to the unavailability of dysphagia evaluation and training tools. Those are available internationally but are

either unavailable in the Jordanian market and/or expensive. Examples of resources needed for swallowing and therapy include chewy tubes, oral and facial massagers, brushes, modified cups and spoons, food thickeners, expiratory pressure threshold devices, and electrical stimulator massagers.

4.2 Members of the Team Involved in Dysphagia Management

The management of dysphagia conditions tended to be delivered in a hierarchical manner where the physicians and nurses formulated the first line of screening patients with dysphagia. Physicians were the sole professional who performed the screening, evaluation, and treatment of dysphagia, and nurses apply the physician's instructions, educate the client and their family members, and perform positioning, exercises and manoeuvres to facilitate safe swallowing. If, and only if, viewed necessary, the physicians unsystematically refer the patient to other allied health professionals. There is a minimal role assumed by the rehabilitation professionals (speech pathologists, occupational therapists and physiotherapists). This manifests that the roles of rehabilitation professionals are not well defined; consequently, they are not consulted at the first stages of identification of a swallowing problem. This seems somewhat rather unusual since international and local legislations define dysphagia screening, evaluation and treatment as part of the scope of practice of speech-language pathologists and/or occupational therapists. For example, the ASHA (n.d.b) defines the speech-language pathologist (SLP) "as the professional who engages in professional practice in the areas of communication and swallowing across the life span" (ASHA, n.d.b, p. 1). Speech- language pathologists certified by the Jordanian Ministry of Health (MOH) (2013) consider dysphagia as common practice (Personal Communication, Yaser Natour, representative of public universities in the MOH committee for licensing speech pathology practice). Also, the Canadian Occupational therapists collaborate with stakeholders at national and regional levels to promote and engage in research to further best practices in all areas of feeding, eating and swallowing including dysphagia assessment and management (ASHA, n.d.b; Clark, Avery-Smith, Wold, Anthony, & Holm, 2007).

According to the ASHA (n.d.a) the management of dysphagia requires a team of professionals consisting of physicians, nurses, nutritionists, psychiatrists, occupational therapists and physiotherapist, and this team is led by speech pathologists. The role of a speech pathologist is to evaluate and treat patients with dysphagia by performing the necessary modifications of physiologic responses and diet modification. Occupational therapists evaluate and treat sensory and motor impairments and assess the need for prosthesis or equipment that can facilitate self-feeding and swallowing. Physiotherapists are required to evaluate and treat body positioning, sensory function and motor movements necessary for safe and efficient swallowing ASHA (n.d.a). Also, they recommend seating equipment to support proper feeding. The physicians' role is mainly directed at evaluating and treating the main medical condition causing dysphagia, while nurses are responsible of working closely with the patient and his/her family members in implementing safe swallowing techniques and compensatory or facilitation strategies for swallowing.

In this study, none of the participants were occupational therapists as the researchers could not identify

any single occupational therapist to be regularly involved in the dysphagia management team. Dysphagia cases were rarely, if not at all, referred to occupational therapy services. Part of that is because professionals, in particular the physicians, lacked the knowledge about the role of other professionals in dysphagia management. The other part may relate to the lack of knowledge and experience of occupational therapists in dysphagia which limits them from assuming their role in dysphagia management.

The American Occupational Therapy Association (AOTA) (2011) expresses the vital role of occupational therapists in dysphagia. Occupational therapy services are numerous and comprehensive in dysphagia where the physical, social and cultural environments are targeted to guarantee the best feeding, eating and swallowing. This is mainly delivered by teaching the client and caregivers compensatory swallowing strategies, diet texture modification, provision of adapted utensils, positioning, and creating a setting that fosters attention to meal (AOTA, 2011).

Occupational therapists may not be promoting their role in dysphagia screening, evaluation, and management. In Jordan, as well as in the Arab region, where OT is considered as a developing speciality in the domain of rehabilitation services and no scope of practice is yet defined for the profession of OT. Occupational therapists' role needs to be activated in relation to dysphagia management in Jordan. This can be achieved, in part, by offering training opportunities for occupational therapists in managing dysphagia patients, and by increasing their knowledge about this condition by the integrating of this topic in the curricula, and by offering continuous professional development (CPD) opportunities through workshops and courses.

This study showed that Jordanian professionals involved in the management of dysphagia do not work collaboratively. Such matter would cause replication of some services and potential contradicting form of consultations or procedures. As such, the care delivered to clients with dysphagia lacks the holistic and comprehensive approach. There is a need for the various professionals to be involved in the management of patients with dysphagia where their roles as team members are defined. Both the medical services and the rehabilitative services need to be provided side by side for a comprehensive and effective management of dysphagia conditions. For example, some dysphagia cases are of a behavioural cause which may require the evaluation of a speech pathologist and the intervention of an occupational therapists and/or a psychiatrist (ASHA, n.d.a).

The healthcare system in most medical institution in Jordan lacks clear guidelines for the management of dysphagia. The Legislations governing the speech-pathology licensing in Jordan issued by the MOH (1999; Amended, 2014) do not contain a detailed description of the scope of practice of speech language pathologists. However, Speech- language pathologists certified by the Jordanian Ministry of Health and guided by international regulations consider dysphagia as common practice. In fact, a number of speech language pathologists are also certified by international organization such as ASHA. There is not a clear delineation between the roles of various specialists who are involved in the management of dysphagia conditions.

4.3 Knowledge about Dysphagia

In Jordan, there are no clear guidelines that govern the evaluation or the detection of dysphagia. Several dysphagia conditions are not detected by professionals, and the client and/or his caregivers were the ones to initiate the process by reporting a complaint related to quality of swallowing or its complications such as aspiration pneumonia. Physician and nurses in particular, are not well trained to detect dysphagia, especially if it was of the “silent” type. Some professionals, i.e., nurses, lacked either interest and/or knowledge about dysphagia. This is marked by the fact that several possible dysphagia conditions were identified by the research team as possible candidates for formal assessment. Those potential patients have been admitted to the ward for weeks – months while nurses were not aware that those clients may have dysphagia. This might call for administering both theoretical and hands-on training courses on dysphagia screening and nursing management.

Several professionals involved in the management of dysphagia used procedures unsupported by evidence-based research to screen for dysphagia. 22.7% of the professionals who participated (in this study reported that the absence of a gag reflex is an important indicator of dysphagia. However, depending on the integrity of the gag reflex upon a complaint made by the client or his caregiver concerning the presence of difficulty in swallowing is not sufficient to confirm or refute the presence of swallowing disorders (Leder, 1996). In his study, Leder (1996) found that although all subjects were referred for bedside dysphagia evaluations specifically because they had no gag reflex, 86% (12/14) were nevertheless able to eat at least a puree diet. The gag reflex, traditionally considered part of the bedside dysphagia evaluation, was absent in 13% (9/69) of non-dysphagic subjects, raising further doubts regarding its clinical relevancy.

Several professionals involved in the management of dysphagia reported to acquire the knowledge and skills required to manage conditions of dysphagia from their own resources. Thus, there is a need to provide the necessary knowledge, training, and skills for the assessment and management of dysphagia to professionals in order to enhance patients’ safety, and the effectiveness of services provided (Ho et al., 2014).

Professionals did not assume the required role in teaching the clients and their caregivers about dysphagia and its management as they themselves, did not have sufficient knowledge. The ASHA (n.d.b) deems the patients and their caregiver as part of the team required for an effective management of dysphagia. A large proportion in dysphagia management depends on the clients’ education. For example, GERD management requires teaching the client about the effects of smoking and alcohol on this condition. Clients had limited knowledge about the role of rehabilitation professionals in dysphagia and though they may need rehabilitation services, there was not enough education provided to them. This was expected because of the scarcity of dysphagia specialists and research projects directed towards dysphagia in Jordan. Public awareness and community service activities directed towards raising awareness about dysphagia are very limited in number and quality. Consequently, some patients and caregivers had to seek answers through unprofessional means such as asking a former patient

and/or caregiver who had the same problem or seeking internet resources that are not always based on documented research. Additionally, dysphagia is relatively a newly promoted subspecialty of the rehabilitation professions in Jordan, and in the speech-language pathology profession in particular.

Organized initiatives directed at raising public awareness about dysphagia are strongly recommended. For example, there are days designated for promoting awareness regarding different disorders/diseases. An example is the “National Dysphagia Awareness Month” that is mentioned by the National Foundation of Swallowing Disorders, USA (2016). Such public awareness events may be of vital importance to raise awareness about dysphagia among professionals working in the field, patients and their caregivers.

5. Conclusion

This study targeted the dysphagia and the rehabilitative services offered for dysphagia patients in Jordan. The study and consequent studies may pave the way for future investigations regarding the rehabilitative services for Jordanian patients with dysphagia and develop ways to improve the quality of such services.

6. Key Points

- Rehabilitation services need to be integrated the current model of management of dysphagia in medical institutions in Jordan.
- There is a need for professionals to acquire more knowledge, skills and experience required for the management of dysphagia.
- Patients with dysphagia and their families are part of the dysphagia team and educating them is the responsibility of the professionals.
- Clinical guidelines need to be developed to better organize the work of professionals involved in the management of dysphagia.

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