

SPEECH THERAPY

Social importance of dysphagia: its impact on diagnosis and therapy

Il peso sociale della disfagia: il suo impatto sulla diagnosi e sul trattamento

A. FARRI, A. ACCORNERO, C. BURDESE

Department of Clinical Pathophysiology, University of Turin, Turin, Italy

SUMMARY

Until now, a limited number of studies have been carried out on the social importance of dysphagia and its consequences on the quality of life. Dysphagia is considered a disabling disorder for the individual from the functional point of view of swallowing, as well as the emotional-relational viewpoint. Aim of the study was to detect both the social consequences and the emotional implications which lead the dysphagic patient to evaluate the worsening of the quality of life after the onset of the disorder and how speech therapy can improve it. A survey was carried out on 73 patients, aged between 40-80 years, who had undergone one of the following operations: ENT, maxillo-facial, neurological and presbiphagic. A questionnaire was prepared comprising 25 questions concerning: medical history, eating habits, personal feelings, information about dysphagia and state of health. Research was carried out on a sample of patients who were still actively working and enjoyed an intense social life; almost 50% were under 60 years of age. After the surgical operation, they were found to be more fragile, lacked self-confidence, with limited social relationships and consequently, a tendency to isolation. Most patients, who had previously considered mealtimes an opportunity to meet others and a social gathering, no longer believed them to be a pleasant aspect of their day on account of the difficulty in swallowing. As a result, food consistency had to be changed and strategies had to be invented in order to make the meal less embarrassing. All patients agree they received, initially, little information on dysphagia. They maintain they benefited from speech therapy re-education and placed their confidence in the doctors who were treating them. Dysphagia is a disorder which has a negative influence on the patient's life, worsening it qualitatively from both a social and an emotional point of view. The patient tends to isolate him/herself, and experiences a sense of discomfort and diversity compared to his/her fellows, leading to a decrease in self-esteem. Research shows that patients are duly informed by doctors and health care professionals concerning the problems related to dysphagia and the rehabilitation therapy to be followed. Patients feel more safeguarded and there is an overall improvement in their lives.

KEY WORDS: Dysphagia • Quality of life • Diagnosis • Speech therapy

RIASSUNTO

Il peso sociale della disfagia ed il risvolto a livello di qualità della vita nel paziente è stato oggetto, fino ai giorni nostri, di un numero limitato di studi. La disfagia è vissuta come una patologia invalidante per la persona sotto l'aspetto sia funzionale della deglutizione sia emotivo-relazionale. L'obiettivo è stato individuare le conseguenze sociali ed i risvolti emotivi che portano il paziente disfagico a valutare il peggioramento della qualità della vita dopo l'insorgenza della malattia e, nello specifico, quanto il trattamento logopedico la possa migliorare. L'indagine è stata condotta su un campione di 73 pazienti, di età compresa tra 40-80 anni, sottoposti ad interventi chirurgici ORL o maxillofacciali, affetti da patologia neurologica o presbifagici. Strumento di indagine un questionario strutturato in 25 domande su: anamnesi, abitudini alimentari, sensazioni personali, informazioni sulla disfagia e stato di salute. La ricerca è stata condotta su un campione di pazienti con un'età, nella quasi metà dei casi, inferiore ai 60 anni, attive nel mondo del lavoro, con una vita sociale intensa e che, dopo l'intervento chirurgico, si sono riscolpite più fragili, insicure, con limitazione dei propri rapporti sociali ed una conseguente tendenza all'isolamento. La maggior parte dei pazienti ritiene che il momento del pasto, prima visto come occasione di incontro e momento di aggregazione sociale, non sia più un aspetto piacevole della giornata a causa della deglutizione problematica, con conseguente modificazione della consistenza degli alimenti ed elaborazione di strategie per rendere il pasto meno difficoltoso. Tutti i pazienti concordano di avere ricevuto, inizialmente, poche informazioni sulla disfagia, di avere ottenuto grandi benefici dalla rieducazione logopedica e di nutrire fiducia nei confronti dei medici che li hanno in cura. La disfagia è una patologia che influenza negativamente la vita dei pazienti, peggiorandola qualitativamente sotto l'aspetto sia sociale sia emotivo. Porta le persone a vivere un maggior isolamento, un senso di disagio e di diversità nei confronti del prossimo, con conseguente diminuzione di autostima. Dai risultati della ricerca si può affermare che, se vengono debitamente informati dai medici e dagli operatori sanitari sui problemi che la disfagia comporta e sui trattamenti riabilitativi da seguire, i pazienti si sentono maggiormente tutelati e la qualità della loro vita migliora a 360 gradi.

PAROLE CHIAVE: Disfagia • Qualità della vita • Diagnosi • Terapia logopedica

Introduction

The term dysphagia, swallowing disability or disorder, can refer to any discomfort in swallowing (a subjective aspect of the individual) or any swallowing dysfunction which can be objectively detected directly or indirectly on account of its consequences.

Until now, a limited number of studies have been carried out on the social importance of dysphagia and its consequences on the quality of life (QoL).

The present study was commenced in 2004, triggered by a project, supervised by Olle Ekberg¹ at the Clinical University of Malmö at the end of the 1990s, on the social consequences and the emotional implications which lead the dysphagic patient to evaluate the worsening of the QoL after onset of the disorder.

Dysphagia is considered a disabling condition for an individual as far as concerns both the functional, as well as the emotional-relational aspects.

Aim of the study was to detect both the social consequences and the emotional implications which cause the dysphagic patient to evaluate the worsening of the QoL after the onset of the disorder and how speech therapy can improve it.

Materials and methods

The survey was carried out on a sample of 73 patients:

- 33 (age range 40-80 years) who had undergone, in the previous 5 years, surgical operations in the maxillo-facial surgical departments at the San Giovanni Battista Hospital, Turin;
- 12 (age range 40-80 years) who had undergone, in the previous 2 years, surgical operations in the First ENT Clinic at the San Giovanni Battista Hospital, Turin;
- 8 (age range 50-80 years) admitted in the previous 2 years to the Neurology Department at the San Giovanni Battista Hospital, Turin;
- 20 (80% over 80 years) residents in the IRV (*Istituto di Riposo per la Vecchiaia*) Institute for the Elderly in Turin.

A questionnaire elaborated by Ekberg (with reference to the Gustafsson B. and Tibblin L. questionnaire)², translated and modified, was used as a research tool.

The questionnaire was administered once to each patient in approximately 15 minutes; the version used, consisted of 25 questions subdivided into 5 study areas:

1. medical history in order to have a general picture of the patient's characteristics;
2. analysis of the patient's eating habits;
3. personal feelings and the importance the patient attributes to mealtimes, evaluating the entity of changes in the patient's QoL due to dysphagia and how this influences his/her social relationships;
4. information given to the patient concerning where and who to refer to for help;
5. evaluation of the patient's general state of health.

Results

The oncological patients were found to have been heavy smokers and drinkers during the pre-surgery period and despite the risk of recurrence, 25% of patients continued smoking or drinking alcohol³. Of the patients interviewed, 40% were under 60 years of age, thus, they were still involved in their working activity, with an intense social life. With the onset of dysphagia, they became emotionally fragile and insecure initially showing loss of self-esteem, limitations to their own social relationships, and, consequently, a tendency to isolation.

At the onset of dysphagia, patients were mostly affected by the following symptoms (Table I): the feeling of a foreign body in the throat upon swallowing, inability to swallow liquids, coughing or pain, loss of appetite and acid regurgitation.

Due to these swallowing problems, all patients had some eating restrictions. Food consistency had to be changed to aid swallowing, cutting the food into small pieces, or blending it better, making it more compact. Moreover, some strategies had to be applied in order to make the meal easier, such as, eating and swallowing more slowly, drinking liq-

Table I. Survey on symptoms.

Patients %	Loss of appetite	Throat discomfort	Pain during swallowing	Feeling of foreign body	Inability to swallow liquid	Cough	Acid regurgitation
Maxillo	33	27	6	18	18	12	6
ENT	0	58	42	67	25	50	8
Neuro	0	50	25	13	25	38	3
IRV	80	40	25	90	25	70	50

Table II. Eating habits.

Patients %	Assistance with meal	Food restriction	Smaller quantities of food	Hunger/thirst after meals	Modification of food consistency
Maxillo	0	100	33	33	100
ENT	0	100	33	25	100
Neuro	25	100	75	63	100
IRV	80	100	0	0	100

uids in small sips and/or chewing the food a long time before swallowing (Table II).

In order to evaluate the QoL of the patients under study, personal sensations and the importance attributed to meals are noteworthy (Table III): all the patients interviewed, agreed that since they had become dysphagic their lives were less enjoyable: because mealtimes were experienced as a problem, swallowing was troublesome and they no longer experienced any pleasure from eating.

Furthermore, the patients who completed the questionnaire, admitted they avoided eating in the company of other people, apart from their close family members, therefore they had stopped eating out at restaurants, pizza parlours, having dinner at friends' homes (Table IV) as they were embarrassed and/or felt particularly anxious, and panicky.

Finally, the study focused on the level of information that doctors and health care workers gave the patients with regard to swallowing problems, bearing in mind also speech therapy re-education.

Data emerging from the questionnaire (Table V) showed that patients with neurological problems received the largest amount of information from doctors and health care workers with regard to swallowing problems, i.e., what the latter actually mean and how to behave accordingly.

Patients trust doctors and health care workers who deal with the treatment of swallowing problems to the extent that 100% of ENT patients, 94% of maxillo patients, 88% of neurological patients considered dysphagia a curable condition.

All the patients confirmed the concept of adopting strategies to improve their swallowing: for example, chewing food more slowly and taking longer, drinking liquids in small sips and resuming eating only after rinsing out their mouths.

Of interest, 100% of ENT and neurological patients claimed they had undergone speech therapy following surgery or after the onset of dysphagia, while hospitalised, or after discharge, in the community in an outpatients' facility. All agreed that mealtimes were still a pleasant aspect of the day

Table III. Importance attributed to mealtimes.

Patients %	Pleasure from eating	Meal as a pleasant moment	Swallowing is a bother	Life less enjoyable
Maxillo	0	100	33	33
ENT	0	100	33	25
Neuro	25	100	75	63
IRV	80	100	0	0

Table IV. Bother caused by swallowing problems.

Patients %	No meals with other people	Feels embarrassed during meals	Feels anxious/panicky during meals
Maxillo	36	33	24
ENT	17	25	25
Neuro	25	13	13
IRV	100	100	10

Table V. Search for help.

Patients %	Information by trained staff	Parents/friends participation	Dysphagia as a curable disease	Speech therapy
Maxillo	45	91	94	33
ENT	25	83	100	100
Neuro	63	100	83	100
IRV	15	50	20	0

and they were optimistic about dysphagia which they considered a curable condition over time.

The speech therapist taught them some techniques to make swallowing easier, such as:

- compensation methods which involve strategies to modify the physiological mechanism directly during swallowing without eliminating the cause, such as, particular swallowing techniques, helpful postures and some behavioural precautions to achieve efficient oro-pharyngeal passage of the bolus and the ability to swallow without inhaling in the airways⁴;
- re-educational techniques by means of training exercises to improve neuromuscular or sensorial deficiencies⁵;
- the IRV patients followed no course of speech therapy, since there are no speech therapists working in this institution.

Discussion and conclusion

To conclude, dysphagia is a disorder which has a negative influence on the patient's life, severely affecting QoL, both the social and emotional aspects (100% of maxillo-facial patients, ENT patients, neuro patients and IRV patients).

Outcomes show that dysphagic patients tend to isolate themselves more, and, in fact, many avoid eating out with other people (36% of maxillo patients, 17% ENT patients, 25% neuro patients and 100% IRV patients), partly because they feel embarrassed (33% of maxillo patients, 25% ENT patients, 13% neuro patients and 100% IRV patients), partly because they need assistance during meals (25% of neuro patients and 80% of IRV patients) and/or feel less interested in food which, however, is limited as far as concerns choice.

The latter, moreover, needs to be modified in consistency (100% of all patients), minced and/or blended, depending on the severity of the dysphagia.

All these aspects contribute to making dysphagic patients feel uneasy, with a sense of "diversity" compared to their fellows, leading to loss of self-esteem.

However, the questionnaire, which was the object of the study, showed that patients' lives improved qualitatively upon their being duly informed, by doctors and health care workers, concerning the problems related to dysphagia, and as a result of the rehabilitation therapy to teach them strategies and methods to improve their swallowing (33% of maxillo patients, 100% of ENT patients and 100% of neuro patients).

Therefore, it would be useful to invite both doctors and health care professionals to provide dysphagic patients with more information so that they can live their lives more serenely.

This may be possible if all health care professionals become more aware and better informed about this problem by exchanging information, especially those caregivers who are in direct contact with the patient in order to work in harmony and thus allow the patient rapid and effective support, aimed at improving their QoL.

Interestingly, all patients agreed that speech therapy rehabilitation allowed them to improve their QoL since they were taught specific techniques to make swallowing easier, proper posture and some behavioural precautions, besides re-educational techniques with exercises aimed at improving the neuromuscular and sensorial deficiencies.

References

- ¹ Ekberg O, Hamdy S, Woisard V, Wuttge-Hanning A, Ortega P. *Social and psychological burden of dysphagia: its impact on diagnosis and treatment*. *Dysphagia* 2002;17:139-46.
- ² Gustafsson B, Tibblin L. *Dysphagia, an unrecognized handicap*. *Dysphagia* 1991;6:193-9.
- ³ McOrmeij CA, Bricker DE, Kramer AE. *The SWAL-QOL outcomes tool for oropharyngeal dysphagia in adults: Conceptual foundation and item development*. *Dysphagia* 2000;15:115-21.
- ⁴ Aguilar NV, Olson ML, Shedd D. *Rehabilitation of deglutition problems in patients with head and neck cancer*. *Am J Surg* 1979;138:501-7.
- ⁵ Schindler O, Farri A, Accornero A, Di Rosa R, Utari C. *La riabilitazione fonatoria, articolatoria e deglutitoria. La qualità di vita in oncologia cervico-cefalica*. XLV Raduno Alta Italia Torino 1999 (Atti del Convegno). Proceedings.

Received: April 3, 2006 - Accepted: December 11, 2006