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Dysphagia

Social and Psychological Burden of Dysphagia: Its Impact on Diagnosis and Treatment

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Abstract. The social and psychological impact of dysphagia has not been routinely reported in large studies. We sought to determine the effects of dysphagia on broad measures of the quality of life of patients and to explore the relationship between the psychological handicaps of the condition and the frequency of diagnosis and treatment. A total of 360 patients selected on the basis of known subjective dysphagia complaints, regardless of origin, in nursing homes and clinics in Germany, France, Spain, and the United Kingdom were interviewed using an established questionnaire. Qualitative interviews with a total of 28 health professionals were conducted to improve understanding of the patient data in the context of each country. Over 50% of patients claimed that they were "eating less" with 44% reporting weight loss during the preceding 12 months. Thirty-six percent of patients acknowledged receiving a confirmed diagnosis of dysphagia; only 32% acknowledged receiving professional treatment for it. Most people with dysphagia believe their condition to be untreatable; only 39% of the sufferers believed that their swallowing difficulties could be treated. Eighty-four percent of patients felt that eating should be an enjoyable experience but only 45% actually found it so. Moreover, 41% of patients stated that they experienced anxiety or panic during mealtimes. Over one-third (36%) of patients reported that they avoided eating with others because of their dysphagia. In a largely elderly population that might accept dysphagia as an untreatable part of the aging process, clinicians need to be aware of the adverse effects of dysphagia on self-esteem, socialization, and enjoyment of life. Careful questioning should assess the impact of the condition on each patient's life, and patients should be educated on their choices for treatment in the context of any coexisting illness. Awareness of the condition, diagnostic procedures, and treatment options must be increased in society and among the medical profession.

Key words: Dysphagia — Swallowing — Quality of life — Nutrition — Eating habits — Psychosocial effects — Deglutition — Deglutition disorders.

Epidemiological data estimates the prevalence of dysphagia among individuals older than 50 years to be as high as 22% [1,2]. Studies have found that 13% of patients in short-term-care hospitals and up to 60% of nursing home occupants have feeding difficulties [3,4].

Dysphagia, which occurs mainly in elderly people, has a series of physical consequences but is less well understood in terms of its social and psychological consequences [5]. Patients with dysphagia are often at increased risk of developing other medical conditions. Unmanaged, dysphagia can lead to dehydration, malnutrition, respiratory infections, and death. The dehydration causes sputum to thicken and patients may be affected by breathing difficulties [6,7]. The associated malnutrition from dysphagia leads to lethargy and decreased ability to perform

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personal hygiene, to work and socialize, and to be mobile [7].

Dysphagia is a risk factor for food aspiration, which can lead to pneumonia and death. About 20% of stroke patients with dysphagia develop aspiration pneumonia [8]. Near-fatal choking episodes and deaths caused by aspiration are common in elderly patients in hospitals or institutions [9,10].

Eating and drinking are social and pleasurable experiences for healthy people, and meals are often the focus of family celebrations and religious holidays. Dysphagia can destroy the social opportunities and pleasures of mealtimes, affect the quality of the patient's relationship with his/her caregiver and family, and can further undermine health and confidence. Patients with dysphagia can become isolated, feel excluded by others, and be anxious and distressed at mealtimes [7]. Dysphagia affects a patient's dignity, self-esteem, and the regard of others.

One study [11] showed that esophageal dysphagia can be ranked as a handicap, according to goal–disability assessment protocols, where handicap is defined as a reduction in functional capacity that limits the individual's ability to attain his or her physical goals. The study demonstrates that dysphagia affects all aspects of life, as expressed by reductions in self-esteem, security, work capacity, exercise, and leisure.

Treatment of dysphagia improves nutrition [6]. Significantly, patients whose swallowing functions do not improve cease to complain as much about their problems. Continuous evaluation of nutritional conditions and swallowing, even if subjective complaints decline, is therefore needed [6]. The decrease in complaints by patients after enduring dysphagia for a while could be partly responsible for the undertreatment and underdiagnosis of dysphagia. Educating patients, assessing them in the context of other illnesses and problems, and offering them appropriate treatment of their dysphagia could prevent the insidious psychological, social, and physical damage to the patient that would otherwise occur.

The scale of the self-evaluated impact on the social and psychological well being of patients with dysphagia has not been investigated in a large, diverse patient population. Using the questionnaire developed by Gustafsson and Tibbling [11] as the basis of our research, we aimed to determine the effects of dysphagia on selected social and psychological aspects of the quality of life of patients and to probe the relationship between the condition and its diagnosis and treatment. One goal was to generate hypotheses for future research.

Material and Methods

The project was supervised by Dr. Olle Ekberg of Malmö University Hospital, with the European Study Group on Dysphagia acting as project advisors. European nursing homes and clinics were located through directories and databases on the Internet, with the assistance of local healthcare professionals, public servants, and a network of regional physicians from the European Study Group on Dysphagia. Between July and August 1999, patients with subjective dysphagia complaints, regardless of origin, were selected from 37 nursing homes and clinics in Germany, France, Spain, and the United Kingdom and were assessed for inclusion in the study. From these, 360 patients who met the inclusion criteria were studied by face-to face interview using a modified revision of the Gustafsson and Tibbling [11] questionnaire.

Patients were included only if they were able to understand and answer questions and regularly experienced one or more of the following subjective dysphagia-related symptoms:

- food sticking in the throat and/or choking on food
- persistent cough or sore throat
- inability to swallow liquids
- loss of appetite
- mild throat discomfort
- pain when swallowing
- heartburn and/or acid regurgitation

Any respondent suffering from only loss of appetite or mild throat discomfort was excluded. Any respondent who was suffering from severe dementia was excluded on the basis that they were unable to answer questions reliably.

Participating Nursing Homes and Clinics

The UK group was drawn from nursing homes and clinics/hospitals in the Manchester area. The French group was drawn from nursing homes and hospitals in the region of Toulouse and Maine-et-Loire. The German group was drawn from nursing homes in the Munich area. The Spanish group was drawn from nursing homes around Madrid.

Interviews and Questionnaire

A team of researchers from Oxford Research A/S, an independent research company, conducted the interviews. A questionnaire developed by Gustafsson and Tibbling [11] was modified. The questionnaire (see Appendix) consists of 28 questions covering five main areas (background information, eating habits, personal feelings and importance, seeking help, and medical status). It was presumed that eating is a pleasurable activity and as such any disruption to this pleasure will reduce a patient's quality of life. Therefore, the "Personal feelings and importance" section was designed to confirm this assumption and to assess those aspects of quality of life that are affected by dysphagia. The questionnaire was specifically modified to elicit problems related to dysphagia rather than the aging process, thus allowing the results to be confidently interpreted as related to dysphagia and not the aging process. The questionnaire allows the patient to respond quickly so as to avoid tiring the patient. As elderly dysphagia sufferers also often have other medical conditions such as Parkinson's disease, Alzheimer's

Table 1. Patient demographics

	UK	Spain	Germany	France	Total
Gender (%)					
Male	24	28	29	55	33
Female	76	72	71	45	67
Age range (%)					
55–59	6.5	2.3	10.6	9.6	7.3
60–64	10.8	3.4	13.8	2.4	7.8
65–69	11.8	6.9	13.8	18.1	12.6
70–74	16.1	10.3	23.4	15.7	16.5
75–79	32.3	16.1	19.1	13.3	20.4
80 +	22.6	59.8	8.1	37.3	33.9
Coexisting medical conditions (% of patients)	79	67	43	81	67

disease, or multiple sclerosis (MS), the questionnaire was made as simple as possible, with open-ended questions kept to a minimum. The questionnaire was translated from English into relevant European languages, with translations incorporating any country-specific cultural differences.

Interviews with Healthcare Professionals

To aid in the discussion of our results, a qualitative study was conducted among healthcare professionals working in the homes, clinics, or hospitals where patients were interviewed (approximately five interviews per country). These 30-minute interviews were entirely open-ended, based on a topic guide and on the results of the patient surveys.

Statistical Methods

Data is presented quantitatively. No formal statistical comparisons were made.

Results

Demographics

A total of 360 patients met the inclusion criteria for the study (approximately 90 patients per country). Of these, 67% were women (Table 1). In the UK, Spain, and Germany there were significantly more women than men, whereas in France there were more men than women (Table 1).

The average age of the study population was 71.6 years. Approximately one-third of the study population was 80 years old or over (Table 1). The Spanish and French patients were on average older than the UK and German patients.

Most patients (67%) also had other serious medical conditions besides dysphagia. These included stroke, Parkinson's disease, Alzheimer's disease, throat cancer, dementia, MS, and head and neck injuries (Table 1).

The exact symptoms and effects experienced by patients varied. Some experienced mild throat discomfort, while others were not able to eat solid foods comfortably. More than half of the patients experienced "food sticking in the throat or choking on food." Almost the same number suffered from "a persistent cough or sore throat." The least frequent symptom was "heartburn/acid regurgitation," suffered by 27% of the respondents (Table 2).

German patients reported the fewest symptoms, while Spanish patients reported the most. Among UK and Spanish patients, the inability to swallow liquids was experienced more frequently than by those in France and Germany. In contrast, patients in France and Germany more frequently experienced loss of appetite and mild throat discomfort. Heartburn and/or acid regurgitation was suffered by almost half of all Spanish patients interviewed.

Diagnosis and Treatment

Only 40% of patients surveyed acknowledged receiving a confirmed diagnosis of dysphagia (Fig. 1). Only 32% of the study population acknowledged receiving treatment for swallowing problems by healthcare professionals. Spanish patients appeared least likely to be offered professional help. In contrast, patients in France and Germany were the most likely to receive professional help. Just 39% of the patients believed their dysphagia could be treated (Fig. 2).

Eating Habits

Overall, 55% of patients found that their swallowing disorders affected their eating habits; they found certain foods too difficult to eat unless their consist-

Table 2. Percentage of patients with symptoms and effects of swallowing disorders

Symptom	UK	Spain	Germany	France	Total
Food sticking in the throat/choking of food	62	79	24	57	55
Persistent cough or sore throat	47	56	15	66	46
Mild throat discomfort	28	60	24	54	41
Inability to swallow liquids	52	59	12	37	40
Loss of appetite	33	48	26	38	36
Pain when swallowing	53	21	46	17	35
Heartburn/acid regurgitation	21	45	27	16	27

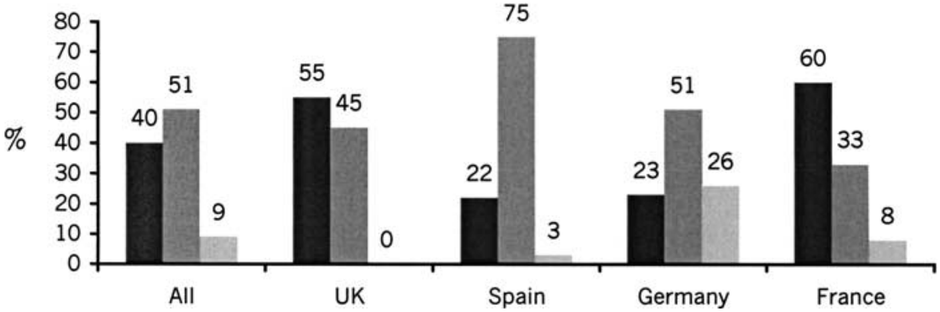


Fig. 1. Have you been diagnosed with swallowing disorders? ■ Yes, ■ No, ■ Don't know.

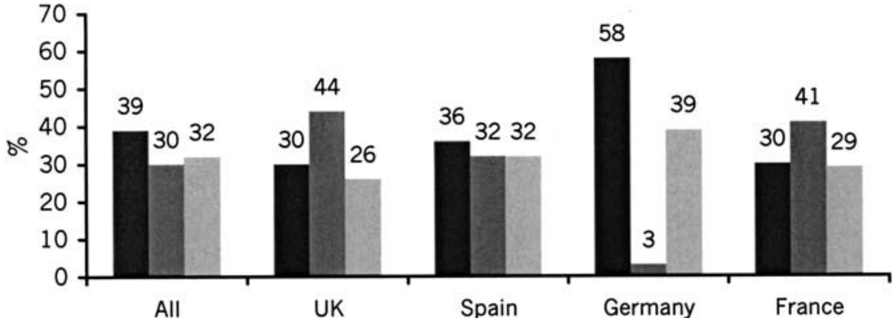


Fig. 2. Do you think your swallowing problems are treatable? ■ Yes, ■ No, ■ Don't know.

Table 3. Eating habits

	UK	Spain	Germany	France	Total
Unable to eat certain foods (%)					
Yes	62	56	47	54	55
No	19	35	47	40	35
Don't know	19	9	6	7	10
Need personal assistance when eating (%)	57	33	16	27	33
Eating less (%)	42	44	53	60	50

ency was changed (Table 3). Most patients had some foods thickened or pureed, a tactic most frequently used for the patients in the UK and Spain.

Over 50% (range-42%–60%) of sufferers tended to eat less because of discomfort (Table 3). One-third of patients claimed that they were still

Table 4. Techniques used to alleviate dysphagia when eating

Technique	UK	Spain	Germany	France	Total
Eat and swallow more slowly (%)	17	49	22	40	32
Take sips of liquid in between bites of food (%)	23	24	28	35	27
Chew food longer before swallowing (%)	8	33	18	20	19
Other (%)	55	3	3	24	22

Table 5. The enjoyable experience of eating

	UK	Spain	Germany	France	Total
Eating **should** be an enjoyable experience (%)	95	74	80	86	84
Eating **is** an enjoyable experience (%)	42	35	47	54	45
Difference between "**should**"and "**is**";	53	39	33	32	39

hungry or thirsty after their meal. Among our study population, 44% (range-36%–49%) had experienced weight loss during the last 12 months.

One-third of patients needed personal assistance when eating (Table 3), with more than half of the UK patients unable to eat by themselves. This was mainly because their swallowing disorder was related to a medical condition such as Parkinson's disease or paralysis. It was found that 59% of patients adapted their eating habits to alleviate the condition by eating and swallowing more slowly, taking sips of liquid in between bites of food, and chewing food for longer before swallowing. Table 4 summarizes the techniques these patients used. In the UK, 55% of patients who attempted to alleviate the condition when eating used special utensils such as spoons and cups adapted for use by disabled people.

Personal Feelings and Importance: Quality of Life

The vast majority of those surveyed (84%) thought that eating should be an enjoyable experience. However, only 45% considered it so (Table 5). This was particularly the case in the UK, where only 4 in 10 enjoyed their mealtimes. As many as 36% of all respondents avoided eating with others because of their dysphagia (Table 6). Of these, 4 in 10 suffered anxiety or panic during mealtimes, primarily because of food sticking in the throat or feeling that they were choking.

More than half of all study respondents stated that their dysphagia made their life less enjoyable

Discussion

In this elderly population from four European countries we have shown that dysphagia has social and psychological consequences that affect quality of life. We found that dysphagia was underrecognized, poorly diagnosed, and poorly managed. Dysphagia also had a negative impact on quality of life for those suffering with it.

Just 39% of the sufferers believed their condition was treatable. This suggests that the majority of patients with dysphagia do not believe there is anything to be gained by discussing their problems with health professionals. This result appears consistent with the finding of Elmståhl et al. [6] on stroke patients with dysphagia.

Our study patients attributed their increased sense of isolation and loss of self-esteem to swallowing difficulties. Over one-third (36% of patients) avoided eating with others because of their dysphagia. Anxiety or panic during mealtimes was experienced by 41% of patients. Only 45% of sufferers found eating enjoyable. These results suggest a positive relationship between dysphagia and reduced social and psychological functioning and it is our assumption that a reduced quality of life is a **consequence** of dysphagia.

Over 50% of patients claimed that they were "eating less", with 44% reporting weight loss during the preceding 12 months. About one-third of the patients reported being still hungry and thirsty after their meal. It is likely that these patients are at risk of malnutrition and dehydration.

Table 6. Psychosocial effects of dysphagia

	UK	Spain	Germany	France	Total
Avoid eating with others because of swallowing problems[a] (%)	49	16	29	52	36
Feel embarrassed at mealtimes because of swallowing problems[a] (%)	68	19	17	39	37
Experience anxiety or panic during mealtimes because of swallowing problems[a] (%)	47	47	22	48	41
Swallowing problems make life less enjoyable	73	45	43	61	55

[a] Questions asked only of persons who were bothered by swallowing at mealtimes, equivalent to 68% of all respondents ($n = 237$).

The second objective of our study was to explore the relationship between the psychological handicaps of the condition and its diagnosis and treatment. In our study we found that only 36% of patients acknowledged that they had received a confirmed diagnosis of dysphagia, and only 32% acknowledged receiving professional treatment for it. Our results showed that unless asked by their caregiver to explain their swallowing problems, patients were unlikely to take the initiative themselves and inform healthcare professionals or even relatives of their difficulties. In particular, those in the UK and France were least likely to voice their concerns.

There were significant differences among the patients from the four European countries. In France there were more males with dysphagia than females, whereas in the other three countries at least two-thirds of the patients were female. Patients in Spain and France tended to be older than patients in the UK and Germany. Patients in Germany complained the least about their symptoms, whereas patients in Spain complained the most. Patients were more likely to be diagnosed with dysphagia in France and the UK and least likely in Spain and Germany. Interestingly, once diagnosed, patients were more likely to be treated in Germany and least likely in France and the UK.

We hypothesize that if patients are psychologically isolated and do not believe they can be helped, they will not complain vigorously to health professionals. Instead they will become fatalistic about their condition. If health professionals are unaware of the wide-ranging social and psychological handicaps of dysphagia or of humane ways of treating it and they receive no complaints from sufferers, then patients will not be offered appropriate solutions to their eating problems. By educating the patient, assessing him/her in the context of other illnesses and problems, and offering the patient appropriate treatment for dysphagia, health professionals could avoid the insidious psychological, social, and physical damage to the patient that would otherwise occur.

The qualitative interviews with healthcare professionals at the participating nursing homes helped us interpret the patient data and the differences among the hospitals. Many differences exist in the treatment and perception of dysphagia across the four countries. This may be due to national or local differences. However, differences in the proportion of residents with dysphagia are also relevant (these varied from 3% to 50%). These differences in the proportion of patients with dysphagia put very different demands on the healthcare professionals and can, at the same time, affect the level of experience of the staff when it comes to noticing, diagnosing, and treating the swallowing dysfunction.

The healthcare professionals interviewed also perceived the problem of diagnosing swallowing difficulties differently. Some stated that swallowing problems are usually easily recognizable when observing the residents at mealtimes. Others found the dysfunction harder to identify, perhaps because swallowing difficulties can be a consequence of other serious diseases or sometimes it is related to depression. We believe that increased sensitivity by health professionals in all countries to the possibility of dysphagia in patients and recognition of appropriate therapy in the context of the patient's other problems will relieve suffering and improve the quality of life for many patients.

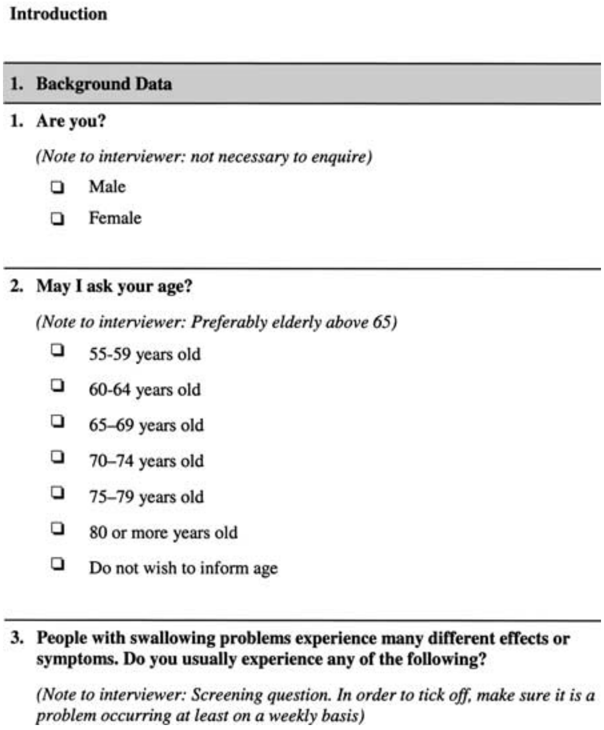
In two recent articles, McHorney et al. [12,13] elaborated on a detailed patient-based dysphagia-specific outcomes tool for understanding swallowing physiology and the human experience of living with dysphagia. The result of our much less elaborate questionnaire supports the need for such a detailed measure.

In another recent article, Blazely et al. [14] studied quality-of-life measurement in patients with esophageal cancer. They found that swallowing ability was representative of overall quality of life. However, dysphagia was by no means the dominant determinant of quality of life; it was rather a combination of dysphagia, nutrition, performance status, and other symptoms as well as social and psychological well-being that constituted quality of life for patients with esophageal cancer. Our study shows that such quality-of-life issues are also relevant in other groups of dysphagia patients and in several different European countries. Further studies are therefore indicated.

In conclusion, the social and psychological impact of dysphagia is severe and the condition is underdiagnosed in European hospitals and clinics. Increased recognition by health care professionals in all countries to the possibility of dysphagia in patients and an understanding of treatment options in the context of comorbid conditions will relieve suffering and improve quality of life in many patients. The authors recommend that healthcare resources be allocated to the training of healthcare professionals and to providing management and treatment options.

Appendix

Questionaire—UK Version



Introduction

1. Background Data

1. Are you?

(Note to interviewer: not necessary to enquire)

☐ Male
☐ Female

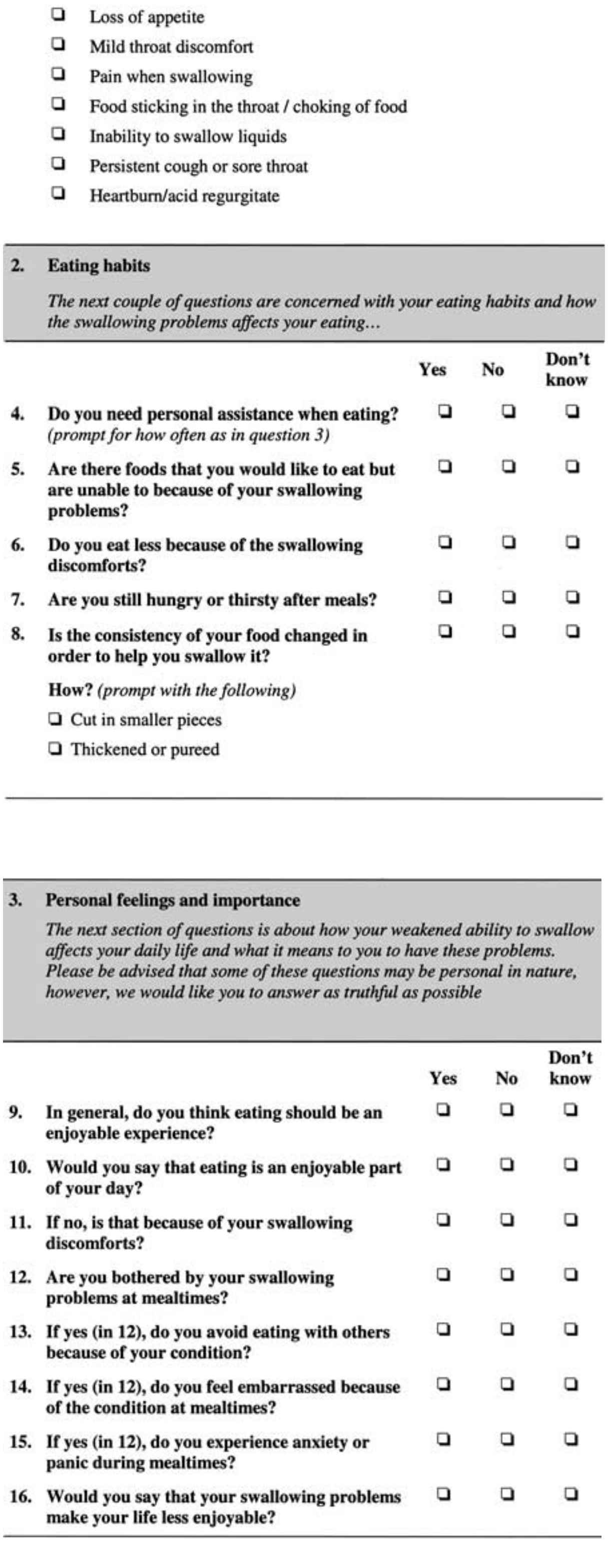
2. May I ask your age?

(Note to interviewer: Preferably elderly above 65)

☐ 55-59 years old
☐ 60-64 years old
☐ 65–69 years old
☐ 70–74 years old
☐ 75–79 years old
☐ 80 or more years old
☐ Do not wish to inform age

3. People with swallowing problems experience many different effects or symptoms. Do you usually experience any of the following?

(Note to interviewer: Screening question. In order to tick off, make sure it is a problem occurring at least on a weekly basis)



☐ Loss of appetite
☐ Mild throat discomfort
☐ Pain when swallowing
☐ Food sticking in the throat / choking of food
☐ Inability to swallow liquids
☐ Persistent cough or sore throat
☐ Heartburn/acid regurgitate

2. Eating habits

The next couple of questions are concerned with your eating habits and how the swallowing problems affects your eating…

		Yes	No	Don't know
4.	**Do you need personal assistance when eating?** *(prompt for how often as in question 3)*	☐	☐	☐
5.	**Are there foods that you would like to eat but are unable to because of your swallowing problems?**	☐	☐	☐
6.	**Do you eat less because of the swallowing discomforts?**	☐	☐	☐
7.	**Are you still hungry or thirsty after meals?**	☐	☐	☐
8.	**Is the consistency of your food changed in order to help you swallow it?**	☐	☐	☐

How? *(prompt with the following)*

☐ Cut in smaller pieces
☐ Thickened or pureed

3. Personal feelings and importance

The next section of questions is about how your weakened ability to swallow affects your daily life and what it means to you to have these problems. Please be advised that some of these questions may be personal in nature, however, we would like you to answer as truthful as possible

		Yes	No	Don't know
9.	**In general, do you think eating should be an enjoyable experience?**	☐	☐	☐
10.	**Would you say that eating is an enjoyable part of your day?**	☐	☐	☐
11.	**If no, is that because of your swallowing discomforts?**	☐	☐	☐
12.	**Are you bothered by your swallowing problems at mealtimes?**	☐	☐	☐
13.	**If yes (in 12), do you avoid eating with others because of your condition?**	☐	☐	☐
14.	**If yes (in 12), do you feel embarrassed because of the condition at mealtimes?**	☐	☐	☐
15.	**If yes (in 12), do you experience anxiety or panic during mealtimes?**	☐	☐	☐
16.	**Would you say that your swallowing problems make your life less enjoyable?**	☐	☐	☐

4. Seeking Help

The following questions relate to any communication you have had about your swallowing problems and if you have received any treatment for your condition

	Yes	No	Don't know
17. Has a doctor or nurse asked you about swallowing discomforts?	☐	☐	☐
18. If no (in 17), have you asked a doctor or nurse about your swallowing discomforts?	☐	☐	☐
19. Have you spoken to any of your relatives about your swallowing discomforts? *(Prompt with: spouse, siblings (sisters, brothers), children and their spouses)*	☐	☐	☐

20. If no (in either 18 or 19), why not? *(Prompt with embarrassing, afraid, its part of growing old, it can't be treated)*

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	Yes	No	Don't know
21. Do you think your swallowing problems are treatable?	☐	☐	☐
22. Do you do anything yourself to help alleviate the condition?	☐	☐	☐

23. If yes, what do you do? *prompt with:*

☐ Eat and swallow more slowly

☐ Take sips of liquid in between bites of food

☐ Chew food longer before swallowing

Others, please list

____

____

	Yes	No	Don't know
24. Do you get any treatment/therapy by a healthcare professional with your swallowing disorder? *(Prompt with: Movement therapy with a speech therapist, surgery)*	☐	☐	☐

5. Medical Status

The very last questions are about your medical status. (Note to interviewer: Please ask healthcare professionals to verify information, if possible).

	Yes	No	Don't know
25. Have you lost weight over the last twelve months?	☐	☐	☐
26. Have you been diagnosed with swallowing disorders?	☐	☐	☐
27. Do you suffer from any serious medical conditions? *(note to interviewer: such as stroke, Parkinson's and Alzheimer's, multiple sclerosis, etc.)*	☐	☐	☐

28. If yes (in 27), which? (please list)

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Thank you so much for your participation!

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