

Emotional Consequences for Patients with Dysphagia

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Abstract

This study aimed to measure emotional consequences for patients with dysphagia within Jordanian society. A total of 95 patients with dysphagia attending speech therapy clinics, neurology clinics, gastroenterology clinics, and rehabilitation centers were asked to fill out a questionnaire. The items were chosen based on several studies that have been published on this topic. The results showed that most patients reported that they suffer from avoidance of eating, feeling embarrassed, and nervous and anxious while eating with others due to dysphagia. Most of them have reported that they do not feel pleasure while eating, feel discomfort while swallowing, their lives are less enjoyable due to dysphagia, and have difficulty swallowing liquids. Most of them reported that they expect their condition to improve. It would be helpful for patients with dysphagia if the healthcare professionals who treat them become more aware of the emotional consequences they are feeling, give them advice on how to deal with these emotional consequences, involve them in developing the treatment plan and provide them with realistic expectations about their prognosis.

Keywords: Dysphagia, emotional consequences, symptoms, and swallowing disorders.

Introduction

Dysphagia has several definitions. The most frequent one is having difficulties transporting food from the mouth to the stomach. Swallowing difficulties can be caused by several congenital defects, structural damages, and/or medical illnesses (Jeri, A. 1998).

Social isolation results from embarrassment caused by an inability to eat and drink in a socially acceptable manner, low self-esteem, fear, worry, frustration, and sadness are all possible side effects of Dysphagia (Pizzprni, N. 2017). Eating patterns may be disrupted, especially if more limited diets and enteral feedings are introduced (Pizzprni, N. 2017; Alali, D. Ballard, K. Bogaardt, H. 2018). Along with their decreased oral hygiene and fear of shame in social circumstances, their family routines and eating environments had to adjust (Lang, H. et al. 2013). Their attitudes toward food, especially food appreciation and enjoyment, have shifted, affecting them emotionally and contributing to a decrease in psychological well-being (Ottosson, S. Laurell, G. Olsson, C. 2013).

Printza, A. Triaridis, S. Kalaitzi, M. et al. (2020) studied the prevalence of dysphagia, attitudes, and dysphagia-related QoL in MS patients. A total of 108 patients were enlisted. Overall, one out of every four patients experienced problems or choking while drinking fluids or eating food, as well as coughing while swallowing, food sticking in the throat, the need for food and drink segmentation, and repetitive swallows. Eating enjoyment was found to be minimally influenced. The psychological and social effects of dysphagia appear to be well tolerated by the patients. Patients reported feeling relatively little panic because of their swallowing problems and choking. They have established coping methods since they do not regard the severity of their symptoms as a real threat.

Alali, D. Ballard, K. Bogaardt, B. (2018) studied the prevalence of dysphagia in individuals with MS, as well as the most common symptoms associated with dysphagia and their impact on patients' quality of life. A total of 103 persons with MS agreed to take part in the trial. According to the findings, 38 percent of adults with MS had swallowing difficulty, which resulted in a variety of medical and social effects such as coughing, throat clearing, choking on food and fluids, decreased eating desire, increased eating duration, and mealtime anxiety.

Johansson, A. & Johansson, U. (2009) examined the experiences of relatives dealing with their relatives' eating and swallowing difficulties are described in this study. Nine informants were interviewed after a strategic sample was taken. Three themes emerged from data analysis using a constant comparative approach: caregiver for health and well-being, sensitive views toward the next of kin's changed look, and adaptation to the new situation. Caring and concern were among the attributes that the informants possessed. Food preparation was critical, with more time spent on it than in the past. It dominated working hours when combined with haphazard eating. Emotional reactions to eating behavior were expressed by the informants. They were saddened by the loss of decent, proper food and companionship at meals.

Maclean, J. Cotton, S. & Perry, A. (2009) looked into the impact that dysphagia has on people's quality of life (QoL), functioning, and psychological well-being. All members (N = 197) received a questionnaire battery. The quality of life and functioning of the participants were evaluated. The Depression Anxiety and Stress Scale was used to assess psychological well-being (DASS). There was severe impairment in functioning as well as a significant reduction in social participation. Those laryngectomees who had dysphagia were shown to have significantly greater levels of despair and anxiety.

It is becoming increasingly important to healthcare professionals to understand the emotional consequences that arise from dysphagia and its effects on patients' quality of life to help and educate them about how to manage and deal with these emotional consequences and reduce its effects on patients' life. Consequently, the current study was an attempt to use a questionnaire-based survey to understand the emotional consequences of swallowing disorders in Jordanian society. This is the first study to assess the emotional consequences of dysphagia in Jordanian society.

Methods

A total of 95 patients with dysphagia attending gastroenterology clinics, neurology clinics, speech therapy clinics, and rehabilitation centers in major Jordanian cities were asked to fill out a self-developed questionnaire (Appendix) (using the Farri, A. Accornero, A. & Burdese, C. questionnaire as a guide), based on recognized subjective dysphagia problems, regardless of origin.

The questionnaire was divided into five study areas: The Demographic part, the Symptoms part, emotional consequences brought on by swallowing difficulties Part, Personal feelings and the importance attributed to meals, and prediction of improvement part. The questionnaire was accompanied by a cover letter that explained the purpose of the study. The letter expressed gratitude for participating and assured confidentiality.

Results

The following tables illustrate the results that we obtained from the questionnaire about gender, city of residence, level of education, symptoms were experienced by patients, emotional consequences that patients suffer from due to swallowing disorders, personal feelings, the importance attributed to meals, and patient's expectation of improvement.

Table 1. Gender, place of residence, and level of education of the study participants.

Characteristics	Category	Percentage %
Gender	Male	66
	Female	34
City of residence	Amman	42
	Irbid	33
	Al-Zarqa	25
Level of education	High school and lower	22
	Bachelor's degree	66
	Master's degree	10
	Ph.D.	2

Table 1 shows that most of the participants in this study were males (66%) and the proportion of females was (34%). Most of the participants were from Amman (42%) and the proportions of participants from Irbid and Aqaba were (33%) and (25%), respectively. 66% of participants had a bachelor's degree, 22% of them had a high school degree or lower, 10% had a master's degree, and 2% had a Ph.D. degree.

Table 2. Symptoms were experienced by patients: a sensation of a foreign body in the throat when swallowing, swallowing liquid with difficulty, coughing, loss of appetite, acid regurgitation, throat irritation, and pain during swallowing.

Symptoms	Appetite loss	Throat irritation	Pain during swallowing	Feeling of foreign body	swallowing liquid with difficulty	Coughing	Acid regurgitation
Percentage %	47	34	31	51	56	47	7

Table 2 shows that the most common symptom of Dysphagia among patients who participated in this study was swallowing liquid with difficulty. 56% of participants reported that they suffered from it. The least common symptom was acid regurgitation. 7% of them reported that they suffer from it. There was 51% of them reported that they suffer from a feeling of foreign body, 47% of them reported that they suffer from appetite loss and, and 47% of them reported that they suffer from cough. Also, 34% of them indicated that they suffer from throat irritation and 31% of them suffer from pain during swallowing.

Table 3. Emotional consequences that patients suffer from due to Dysphagia: avoiding eating with others, feeling embarrassed while eating with others, and feeling nervous and anxious while eating with others.

emotional consequences	Avoiding eating with others	Feeling embarrassed while eating with others	Feeling nervous and anxious while eating with others
Percentage %	76	64	61

Table 3 shows that there was 76% of participants reported that they avoid eating with others, 64% of them reported that they feel embarrassed while eating with others and 61% of them reported that they feel nervous and anxious while eating with others.

Table 4. Personal feelings and the importance attributed to meals: feeling of pleasure while eating, feeling uncomfortable while swallowing and life less enjoyable.

Personal feelings	Feeling of pleasure while eating	Feeling uncomfortable while swallowing	Life became less enjoyable due to Dysphagia
Percentage %	14	86	61

Table 4 shows that 86% of participants reported that they feel uncomfortable while swallowing, 61% of them reported that their life became less enjoyable due to dysphagia, and only 14% indicated that they feel pleasure while eating.

Table 5. Percentage of patients who expect their condition to improve and those who do not expect their condition to improve.

Category	Expect improvement	Do not expect improvement
Percentage %	67	33

Table 5 shows that most patients with dysphagia who participated in this study reported that they expect their condition to improve in the future (67%), and 33% of them reported that they do not expect their condition to improve.

Discussion and Conclusion

This study aimed to determine the emotional consequences brought on swallowing difficulties. Data were collected by a questionnaire filled out by patients with dysphagia who attending speech therapy, Gastroenterology and neurology clinics in major cities in Jordan.

The percentage of males and females was 66% and 34%, respectively. The results showed that there were no statistically significant differences in participants' emotional consequences based on the demographic characteristics of the participants. Therefore, therapists and healthcare professionals must pay attention to the emotional state of all patients with swallowing disorders.

The most common symptom among participants was swallowing liquid with difficulty. This finding differed from that of Farri, A. Accornero, A. & Burdese, C. (2007) study in Italy that showed the most common symptom was Feeling of foreign body. The least common

symptom was acid regurgitation. This finding is consistent with Farri, A. Accornero, A. & Burdese, C. (2007).

Most of the participants who participated in this study reported that they avoid eating, feel embarrassed, and feel nervous and anxious while eating with others. These findings differ from Ekberg, O. Hamdy, S. Woisard, V. et al. (2002) study in Germany, France, Spain and United Kingdom may be due to difference between Arab and European cultures. Also, most of them reported that they do not feel pleasure while eating, feel uncomfortable while swallowing, and their life is less enjoyable due to dysphagia. These findings differ from Printza, A. Triaridis, S. Kalaitzi, M. et al. (2020).

Most of the participants with dysphagia reported that they expect their condition to improve. This finding differs from Checklin, M., Bain, J., Bath, L., & Lethbridge, K. (2019) study in Australia.

As a result, it would be helpful for patients with dysphagia if the healthcare professionals who treat them become more aware of the emotional consequences they are feeling, give them advice on how to deal with these emotional consequences, involve them in developing the treatment plan and provide them with realistic expectations about their prognosis.

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APPENDIX

Demographic questions Part

1. What is your gender?

(A) female (B) male (C) prefer not say

2. In which country do you live? _____

3. What is your highest educational level? _____

Symptoms Part

4. Choose the symptom/ symptoms that you suffer from due to dysphagia:

(A) acid regurgitation (B) cough (C) swallowing liquid with difficulty

(D) feeling of foreign body (E) appetite loss (F) throat irritation

(G) pain during swallowing (I) if some other, please specify _____

Emotional Consequences Part

5. Choose the emotional consequences that you suffer from due to dysphagia:

(A) avoiding eating with others (B) feeling embarrassed while eating with other

(C) feeling nervous and anxious while eating with others

(D) if some other, please specify _____

Personal Feelings and the Importance Attributed to Meals

6. Do you feel pleasure while eating?

(A) yes (B) no

7. Do you feel uncomfortable while swallowing?

(A) yes (B) no

8. is your life less enjoyable due to Dysphagia?

(A) yes (B) no

Prediction of Prognosis

9. Do you believe that your condition will improve?

(A) yes (B) no

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