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Dysphagia and Rehabilitation Services in Jordan: Patients and Provider Perspectives

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Abstract: There is a scantiness of information regarding the etiology of dysphagia and the rehabilitation services offered to affected individuals in Jordan. This study aims to investigate the perspectives of patients and service providers regarding the etiologies associated with dysphagia and the rehabilitation services provided to patients in Jordan. This cross-sectional descriptive study was conducted in the North and middle regions of Jordan. The participants were adult patients who presented with dysphagia in 4 public and 6 private medical settings. The study also included medical professionals involved in its management located in 5 public and 6 private medical settings. All participants completed an interviewer-administered questionnaire on disorders associated with dysphagia conditions and the services provided to patients presenting with dysphagia. A total of 219 patients presenting with dysphagia and 217 adult medical professionals completed the survey. Patients and professionals perceived medical doctors as the professionals entitled to work with dysphagia. Further, medication is perceived by 99 (45.2%) patients as the primary mode of treatment for dysphagia while the majority of professionals 150 (69.1%) perceived nonoral feeding the primary mode of treatment for dysphagia. It is concluded that well-developed professional dysphagia intervention programs in Jordan are scarce and concerned professionals (i.e., speech language pathologists and occupational therapists) are not fully involved in the rehabilitation of patients with dysphagia.

Key words: Dysphagia, Jordan, medical setting, occupational therapists, speech pathologists, therapists

INTRODUCTION

Dysphagia is any problem or difficulty in swallowing (Sura *et al*., 2012; Aslam and Vaezi, 2013). It is associated and caused by either structural problems/actions (such as esophageal tumors, Zinker's diverticulum or radiotherapy) or motor problems (e.g., stroke, dementia and amyotrophic lateral sclerosis) (Aslam and Vaezi, 2013). Dysphagia per, may contribute to a negative health prognosis and lead to lung disease, poor nutrition, extended hospitalization, poor quality of life or even death (Altman *et al*., 2010).

According to a study conducted in the United States, stroke is the most prevalent cause of dysphagia conditions (11.2%) and other neurological disorders come second (7.2%), followed by head and neck cancer (4.9%) (Bhattacharyya, 2014). Wilkins, Gillies, Thomas and Wagner found that 22.6% of 947 patients in the United States who attended primary care have dysphagia conditions frequently or several times monthly. Most of those patients were females (80.8% compared to 19.2%) males (mean age of 48.1 years) (Wilkins *et al*., 2007). A study conducted on 40 stroke patients in Egypt targeted Gugging Swallowing Screen test (GUSS) reference found that 55% of the patients presented with dysphagia with 14 (35%) males and 8 (20%) females presented with dysphagia (Bassiouny *et al*., 2017). Dysphagia requires the involvement of several professionals that conduct evaluation and treatment. It also requires collaboration of multiple health professionals along with patients and family members in the form of disciplinary or multidisciplinary teams (ASHA., 2019b).

Several strategies of evaluation and treatment are available and documented in the literature. Evaluation consists of bedside assessment and the use of one or the other many available instruments such as fiber-optic

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endoscopic examination of swallowing (Ramsey *et al*., 2003; Carnaby-Mann and Lenius, 2008). As for treatment, medical and rehabilitative interventions are the main approaches used in managing dysphagia. Medical treatment of dysphagia may include surgical intervention and chemoradiotherapy or substitute strategies such as non-oral feeding (Aslam and Vaezi, 2013; Douglas *et al*., 2019). Rehabilitative treatment of dysphagia conditions may target environmental adjustment, diet modification, nutrition therapy, sensory stimulation, postural adjustment, maneuvers (compensatory strategies) and oral motor exercises (Gaziano, 2002; Garcia and Chambers, 2010; Kagaya *et al*., 2011; Sura *et al*., 2012; Iwamoto *et al*., 2014; Langmore and Pisegna, 2015).

Several studies have evaluated dysphagia in medical settings (Sura *et al*., 2012; Smithard, 2016; Snippenburg *et al*., 2019). However, very few were conducted on Arab populations. A study conducted in Egypt addressed a method of assessment dysphagia in 40 stroke patients (Bassiouny *et al*., 2017). However, the focus of the study was on a specific assessment method GUSS.

Studies that examined dysphagia and its rehabilitation services from the perspectives of the patients and health professionals are also scarce in the Middle East. In fact, the Middle East and North Africa have specific dietary habits that have transformed from traditional healthy food to manufactured processed foods which led to a higher incidence of chronic diseases (Fahed *et al*., 2012). As such, it seems valuable to investigate the perspectives of both patients and service providers with regard to dysphagia and its rehabilitative services in Jordan. Specifically, this current study aims to investigate the perspectives of patients and service providers regarding etiology of dysphagia and the rehabilitation services provided in Jordan.

MATERIALS AND METHODS

Study setting: This descriptive cross-sectional study was conducted from July to October 2016 in North and middle regions of Jordan. Interviewing patients was conducted in 10 (4 public and 6 private) medical settings in two cities (Amman and Jerash). Professionals working in 11 (5 public and 6 private) medical settings in the 2 cities (Amman and Jerash) in Jordan were also interviewed.

Participants: Participants were patients who presented with dysphagia and medical professionals who were expected to manage patients with conditions associated with dysphagia (ASHA., 2019b). All consenting adult (>18 years) patients with dysphagia were eligible to participate in the study. Caregivers or family members completed the questionnaire for patients who were unconscious or unable to respond to survey questions orally. All available professionals and patients in this study were invited to participate in the survey and those that gave consent were interviewed. Professionals were invited based on presumed relevance to the field of dysphagia and those who were reported to deal with patients presenting with dysphagia.

Data collection: The study was approved by the Deanship of Scientific Research at the University of Jordan and from the Institutional Review Board committee at the University of Jordan Hospital. Also, each participant who was asked to complete the questionnaire and signed a written informed consent before participating in the survey. Participants were encouraged to ask questions regarding the questionnaire. Two forms of the study questionnaire were used: one that was designed for dysphagia patients and the other was given to professionals working with dysphagia patients. Participants were asked to choose answers from a group of already printed choices. They also gave additional comments if the choice they mentioned was not among the listed choices.

The patient's questionnaire included demographic information, questions regarding their perception of the etiology of dysphagia, professional's that should be involved evaluation and therapy and the nature of rehabilitation and treatment procedures received. Also, the professional's questionnaire consisted of several sections including perceptions regarding the professionals who worked with dysphagia conditions, the associated disorders of dysphagia, dysphagia evaluation, rehabilitation and treatment procedures.

The investigators explained some of the choices to the patients and their family members when needed (e.g., describing endoscopy) in order to get as much accurate information as possible. Information was also collected from family members for those patients who were not able to communicate orally.

Analysis: Frequencies and percentages were calculated using Microsoft Office Excel (2016).

RESULTS AND DISCUSSION

The study sample consisted of professionals and patients. Two hundred and nineteen patients included 105 (47.9%) males and 114 (52.1%) females with a male to female ratio of 0.9:1. The patients age range was 18-100

Table 1: Sociodemographic characteristics of the participants

	Patients (N = 219)	Professionals (N = 217)
Variables	n (%)	n (%)
Age group (years)		
≤40	48 (21.9)	165 (76.0)
>40	171 (78.1)	52 (24.0)
Gender		
Male	105 (47.9)	114 (52.5)
Female	114 (52.1)	103 (47.5)
Education		
None	29 (13.2)	0 (0.0)
Primary	94 (42.9)	0 (0.0)
Secondary	20 (9.1)	0 (0.0)
Tertiary	72 (32.9)	202 (93.0)
Postgraduate	4 (1.8)	15 (6.9)
Department		
Anesthesia	0 (0.0)	3 (1.4)
Blood disease	22 (10.0)	4 (1.8)
Intensive care unit	10 (4.6)	26 (12)
Ear-nose-throat	1 (0.5)	11 (5.1)
Internal medicine	123 (56.2)	26 (12)
Surgery	36 (16.4)	0 (0.0)
Psychological	0 (0.0)	3 (1.4)
Physiotherapy	7 (3.2)	30 (13.8)
Occupational therapy	0 (0.0)	11 (5.1)
Speech therapy	8 (3.7)	5 (2.3)
Radiology	9 (4.1)	7 (3.2)
Others	3 (1.4)	91 (41.9)

Table 2: *Disorders associated with dysphagia conditions

	Patients (N = 219)	Professionals (N = 217)
Variables	n (%)	n (%)
Achalasia	0 (0.0)	88 (40.6)
Amyotrophic lateral sclerosis	0 (0.0)	30 (13.8)
Autism	0 (0.0)	20 (9.2)
Cancer	45 (20.6)	42 (19.4)
Cerebral palsy	1 (0.5)	78 (35.9)
Cleft lip and palate	1 (0.5)	91 (41.9)
CVA/stroke	57 (26.0)	147 (68)
Digestive system diseases	29 (13.2)	118 (54.4)
GERD	9 (4.1)	94 (43.3)
Heart attacks	0 (0.0)	20 (9.2)
Medications	20 (9.1)	61 (28.1)
Meningitis	0 (0.0)	32 (14.8)
Multiple sclerosis	4 (1.8)	50 (23.0)
Myasthenia gravis	0 (0.0)	33 (15.2)
Parkinson's disease	0 (0.0)	55 (25.4)
Spinal cord injuries	0 (0.0)	48 (22.1)
Traumatic brain injury	17 (7.8)	116 (53.5)
Others	35 (15.9)	9 (4.1)

*It must be noted that participants nominated multiples responses

years (mean 52 years±16.8). The most common occupation of the patients who participated in the study were 94 (42.92%) housewives, 56 (25.57%) of nonvocational jobs and 29 (13.2%) were retired.

The professional's surveyed consisted of 217 subjects 114 males (52.5%) and 103 (47.5%) females with a ratio of 1:0.9. The medical professionals ages range from 21-53 years (mean 33 years±8.7). Their research experience ranged from 0-30 years mean = 8.6 years±7.6). Table 1 demonstrates professional's and patient's

Table 3: *Participant's perception of the specialists who work with dysphagia

	Patients (N = 219)	Professionals (N = 217)
Variables	n (%)	n (%)
Medical doctor	171 (68.5)	152 (66.8)
Nurse	34 (15.5)	29 (13.4)
Nutrition	16 (7.3)	19 (8.8)
**OT	6 (2.7)	35 (16.1)
Patient and family	13 (5.9)	5 (2.3)
**PT	6 (2.7)	9 (4.6)
**SLP	12 (5.5)	42 (19.4)
Team	11 (5.0)	21 (9.7)
"I do not know"	27 (12.3)	12 (1.8)

*It must be noted that participants nominated multiples responses; **OT (Occupational Therapist), PT (Physiotherapist), SLP (Speech Language Pathologist)

sociodemographic characteristics. The designation of professionals participating in the study is demonstrated in Fig. 1. Most of the interviewed professionals were nurses 92 (42.9%) followed by medical doctors 34 (21.7%).

The disorders associated with dysphagia are demonstrated in Table 2. According to the patient's responses listing stroke/CVA 57 (26.0%), cancer 45 (20.6%) and other diseases (e.g., diabetes) 35 (15.9%) were the three most common causes of dysphagia in Jordan. According to the professional's nomination, stroke/CVA 147 (68%), digestive system diseases 118 (54.4%) and traumatic brain injury 116 (53.7%) were the three most common associated disorders.

The participant's perception of which specialists work with dysphagia is demonstrated in Table 3. According to the participant's nomination, the two most common professionals identified by the patients were medical doctors 171 (68.5%) followed by nurses 34 (15.5%). On the other hand, 27 (12.3%) of the patients did not know the professionals who manage dysphagia. The three most common specialists in the management of dysphagia identified by the professional's surveyed were medical doctors 152 (66.8%), Speech language pathologists 42 (19.4%) and occupational therapists 35 (16.1%).

The patient's and professional's perception of dysphagia evaluation and treatment is demonstrated in Table 4. Less than half of the patients 91 (41.6%) believed that there is an evaluation for dysphagia conditions compared to 163 (75.1%) of professionals.

As for the perception of evaluation types, 54 (24.7%) patients nominated endoscopy as the most used type of evaluation followed by 34 (15.5%) bedside evaluation then 22 (10.0%) modified barium swallow/fluoroscopy consecutively. On the other hand, 123 (56.7%) professionals nominated endoscopy, 82

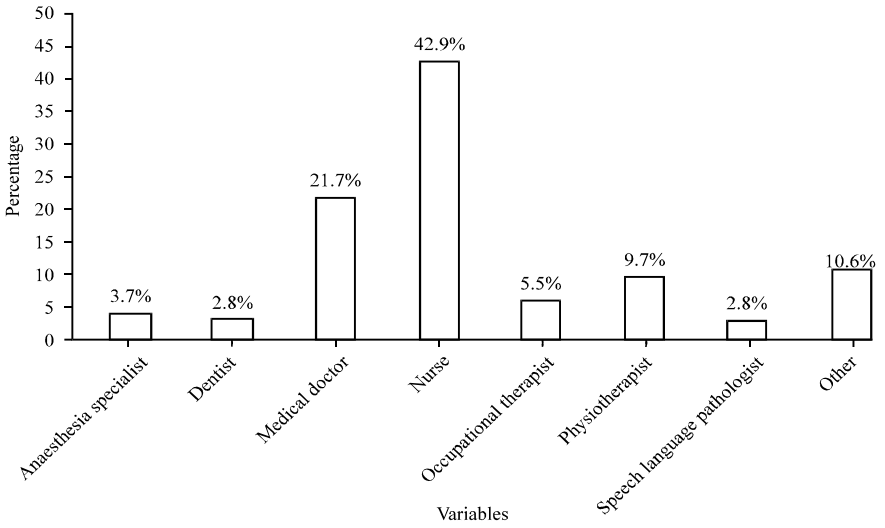

Fig. 1: Professional designation of the professionals included in the survey

Table 4: *Evaluation and treatment of dysphagia conditions

	Patients (N = 219)	Professionals (N=217)
Variables	n (%)	n (%)
Is there an evaluation for dysphagia?		
Yes	91 (41.6)	163 (75.1)
No	128 (58.4)	54 (24.9)
Types of evaluation used		
Bedside evaluation	34 (15.5)	81 (37.3)
Endoscopy	54 (24.7)	123 56.7)
Esophageal manometry	4 (1.8)	23 (10.6)
Food trial	12 (5.5)	15 (6.9)
Modified barium swallow/fluoroscopy	22 (10.0)	82 (37.8)
Other	13 (5.9)	31 (14.3)
Do not know	128 (58.5)	54 (24.9)
Types of treatment used		
Change of food texture and bolus size	23 (10.5)	87 (40.1)
Family counselling	0 (0.0)	35 (16.1)
Maneuvers and exercises	1 (0.5)	56 25.8)
Medications	99 (45.2)	101 (46.5)
Nonoral feeding	23 (10.5)	150 (69.1)
Nutrition program	1 (0.5)	20 (9.2)
Oral exercise	7 (3.2)	74 (34.1)
Positioning	23 (10.5	63 (29.0)
Surgical intervention	20 (9.1)	71 (32.7)
Using specific utensils	1 (0.5)	26 (11.9)
Does not know	73 (33.3)	10 (4.6)
Other	23 (10.5)	17 (7.8)

*It must be noted that participants nominated multiples responses

(37.8%) modified barium swallow/fluoroscopy and 81 (37.3%) bedside evaluation consecutively. Mean of the number of evaluation procedures chosen by the patient group was $(\bar{x} = 0.6)$ while the mean of total evaluation procedures was in professional's group was $(\bar{x} = 1.6)$.

As for the perception of treatment types, 99 (45.2%) of the patients nominated medication as the most used type of treatment, 23 (10.5%) non-oral feeding, then 23 (10.5%) change of food texture and bolus size consecutively. On the other hand, 150 (69.1%) medical professionals nominated non-oral feeding as the most common type of treatment, 101 (46.5%) medications, then 87 (40.1%) change of food texture and bolus size consecutively. Mean of the number of treatment procedures for participants was calculated in both groups. Mean of the number of nominated treatment procedures was $(\bar{x} = 1.2)$ while professionals was $(\bar{x} = 3.2)$.

Patients: According to the findings of the current study, the number of female patients who presented with dysphagia (52.1%) was slightly higher than that of male patients (47.9%). Although, these results resonate with the study conducted by Wilkins *et al.* (2007) in that female numbers in their study were higher (80.8%) than males (19.2%) as compared to the present study. It should be noted that some studies found that males are considered at a higher risk of having conditions associated with dysphagia such as pneumonia (El-Solh *et al.*, 2010). Therefore, further studies are needed to investigate the effect of gender on disorders associated with dysphagia.

Dysphagia associated disorders: The current study is consistent with Bhattacharyya's study (Bhattacharyya, 2014) regarding the fact that stroke is the most prevalent cause of condition associated with dysphagia according to 57 (26%) patients and 147 (68%) professionals. However, the current study results showed a higher percentage of dysphagia conditions associated with stroke as reported by patients and professionals compared to what was mentioned in Bhattacharyya's

study (11.2%). There seems to be a growing number of incidences of stroke in the Middle East (El-Hajj *et al*., 2016) which indicates that dysphagia conditions may also increase as a result of that.

Participant's perception dysphagia of specialists who work with dysphagia. With regard to the perception of specialists who work with dysphagia conditions, most of the patients (68.5%) mentioned medical doctors while only 5.5% of the patients nominated speech pathologists and 2.7% occupational therapists as professionals who manage dysphagia. This may indicate that most of the patients are not usually, examined by the rehabilitation specialists. It also indicates that patients lack the awareness of knowing the role of other rehabilitation team in dysphagia management. A small number of patients (5%) mentioned that dysphagia conditions are managed by a team of specialists. This also leads to the same conclusion where there is lack of awareness among patients regarding the role of rehabilitation specialists and interdisciplinary teams.

Findings also revealed that 66.8% of professionals nominated medical doctors while only 19.4% speech pathologists and 16.1% occupational therapists as specialists who manage dysphagia. This implies that some professionals are not aware of the important role of other rehabilitation specialists in charge of dysphagia management. Since, the majority of professionals nominated medical doctors, they are not expected to refer patients with dysphagia to other rehabilitation staff such as speech pathologists (Kiyani and Butt, 2014). Results may also explain the little number of speech pathologists (2.8%), for example, who were met during data collection compared to medical doctors (21.7%). It is expected that medical settings may lack the required number of rehabilitation staff employees, since, they depend mainly on medical doctors in dysphagia management.

Furthermore, 9.7% of professionals stated that dysphagia conditions are addressed by a team of specialists. This indicates that professionals did not realize the crucial need to have a group of specialists including the speech pathologist and occupational therapist working together to meet the patient's different needs. This small percentage of responses may indicate that there is a little number of interdisciplinary teams in medical settings or these interdisciplinary teams do not work with dysphagia conditions.

Overall, there is a consistency in the level of awareness between patients and professionals regarding the role of medical doctors and other rehabilitation specialists in managing dysphagia. Based on the findings, there is a need for public awareness among patients and professional training among professionals about the importance of rehabilitation teams and interdisciplinary teams (including rehabilitation staff). It is the rehabilitation team's duty to spread awareness regarding their roles and how they may collaborate with others as part of interdisciplinary teams.

In Jordan, although, there is a master's program in communication disorders and speech pathology stationed at the University of Jordan, there is still a lack of focus on specific topics such as dysphagia. As such the number of speech pathologists specialized in dysphagia is not large enough. Therefore, it is suggested that students who wish to be specialized in swallowing disorders get more practicum hours that focus on swallowing disorders and get certification in a clinical speciality (ASHA., 2019a).

Evaluation and treatment of dysphagia conditions: Regarding the perception of evaluation of dysphagia, most of the professionals (75.1%) mentioned the presence of a formal evaluation for dysphagia conditions while most of the patients (58.4%) did not. This disagreement between professionals and patients could be because patients are not aware that a formal evaluation of conditions presenting with dysphagia exists or because there is no implementation of a concise dysphagia evaluation. It is recommended that medical professionals inform patients prior to assessment about the procedures that will be part of the assessment protocol/session. Medical doctors usually have full caseloads (Altschuler *et al*., 2012) and they may sometimes not have enough time to discuss and answer patient's questions. Therefore, it is suggested that medical assistants and other health professionals such as SLPs and OTs contribute to that need.

The majority of patients (24.7%) mentioned endoscopy as the used procedure for dysphagia evaluation. This could be due to the fact that patients depended very much on obvious procedure they visualized. The least percentage of patients (1.8%) mentioned esophageal manometry as an evaluation procedure conducted and this could be because they were not familiar with this procedure's name. This could also be explained by the fact that the majority of patients (42.9%) were housewives and almost half of the patients were either uneducated (13.2%) or had an elementary education (42.9%). Lower level of education may have affected patient's awareness of dysphagia evaluation. These patient's knowledge may be less than that of other patients, especially, that in the age of internet, basic or advanced information can be easily obtained by an average educated person.

On the other hand, the majority of professionals (56.7%) mentioned endoscopy as part of evaluation procedure. This is expected because it is a very important tool for dysphagia testing. The professional's least choice (6.9%) was "food trial" and this could be due to the fact

that it might be life threatening if not applied properly. Applying food trials depends on clinical judgment considering if the patient is ready for oral intake without complications (Carnaby-Mann and Lenius, 2008).

Perception of evaluation was also examined by comparing the means of number of nominated choices for each participant. Mean of the number of evaluation procedures was higher in professionals ($\bar{x}=1.6$) compared to that in patients ($\bar{x}=0.6$) as expected. This indicates that patients are not familiar with most of the used dysphagia evaluation procedures. It is worthwhile to mention that both patients and professionals nominated endoscopy as the evaluation procedure used. This agreement maybe because specialists depend on endoscopy as the main procedure for evaluation.

As for the perception of treatment, most of the patients (45.2%) stated that dysphagia conditions are treated by medications. This could be explained by either the lack of the patient's awareness of treatment conducted or the dominance of medical treatment over the other used procedures. This could also mean that the majority of patients at the time of data collection did need medical intervention due to their medical conditions. On the other hand, most of the professionals (69.1%) mentioned nonoral feeding as a treatment procedure used. It may mean that the majority of patients seen by the interviewed professionals did need non-oral feeding over other procedures.

Means of the numbers of nominated treatment procedures for patients and professionals were also compared. The mean of number of nominated treatment procedures for patients was ($\bar{x}=1.2$) while professional was ($\bar{x}=3.2$). This indicates that professionals have chosen more treatment procedures compared to patients. It is expected from professionals to be more familiar with the conducted treatment procedures compared to patients.

Overall findings of both patients and professional's responses showed that most of the patients and professional's choices are more focused on medical intervention. This may indicate that most of the dysphagia conditions are taken over by the medical professionals and treated medically (which could be due to the small number of speech pathologists who are specialized in swallowing disorders). Those results overemphasize medical intervention over rehabilitation services. This overemphasis is in contrast with the fact that some conditions can be targeted using other techniques such as maneuvers (e.g., Mendelsohn maneuver) (Kagaya *et al*., 2011; Langmore and Pisegna, 2015). This also signifies that there is a lack of knowledge regarding the nature of the roles of the rehabilitation service providers including the speech pathologists and occupational therapists in Jordan who may work hand in hand with the medical professionals.

The results of the present study suggest that professionals should be geared towards professional training on assessment and treatment of dysphagia conditions and patients should be geared towards public awareness (Grannell *et al*., 2001; Ho *et al*., 2014; Menon *et al*., 2014). Such awareness can be targeted through lectures, for example (West *et al*., 2018). Rehabilitation specialists including speech pathologists and occupational therapists should be equipped with good counseling skills that target professionals and employ their counseling skills and give presentations in staff meetings that are held in medical settings in order to introduce their roles.

CONCLUSION

The current study sheds some light on dysphagia conditions in Jordan. Further research on the etiology and rehabilitation services of dysphagia are needed. The current study also stresses the need for professional and patient education through different modes of communication (i.e., continuing education, public lectures, interdisciplinary team work and media). Based on the results, it is suggested that future research target studying the specific kinds of dysphagia conditions and the interventions used with each one. This will help to identify conditions that need rehabilitative interventions and those that need purely medical intervention.

LIMITATIONS

The current study has some limitations. First, it is difficult to make any causal inference because this study is a cross-sectional study. Second, the recruited participants were met based on their availability during their working hours while investigators visited medical settings. This convenient sample of participants could have different results if participation was not based on the professional's availability. Therefore, it is recommended that future studies be on a bigger number of participants including private clinics and other health and rehabilitation facilities. Finally, the collected data were from North and middle regions of Jordan, therefore, findings may not be generalized to the whole country.

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