



Social and Psychologic Impact of Dysphagia

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Contents

1	Introduction	874
2	Social Participation	875
3	Affective Response to Swallowing Impairment	876
4	Eating Habits	878
5	Enteral Feeding	878
6	Impact on Caregivers	879
7	Assessment of Psychosocial Burden of Dysphagia	881
7.1	Swallowing Quality of Life (SWAL-QOL).....	881
7.2	International Classification of Functioning (ICF).....	881
7.3	Psychological Assessment.....	884
8	Implication for Clinical Practice	884
	Conclusion	884
	References	885

Abstract

Complications of oropharyngeal dysphagia include aspiration pneumonia, malnutrition, dehydration, and impact on psychosocial well-being. However, patients, caregivers, and clinicians perceive the importance of these complications differently, with patients addressing psychosocial sequelae as predominant. The chapter provides an overview of the psychological and social impact of dysphagia on patients and their caregivers. Embarrassment due to inability to eat and drink in a social acceptable way leads to social isolation. Diminished self-esteem, fear, anxiety, frustration, and depression may be experienced. Eating habits may be overturned, especially in case of more restricted diets and introduction of enteral feedings. Over time, patients find a range of coping strategies, which may be beneficial for some, while negative for others. Caregivers have to cope with changes of their role and responsibilities; in reaction to these, affective symptoms may arise. Implications for clinical practice are discussed, including a multidisciplinary and holistic assessment of the patient and the caregiver to be performed periodically, personalization of the counseling, skill-building programs, and interactions with other patients.

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1 Introduction

Eating and drinking are fundamental activities in our lives. Meals in part rule the organization of our days. Eating habits reflect a person’s social, cultural, religious, geographical, and economic background. The taking of food and drink is a social event that symbolizes acceptance, friendship, and community. Hence, it is not surprising that the onset of a swallowing problem may lead to psychosocial sequelae.

Among dysphagia’s complications, studies have mainly focused on physical consequences, i.e., aspiration pneumonia, malnutrition, and dehydration. Martino et al. (2009, 2010) have investigated the perceptions of patients, caregivers, and clinicians of the relevance and the interaction of dysphagia sequelae. All interviewed participants agreed on the fact that psychological, pulmonary, and nutritional status may be affected by swallowing impairment. However, when ranking the importance of these three complications patients considered the psychological consequences of greatest importance, whereas caregivers and clinicians placed greater value on biomedical consequences. Moreover, clinicians and caregivers recognized only few of the psychological consequences reported by patients. When analyzing dysphagia’s complications from clinicians’ point of view, pulmonary, nutritional, and psychological sequelae are considered separately (Fig. 1). Each one of the complications is believed to be related to the severity of dysphagia

but no interaction with each other was identified. Caregivers described a causal feed-forward or feed-back relationship between the three consequences (Fig. 2). For instance, choking (pulmonary) is perceived to be linked to the fear of it (psychology), leading the patient to avoid eating and drinking and therefore increasing the risk of malnutrition and/or dehydration (nutritional), which will ultimately expose the patient to a higher probability of developing lung infection (pulmonary). Patient’s view depends on the duration of swallowing impairments. The connection between pulmonary (i.e., choking) and psychological (i.e., fear) was predominant for acute patients with the onset of dysphagia within the last 3 months, while little attention was given to nutritional status (Fig. 3). In chronic patients, psychological consequences of dysphagia were judged to be the most relevant complication of

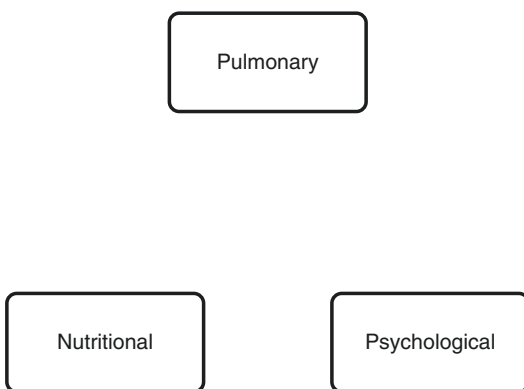


Fig. 1 Dysphagia complications from clinicians’ perspective (adapted from Martino et al. 2010)

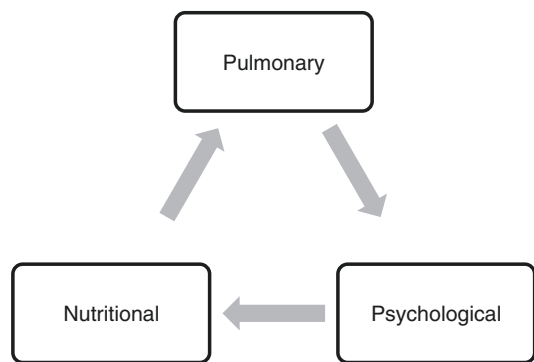


Fig. 2 Dysphagia complications from carers’ perspective (adapted from Martino et al. 2010)

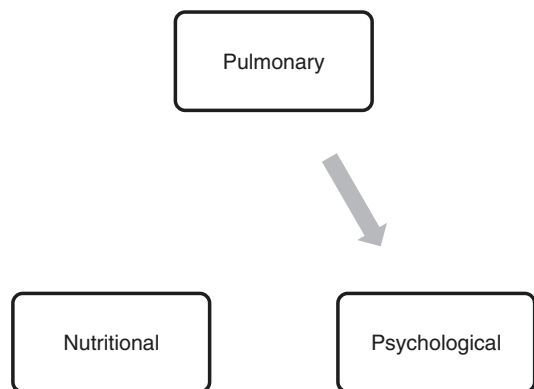


Fig. 3 Dysphagia complications from acute patients’ perspective (adapted from Martino et al. 2010)

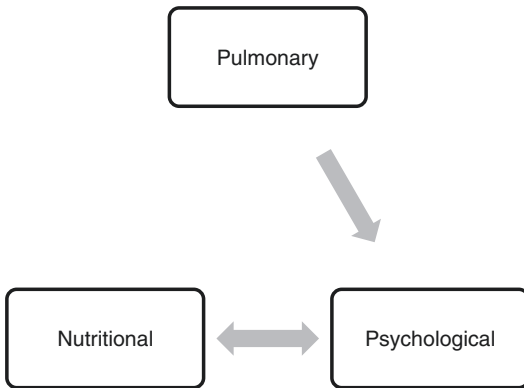


Fig. 4 Dysphagia complications from chronic patients' perspective (adapted from Martino et al. 2010)

dysphagia. Compared to acute patients, pulmonary complications were ranked as less important while nutritional status acquired importance and has a potential feed-forward and feedback interactions with the psychological dimension (Fig. 4).

Thus, stating the difference in the perspectives of clinicians, caregivers, and patients concerning dysphagia consequences, it stresses the need for clinicians to better understand and take into account the social and psychological burden experienced by individuals with dysphagia and their families.

2 Social Participation

Wedding reception, birthday party, family celebrations, religious ceremonies, working meeting, and dating are strongly associated with meals, banquets, aperitifs, and appetizers. Consequently, eating and drinking are not just nutrient supply, but form an important part of social interaction, being linked to many of the most enjoyable activities and having an impact on how individuals see themselves in relation to others.

Full social participation is suggested to be a key outcome indicator for rehabilitation (Heinemann 2005; Piškur et al. 2014). Individuals post-stroke, for instance, give more emphasis to engagement in social world over discrete physical function when appraising their recovery (Burton 2000). Therefore, examining the impact of dysphagia on social participation is of greatest

importance. The International Classification of Functioning, Disability and Health (ICF) defines participation as “involvement in a life situation or as ‘the lived experience’ of people in the actual context in which they live” (WHO 2001). However, the ICF does not define social participation and a specific definition for this concept is still lacking (Piškur et al. 2014). For the purpose of this chapter we may accept Levasseur and colleagues' definition of social participation as “a person's involvement in activities that provide interaction with others in society or the community” (Levasseur et al. 2010).

An important issue for patients with dysphagia is eating and drinking in socially acceptable manner. Individuals with dysphagia experience feelings of uncertainty, particularly in the acute phase, regarding on how to behave in the company of others (Medin et al. 2010). Socially acceptable behaviors include staying clean during meals and adequately managing saliva. Having to continually wipe the mouth or to have a handkerchief available because of scialorrea or food dropping may be perceived as a stigma (Miller et al. 2006). The possibility to suddenly start coughing during mealtime in company of other people is source of anxiety and embarrassment. The comparison between their present way of eating with their own values regarding what is acceptable or not may lead to different behaviors (Medin et al. 2010). Studies focusing on the social burden of dysphagia report a high percentage of patients avoiding eating with others or outside their homes because of their swallowing problem (Ekberg et al. 2002; Farri et al. 2007; Medin et al. 2010; Patterson et al. 2015). Other people comprise formal caregivers, spouses, family members, friends, and unfamiliar people. Only few patients become withdrawn from close family mealtimes, feeling understood by familiar others and generally appreciating the help they gave. On the other hand, unfamiliar people make it more difficult for some individuals, feeling uncomfortable, embarrassing, and hard. Regardless of the familiarity, patient's slowness when consuming a meal results in remaining at the table long after others had finished and therefore contributing to the perceived burden of dysphagia and detriment of the personal

and social enjoyment of eating (Miller et al. 2006). Patients alter their social habits connected with eating, avoiding eating out at restaurants, clubs, and friend's homes, as well as stopping inviting friends for a meal. Changes are observed also with regard to religious rituals such as taking communion at the local church. Therefore, it derives an increased sense of isolation due to dysphagia (Ekberg et al. 2002).

However, dysphagia does not always result in the same restriction to social participation, being related to what was important to each person. Positive coping strategies may be found; however, what might be a solution for one family proved negative for another. Whereas some individuals struggle to "get back to normal" as things were before the onset of dysphagia, others simply try to get by somehow making some adjustments and adaptations. Development of coping strategies may be reached thanks to different mechanisms. First of all, by trial and error and testing what work and what do not work in eating situations the person discovers new ways of doing things. Moreover, getting advices from others may help finding ways of mastering eating in social contexts (Medin et al. 2010). Of particular importance for patients are adequate information by health-care providers and strategies and methods learned during the rehabilitation therapy (Farri et al. 2007). Positive coping strategies may include:

- Eating smaller portion and more often allowing patients to manage their portion in the time relatives and friends take for the whole meal
- Finding restaurants serving food they can manage (e.g., adding extra sauce)
- Retaining a role in group eating situations (e.g., entertaining children) (Patterson et al. 2015).

3 Affective Response to Swallowing Impairment

Several emotions are felt by persons with dysphagia. Fear of choking is a prominent feature during mealtimes, especially in the first period

after the onset of the swallowing disturbance. Feeling of guilt may be experienced as well, because of the disruption caused to the whole family in terms of extra time and energy to spend in meal planning and cooking. The sense of diversity compared to their peers may lead to loss of self-esteem.

Studies have reported the presence of affective complaints in almost half of the patients with dysphagia (Ekberg et al. 2002; Verdonschot et al. 2013, 2016). In particular, Verdonschot and colleagues conducted two studies aiming to detect symptoms of anxiety and/or depression and to investigate their relationship with signs of dysphagia in a sample of patients following head and neck oncological treatment (2013) and in a sample of individuals with oropharyngeal dysphagia of different etiology (2016). Although no causal relationship was demonstrated due to the cross-sectional design of the study, the authors identified some connections between affective complaints and dysphagia. The severity of diet restriction was not found to be a determinant of clinically relevant symptom of anxiety, while patients with a more restricted diet showed higher risk of having symptoms of depression. On the other hand, no significant association between clinically relevant depressive symptoms and the FEES outcome variables was found, while clinically relevant symptoms of anxiety were significantly associated with some FEES variables (piecemeal deglutition and post-swallow vallecular pooling). Apparently, a greater severity of oropharyngeal dysphagia did not increase the probability of having affective complaints. The authors suggested that patients experiencing more severe dysphagia often had a long history of disease and therefore may have already adapted to their physical limitations, unlike patients with mild dysphagia in the early stages or acute onset of disease.

Indeed, changes in affective response to swallowing impairment have been reported by other authors. Martino et al. (2010) analyzed patient's perception of psychological issues related to dysphagia in acute patients (with dysphagia onset of 3 months or less) and in chronic patients (with dysphagia onset greater than 3 months).

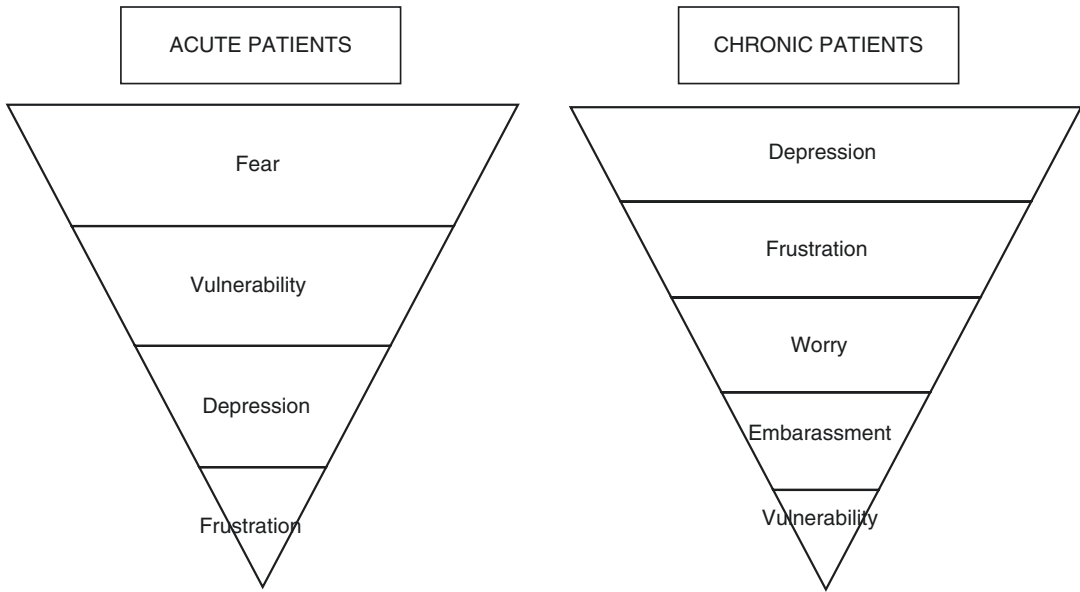


Fig. 5 Comparison of relevant psychological domains between patients with acute and chronic dysphagia, according to Martino et al. (2010)

Their results showed differences between acute and chronic patients on how they perceive and prioritize major psychological dimensions, as summarized in Fig. 5. Generally, acute patients experience increased anxiety, while chronic patients increased depression. The “fear of choking to death” is prevalent in individuals with acute onset of dysphagia. In this population the issue of fear is overwhelming, leading some patients to refuse drinking prescribed fluids even when they are thirsty to avoid the risk of choking. The sense of vulnerability related to the inability to predict or manage the symptoms of dysphagia intensifies the feeling of fear. On the other hand, chronic patients develop adaptive strategies that help them better manage their dysphagia symptoms, increasing the sense of control and decreasing the feeling of vulnerability. Together with it, the feeling of fear changes into a more measured “worry” of choking. The ability to consciously apply environmental supports as well as food selection criteria gives them self-confidence. However, over the course of the disease the possibility of choking, especially in public venues, is not experienced as frightening anymore but as embarrassing. Moreover, the

realization of the limitations because of their swallowing problems, the feelings of deprivation over not being able to eat the foods they liked, the loss of hope for swallowing recovery, and the need to continually manipulate social eating situations may make them either depressed or frustrated.

Nund et al. (2014c) investigated the mechanisms underlying the emotional adjustments in a sample of patients with dysphagia secondary to head and neck nonsurgical treatment. In particular, they identified three phases:

1. Entering the unknown
2. Making practical adjustments to live with dysphagia
3. Making emotional adjustments to live with dysphagia

Entering the unknown was a key theme especially because patients stated that they had not anticipated the severity and duration of swallowing impairment. This stresses the need for adequate education from health professionals regarding the potential side effects of dysphagia, including both the physical aspects and its

potential impact on other aspects of life. Emotional adjustments and changes in perceptions are required to live with dysphagia. Some patients addressed taking a positive attitude, while others spoke about not letting their difficulties with food become a barrier. Ultimately most of the patients reached a point in their recovery where they had accepted the changes to their swallowing ability. Other strategies to make emotional adjustments to live with dysphagia include remaining hopeful that their eating abilities would return to normal, enjoying food vicariously through other people and what they could eat, shifting their focus from food and meals, and believing that there was always someone who was worse off than they were. The support received from family, friends, and other patients is fundamental. Family members were identified as a significant source of support for people with dysphagia, particularly regarding meal preparation and encouragement to keep eating. Patients highlighted the importance for their family/friends to understand their eating difficulties, though it does not always occur.

4 Eating Habits

One of the first studies which specifically investigated the psychological and social burden of dysphagia showed that more than half of the 360 dysphagic patients from different European countries had to modify their eating habits because of their swallowing impairment (Ekberg et al. 2002). Food is selected for its nutritional content and on what people could “get down.” The meaning of food may be reduced to its medicinal and nutritional qualities. Patients adapt their eating habits to alleviate the condition by eating and swallowing more slowly, taking sips of liquid in between bites of food, chewing food longer before swallowing, and changing the routine of mealtimes eating less but more often.

Texture modification is a common strategy for oropharyngeal dysphagia. However, patients’ non-adherence with prescriptions for modified boluses is a recurring issue, with many patients expressing a strong dislike of the altered textures (Swan et al. 2015). When puree diet is recommended, people

complain that their food is boring due to meal repetition (Patterson et al. 2015). Residents’ transition from normal food to texture-modified food involved the experience of eating food out of necessity and hunger, rather than eating food for enjoyment and pleasure, involving a change to the meaning of eating (Ullrich and Crichton 2015). The degree of distress associated with the transition markedly depends on the comprehension of the rationale for the texture modification by the patients and their families (Ullrich and Crichton 2015). Swan et al. (2015) conducted a review of literature on the effect of bolus modification on health-related quality of life (HRQoL), defined as the way the disease or disorder affects the individual not only from a physical point of view, but also from psychological, social, and environmental views in combination with the individuals’ underlying value system. The review showed that generally:

- Participants receiving less modified textures had better HRQoL than those receiving more modified textures.
- Modifications to food textures may have a more substantial impact to HRQoL than modifications to fluids.

Therefore, clinicians should be aware of the potential negative impact bolus modification may have on HRQoL and take this into consideration when choosing to prescribe bolus modification, especially in patients with chronic dysphagia. Moreover, strategies to assist the transition to a modified diet should be adopted by health professionals, providing appropriate information and opportunities for negotiation and familiarization with the texture-modified food as well as establishing periodical follow-up procedures.

5 Enteral Feeding

Eating habits are further overturned by the introduction of enteral feeding. The time schedules related to feeding tube require a reorganization of the daily routines of the patients and their families. Life has been described as “happening ‘between feedings’” (Penner et al. 2012). When a

nighttime feeding is not scheduled, the time required for feeding during the day may leave only little time for other responsibilities or leisure activities, consequently affecting patients and caregivers' social lives.

On the other hand, enteral feeding meets the goal of ensuring an adequate nutrition to the patients. This was found to be a key theme for caregivers, who feel frustrated when they perceive that their nutritional intake was inadequate only relying on oral feeding (Penner et al. 2012). Moreover, shorter meals are experienced as more enjoyable for both patients and their caregivers when feeding is provided through a mixed oral and enteral nutrition (Sleigh 2005). Indeed, mothers of children with dysphagia who are fed orally report of prolonged mealtimes lasting between 5 and 8 h a day and meals are described as "a battle" or "a war" (Craig et al. 2003).

Despite these advantages, an initial opposition to the suggestion of gastrostomy is common, as well as the non-adherence with the *nihil per os* regimen once the gastrostomy-tube (G-tube) is inserted. Several studies have focused on the concerns and the reasons for non-adherence among parents of children with neurodevelopmental disorders and G-tube (Craig et al. 2003; Petersen et al. 2006). The following themes can be identified:

1. Seeing the G-tube as a confirmation of the permanence of the disability
2. Perceiving the G-tube as a "failure of the caregiver"
3. Viewing the loss of oral feeding as a denial of a basic or an essential human instinct and nature
4. Fearing increased discrimination from an added stigma
5. Negatively impacting mealtime associations and familial bonding
6. Preventing the child's pleasure in eating.

First of all, gastrostomy may be sometimes perceived as the last resort, the signal that the child will never go to feed properly. This sense of resignation is associated with a feeling of failure of their parental role to properly care for their children, being unable to manage mealtime

problems. The loss of the maternal experience of feeding the child has deep significance for caregivers. Being eating the "natural" way to receive nutrition, parents are afraid that their child could be seen as somewhat "less human." Traditional forms of food, such as small amount of food by mouth or otherwise regular foods provided through the G-tube, are believed to have a higher value than enteral nutrition formulas from parents' perspective. The G-tube exhibits an advantage over the nasogastric tube in terms of visibility, partly reducing the stigmatizing effect connected with enteral nutrition. A concern that gastrostomy feeding might exclude the child from participating in school and family life was raised. Meals are recognized to be a "special time" for both familial bonding and closer contact with peers. However, some parents considered the gastrostomy a facilitator rather than a barrier to social interaction by allowing the child to "join in" with peers during school meals instead of concentrating solely on oral feeding. As the relationship with food is highly individual, parents highlighted the importance for the child to experience different tastes, textures, and enjoyment of food.

A complex process of negotiating a new normal starts after the introduction of enteral feeding. A main aspect of this process is negotiating changing roles (Penner et al. 2012). Indeed, caring for someone who is dependent on tube feeding means that caregivers need to acquire new skills and unique knowledge in relation to its use. Caregivers often feel little prepared and anxious about undertaking this responsibility. Information, communication, and support are important facilitators of the negotiation process (Mayre-Chilton et al. 2011; Penner et al. 2012).

6 Impact on Caregivers

Regardless of the introduction of enteral feelings, the onset of dysphagia has a social and psychologic impact not only on patients but also on their families. Caregivers are strictly involved in the management of dysphagia. Thus, considering affective symptoms and limitation in participation of caregivers because of their kins'

swallowing impairment is mandatory during the taking charge of patients with dysphagia.

Concerning affective symptoms, Serel Arslan et al. (2017) have recently explored anxiety level of caregiver of neurological patients with and without dysphagia. They found that caregivers of neurological patients with dysphagia had higher anxiety level than caregivers of neurological patients without dysphagia, concerning both momentary and long-lasting anxiety, independently of dysphagia severity, types of feeding, condition of dependency in eating and drinking, and dysphagia duration. It suggests that dysphagia causes additional burden for caregivers of neurological patients, increasing their anxiety level. To explain this finding, several aspects related to life with a person with dysphagia should be taken into account.

First of all, as already discussed in the previous paragraph, living with a person with dysphagia also mean changes to the carer's roles and responsibilities. Nund and colleagues stated "additional roles taken on by the carers included problem solver, household manager or 'parent', nutritionist, chef, and life coach" (2014a). Caregivers become the primary responsible for dysphagia care and management, having to control food consistency modifications and body positioning as well as to continuously observe the patient throughout the meal. Caregivers may have concerns about adequate nutritional and fluid intake in order to avoid medical complication. Along with these responsibilities, the fear of choking is an additional worry. Therefore, during food preparation caregivers should take into account both the quality of nourishment and the type of texture. This requires spending more time planning, shopping, and cooking for meals. Moreover, carers would often have to prepare two separate meals, leading to time restriction in daily life for other activities.

Conflicting emotions are associated with the increase of responsibility. Caregivers may feel incapable of providing sufficient care and problem solving during dealing with dysphagia. Moreover, at times the patients may request and be served their favorite dishes, although they may be unsuitable for swallowing safety, resulting in severe dysphagia symptoms that frighten the

carers and made them feel uncomfortable (Johansson and Johansson 2009). Carers may experience feeling of guilt as they can eat whatever they wish, while their partners do not. Thus, they may either eat by themselves so as the partner does not see what they are eating or suppress their own choice of food (Penner et al. 2012).

Loss of affinity during meals has been reported (Johansson and Johansson 2009; Nund et al. 2014a, 2016). Mealtimes provide environment for family interactions. While eating people often express different taste sensations in words or gustatory expressions, tokens of pleasure are part of the conversation when socializing. Some routines, such as sharing the breakfast time or drinking a coffee together, may represent a well-established routine in some relationships. Sitting and talking in a relaxed manner while eating is no longer possible. Some spouses may eat in different moments due to the feeling of discomfort that arises when they sit at a dinner table together. Occasionally, family members report to leave the dinner table because they could not cope with their next of kin's eating behavior. All these aspects may enhance the feeling of separation within a couple.

Furthermore, neurological disorders leading to dysphagia are often chronic disabilities. Difficulties in swallowing may have long-lasting consequences including inadequate oral nutrition, pulmonary diseases, and mortality. Thus, cumulative years spent in caregiving without swallowing improvements or recovery may increase caregivers' anxiety. Indeed, in the study of Serel Arslan et al. (2017) caregivers whose patients had a history of previous dysphagia treatment had higher anxiety level. The authors explained it by their expectations from dysphagia treatment, which did not resolve the swallowing impairment though.

Distinct consideration should be made for mothers of children with swallowing disorders. In case the swallowing impairment occurs since birth, mothers have to relinquish the dream of breastfeeding (Sleigh 2005). A redefinition of mother identity must occur (Hewetson and Singh 2009). It implies making sense of societally, professionally, and personally held perceptions and beliefs about the link between the mothering role and the ability to feed a child. The role of mother

is integrated with that of nurse. Gathering of information and establishment of routines and schedules may assist them in gaining control over the challenges of caring for their children.

- Fear
- Mental health
- Social functioning
- Fatigue
- Sleep

7 Assessment of Psychosocial Burden of Dysphagia

Initial and periodical assessment of the psychosocial impact of dysphagia on patients and caregivers is advisable. Besides dialogue with patients and their family, clinicians may rely on some shared tools, such as the SWAL-QOL or the ICF framework. In any event, the multidisciplinary of the team, including psychologists, may allow a better analysis of psychosocial consequences.

7.1 Swallowing Quality of Life (SWAL-QOL)

The SWAL-QOL is a self-administered questionnaire assessing dysphagia-related quality of life and examining real-life functioning of persons with dysphagia via the patients' perspective. The authors of the tool defined quality of life as "an overall state of well-being that is a composite of: (a) the ability to fulfill usual and desired physical, role, and social activities; (b) the psychological effectiveness with which one performs usual and desired activities; (c) satisfaction with health care services related to dysphagia treatment; and (d) dysphagia symptom status" (McHorney et al. 2000a). Firstly developed in 2000 the SWAL-QOL tool has been validated in several languages and shows adequate psychometric properties (McHorney et al. 2000b, 2002).

The 44 items of the questionnaire cover ten domains:

- Burden
- Eating duration
- Eating desire
- Food selection
- Communication

7.2 International Classification of Functioning (ICF)

The World Health Organization International Classification of Functioning, Disability and Health (WHO-ICF) defines health functioning as "an umbrella term, encompassing all body functions, body structures, activities and social participation" (WHO 2001). If an individual is affected by a disease, then an impairment, an activity limitation, and/or a participation restriction may result. Functioning thus does not coincide with the concept of QoL; however, it may affect psychological well-being (Maclean et al. 2009).

The ICF analyzes functioning based on five major components: body structures, body functions, activities, participation, and environmental factors and personal factors. ICF codes are available for all the components except for personal factors. Environmental and personal factors can be evaluated as either facilitators or barriers. All ICF codes had qualifiers that indicate the severity of the limitation or restriction. These universal qualifiers attached to the ICF codes ranged from 0 (no problem or within normal limits) to 4 (complete or profound problem). In addition, a value of 8 indicates unspecific information, while 9 indicates that it was unavailable. The letter C indicates a complication related to health and function.

Threats in 2007 firstly identified 60 ICF codes for body structures, body functions, activities, participation, and environmental factors and personal factors related to dysphagia. Afterward, Nund and colleagues in 2014 identified 52 ICF codes for dysphagia based on interviews to individuals with dysphagia after nonsurgical head and neck treatment (2014b). The identified ICF codes are summarized in Table 1.

The application of the ICF to dysphagia assessment has been suggested by these authors

Table 1 ICF codes for dysphagia (Threats 2007; Nund et al. 2014b)

Body functions		Body structures		Activities and participation		Environmental factors	
ICF code	Name of code	ICF code	Name of code	ICF code	Name of code	ICF code	Name of code
b110	Consciousness function	s3200	Teeth	d230	Carrying out daily routine	e1100	Food
b117	Intellectual function	s3203	Tongue	d2301	Managing daily routine	e1101	Drugs
b1301	Motivation	s3204	Structure of lips	d2302	Completing daily routine	e1151	Assistive products and technology for personal use in daily life
b1302	Appetite	s330	Structure of pharynx	d550	Eating	e240	Light
b140	Attention functions	s340	Structure of larynx	d560	Drinking	e250	Sound
b144	Memory functions	s510	Structure of salivary glands	d630	Preparing meals	e310	Immediate family
b147	Psychomotor functions			d730	Relating with strangers	e315	Extended family
b152	Emotional functions			d760	Family relationships	e320	Friends
b1642	Time management			d7600	Parent-child relationships	e325	Acquaintances, peers, colleagues, neighbors, and community members
b1643	Cognitive flexibility			d770	Intimate relationships	e340	Personal care providers and personal assistants
b1644	Insight			d7701	Spousal relationships	e345	Strangers
b1646	Problem solving			d850	Remunerative employment	e355	Health professionals
b1801	Body image			d870	Economic self-sufficiency	e410	Individual attitudes of immediate family members
b2102	Quality of vision			d9100	Informal associations	e415	Individual attitudes of extended family members
b250	Taste function			d9191	Ceremonies	e420	Individual attitudes of friends
b255	Smell function			d9204	Hobbies	e5800	Health services
b2700	Sensitivity to temperature			d9205	Socializing		
b28010	Pain in head and neck			d9300	Organized religion		
b450	Additional respiratory functions						
b5102	Chewing						
b5103	Manipulation of food in the mouth						
b5104	Salivation						
b51050	Oral swallowing						
b51051	Pharyngeal swallowing						
b530	Weight maintenance functions						

in order to provide health professionals with a more holistic view of an individual’s functioning and the real-life outcomes for people with dysphagia. Indeed, the behaviors represented by body functions codes that contribute to successful eating and drinking can be markedly different in the person’s natural environments. For instance, as food is highly culturally characterized, two people with technically the same severity of dysphagia may function very differently because of their culture. Personal factors include demographic information, and personality traits, such as coping style and motivation. Eating and drinking are individual experiences. When persons have dysphagia, preferences and personality traits influence both their reaction to dysphagia and patients’ compliance to clinicians’ prescriptions. Moreover, the application of the ICF framework may help clinicians to identify most critical aspects for patient

functioning and, consequently, focus dysphagia treatment on these (Sonies 2000).

As dysphagia has an impact not only on the patients, but also on their caregivers and families, the group of Nund suggested the application of the ICF to study third-part disability of caregivers of patients with dysphagia in order to provide a more holistic and family-centered approach in the management of dysphagia (2016). Third-party disability refers to the “disability and functioning of family members” due to health condition of significant others (WHO 2001). The ICF codes related to the third-party disability are reported in Table 2.

However, several limitations of the ICF in describing functioning and participation of people with dysphagia have been highlighted. Firstly, some of the ICF codes oversimplify the meaning of the activities related to eating and therefore underestimate the effects of dysphagia. For example, the

Table 2 ICF codes related to third-part disability of dysphagia (Nund et al. 2016)

Body functions		Activities and participation		Environmental factors	
ICF code	Name of code	ICF code	Name of code	ICF code	Name of code
b152	Emotional functions	d175	Solving problems	e1300	General products and technology for education
		d2301	Managing daily routine	e310	Immediate family
		d2302	Completing daily routine	e315	Extended family
		d2400	Handling responsibility	e320	Friends
		d2401	Handling stress	e325	Acquaintances, peers, colleagues, neighbours and community members
		d550	Eating	e345	Strangers
		d6200	Shopping	e355	Health professionals
		d630	Preparing meals	e420	Individual attitudes of friend
		d660	Assisting others	e425	Individual attitudes of acquaintances, peers, colleagues, neighbours and community members
		d6604	Assisting others in nutrition	e450	Individual attitudes of health professionals
		d760	Family relationships	e5800	Health services
		d7701	Spousal relationships		
		d7102	Tolerance in relationships		
		d730	Relating with strangers		
		d7500	Informal relationships with friends		
d870	Economic self-sufficiency				
d9205	Socializing				

ICF defines eating as “Carrying out the coordinated tasks and actions of eating food that has been served, bringing it to the mouth and eating it in culturally acceptable ways, cutting or breaking food into pieces, opening bottles and cans, using eating implements, having meals, feasting or dining” (WHO 2001) but this definition does not take into account patient’s enjoyment in eating. Analogously, meal preparation is considered in the ICF as executing a task: “Planning, organizing, cooking and serving meals with a large number of ingredients that require complex methods of preparation and serving, such as planning a meal with several dishes, and transforming food ingredients by combined actions of peeling, slicing, mixing, kneading, stirring, presenting and serving food in a manner appropriate to the occasion and culture.” However, it undervalues the significance of the emotional, psychological, and social aspects of food preparation and its role in caregiving. Secondly, though personal factors are not classified in the ICF, the ICF overlook important aspects such as the person’s unique individual experience in the classification of participation. Moreover, concerns on the ability of the ICF in reflecting the continuous changing nature of participation have been raised (Woodman et al. 2014) as well as the actual applicability of the ICF framework in clinical practice being fairly time consuming (Dong et al. 2016).

Therefore, although the ICF is a valuable tool to provide a more holistic approach to the management of people with dysphagia, there is still a need for the development of this classification to include the above-mentioned aspects.

7.3 Psychological Assessment

A screening of affective response to dysphagia is recommended in patients with dysphagia and in their caregivers. A multidisciplinary team, including not only swallowing experts but also psychologists, is recommended. Several screening tools for symptoms of anxiety and depression are available. Among these, the Hospital Anxiety and Depression Scale (HADS), a validated 14-item questionnaire, is

frequently used as a psychological measurement of affective symptoms in the hospital setting (Zigmond and Snaith 1983; Bjelland et al. 2002).

8 Implication for Clinical Practice

On the basis of this overview on social and psychological impact of dysphagia, the following strategies should be implemented in clinical practice:

- Providing a multidisciplinary approach to the management of patients with dysphagia and their caregivers
- Investigating patients’ previous eating habits in order to understand the impact of potential prescriptions
- Opening a dialogue with patients and caregivers on their needs to better mastering eating and meal preparation allowing a personalization of the information
- Providing periodical evaluations also in the long term including assessment of HRQoL and screening of affective symptoms
- Providing skill-building programs that target activities such as meal preparation and food consumption
- Encouraging the contact with other patients and caregivers to promote the sharing of positively coping strategies

Conclusion

Dysphagia affects social lives and psychological well-being of both patients and caregivers. It is important for clinicians to be aware of the presence of psychosocial issues related to dysphagia, to address them according to the patients’ clinical recovery, and to consider the interplay between psychological and biomedical consequences. By adequately informing and educating patients and their families, assessing them, and offering the appropriate treatments, health professionals can reduce the social and psychological burden of swallowing impairments.

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