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Perception des aidants familiaux concernant l'épaississement des liquides chez les patients âgés ayant des troubles de la déglutition

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Massimiliano Curri. Perception des aidants familiaux concernant l'épaississement des liquides chez les patients âgés ayant des troubles de la déglutition. Médecine humaine et pathologie. 2022. dumas-03693459

HAL Id: dumas-03693459

<https://dumas.ccsd.cnrs.fr/dumas-03693459>

Submitted on 27 Feb 2023

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UFR DE SANTÉ DE ROUEN NORMANDIE

Année 2022

**THÈSE POUR LE
DOCTORAT EN MÉDECINE**

(Diplôme d'État)

par

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Né le 22 juin 1991 à Manduria (Italie).

Présentée et soutenue publiquement le 28 avril 2022.

Perception des aidants familiaux concernant l'épaississement des liquides chez les patients âgés ayant des troubles de la déglutition.

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Perception of family caregivers about liquid thickening in old patients affected by oropharyngeal dysphagia

Abstract

Aim: Oropharyngeal Dysphagia (OD) occurs frequently in old patients. This geriatric syndrome impairs safety and/or efficacy of swallowing resulting in aspiration pneumonia and malnutrition. OD may be assessed by the volume viscosity swallowing test (V-VST). Prevention of the complications of OD include environmental measures and liquid thickening. In old patients, family caregivers are on the front line in the management of OD and liquid thickening. However, the long-term benefit of liquid thickening is controversial.

Our aim was to evaluate, in a qualitative aspect, the feeling of family caregivers about liquid thickening after the hospitalization of an old patient with OD. We also assessed the proportion of old patients with OD truly appropriate for daily liquid thickening at home.

Patients and Methods: This qualitative study included family caregivers and patients with OD hospitalized in an acute geriatric ward. OD was diagnosed with V-VST. Patients truly appropriate for liquid thickening at home were those with preserved cognitive and functional abilities and those with a family caregiver at home daily. The family caregivers participated in an educational session about OD and liquid thickening. Qualitative data about the feeling of the caregivers about OD were collected through phone interviews two weeks after the discharge at home. COREQ criteria for qualitative studies were used. Participants were recruited until the findings reached saturation, and data were analyzed using qualitative content analysis.

Results: One hundred eighty-one patients were hospitalized between January and March 2022 in our acute geriatric ward. Twenty-three had a pathologic V-VST and were discharged home. Eighteen were truly appropriate for liquid thickening because of the daily presence of a family caregiver at home. Eight patient-caregiver dyads were included in the qualitative study. A wide

range of themes emerged from the data and were synthesized into three main categories: family caregivers' empowerment; experience and perception about thickening powder; and change in the patient-caregiver relationship.

Conclusions: This study highlights the consequences of OD and liquid thickening at home on the patient and their family caregiver. The findings emphasize the difficulty of maintaining the liquid thickening by the caregivers at home. This argues for a better education of caregivers about OD but not for a systematic prescription of liquid thickening.

Introduction

Oropharyngeal Dysphagia (OD) is defined as anatomical or structural impairments of one or more parts of the swallowing apparatus from the oral cavity to the esophagus (1). OD impacts patients' safety, well-being, and quality of life. The prevalence of OD ranges from 6 to 94%, depending on the underlying etiology, age, environment, and method of assessment (self-reported or objective).

The prevalence of OD is around 30% in old people living independently, close to 50% in patients in acute geriatric units (2,3), and may rise to 94% among patients with dementia (4). This high prevalence in old patients may be explained by different factors, such as a prolonged reaction time in the submental muscles, an impairment of sensitivity, or a delay in the synapse conduction in the afferent inputs to the central nervous system, but it may also be related to geriatric conditions such as delirium, dementia, sarcopenia, and polypharmacy or psychotropic drugs (5).

Stroke, Parkinson's disease, and head and neck cancer are the main causes of OD in adults and have been widely studied (6,7). However, OD in old people (8) is also considered a multifactorial geriatric syndrome by the European Society for Swallowing Disorders and the European Union Geriatric Medicine Society. Consequences of OD are related to impairment in swallowing safety and/or efficacy. Impaired bolus propulsion may lead to insufficient efficacy of swallowing and thus to dehydration or malnutrition, whereas an impairment of the protection of airways may lead to chemical and/or bacterial aspiration and pneumoniae (9,10). Other direct consequences of OD are a poor quality of life, stress of the caregiver, and social isolation, secondary to different psychological and social aspects (11,12). For example, patients with OD have decreased social participation and increased anxiety and depression, resulting in a poorer quality of life and increased mortality. In addition, family caregivers more often

experience emotional, physical, and financial difficulties; decreased work productivity; and reduced participation in valued activities that increase the burden of the disease (13,14).

Diagnosis algorithm of OD may be divided into three steps (15). First, the screening phase is based on patient and family interviews asking for episodes of coughing or choking during meals, difficulty in swallowing, or weight loss; these may be assessed by questionnaires. Second, a clinical assessment of OD is performed using tests such as the Volume-Viscosity Swallowing Test (V-VST) (16). The V-VST assesses efficacy and safety of swallowing by testing the administration of bolus of different volumes and textures of liquid to the patient (17,18). Moreover, this tool provides information to adapt the texture of liquid for therapeutic purposes (19). Third, an instrumental assessment may also be performed, using an endoscopic evaluation of swallowing or videofluoroscopy (VFS), both requiring trained personnel and specialized materials. This step is mainly performed after a stroke or in patients with other neurological or pharyngo-laryngeal diseases (20,21). In old patients, even those with dementia (22,23), this step can be performed but should be avoided in cases of unstable disease, agitation, or uncooperative patients (24,25).

Texture-modified food and fluids (TMF) are widely used in clinical practice to prevent consequences of OD. The European Society for Clinical Nutrition and Metabolism (ESPEN) guidelines about TMF (26,27) strongly recommend to “*offer texture-modified, enriched foods as a compensatory strategy to support adequate dietary intake*” in old patients with clinical signs of OD and malnutrition or at risk of malnutrition. In addition, thickened liquids are proposed because their high viscosity reduces the flow rate of the oral phase and thus delays the passage from the oral cavity to the pharynx. This phase is highly compromised in patients affected by dementia, mainly because of buccofacial apraxia (28,29). Several studies have shown that this increased viscosity reduces the risk of aspiration and penetration of food associated with impaired swallowing (30).

In the daily practice, however, liquid thickness is subjectively assessed and described, using terms such as “nectar-like” or “pudding-like,” as in the V-VST(29). Appropriate thickening of the liquids is crucial; if not thickened enough it can be ineffective and lead to a mouth-coating feeling, and if too thick it can result in postswallowing residues which could compromise the safety of the procedure and impair swallowing efficiency. ESPEN and recent literature reviews point out the loss of concrete benefits of this practice and its potential risk for old people (31,32). In fact, the level of evidence for the benefit of thickened liquids in patients with dementia or Parkinson’s disease with OD is low. This could be related to the difference between an immediate benefit of this strategy and an increased long-term risk of aspiration pneumonia secondary to postswallowing residues (33).

In addition, TMF provide lower energy and protein intakes than normal food, insufficient hydration, and possibly delayed medication absorption (34,35). This could also be explained by the poor adherence of the patients to thickened liquids because of their impact on quality of life, lower thirst satisfaction, impaired mouth cleanliness feeling, and less drinking pleasure (36). In qualitative studies, patients often described the organoleptic properties of thickened liquids as “vile” and “awful,” influencing the professional and family caregivers’ beliefs about TMF (37).

The management of OD in nursing-home residents and the importance of knowledge and skills about OD in professional caregivers has also been studied (38,39). However, geriatric patients are often at home and are not able to prepare TMF themselves because of functional or cognitive disorders. Thus, family caregivers are the first line in the management of OD, but their perception of and experience with liquid thickening and the challenges relative to its use in old patients at home have been less investigated (40). Thus, the aim of our study was to evaluate in a qualitative aspect the use of thickened liquids in patients diagnosed with OD and the

perception of and experience with liquid thickening of their family caregivers, after a hospitalization in an acute geriatric ward and an education by nurses.

The second aim was to assess the proportion of old patients with OD discharged from hospital to home who were truly appropriate for daily TMF, either because they were able to prepare it alone or because a family caregiver was present daily.

Patients and methods

This monocentric, qualitative, prospective, and noninterventional study included patients over 75 years old hospitalized in the acute geriatric ward of the Rouen University Hospital, France, between January and March 2022. The inclusion criteria were patients with OD confirmed by a pathologic V-VST at discharge from the hospital, discharge to home after the hospitalization, and the daily presence of a family caregiver. Exclusion criteria were patients who did not speak French; patients with OD related to head and neck neoplasia, enteral or parenteral feeding, or recent postextubating procedure; absence of a caregiver; refusal of the patient or of the caregiver(s) to participate in the study; neurological impairment not allowing the realization of V-VST; and OD related only to stroke or to a late-stage of Parkinson's disease.

Description of patients truly appropriate to TMF at home

Among patients discharged at home, those with OD truly appropriate to TMF have two different profiles: patients without cognitive or functional disorders and therefore able to prepare the TMF at home without any help, and patients unable to prepare the TMF but having a family caregiver able to prepare it almost every day.

Thus, to identify the proportion of patients truly appropriate to TMF at home, we retrospectively analyzed electronic medical records of patients hospitalized in our acute geriatric ward during the inclusion period. We collected the place of discharge, the result of the V-VST and the presence or not of a family caregiver at home and if they were present daily or not. Among the patients without a family caregiver, we evaluated whether they were able to prepare the TMF by themselves because of normal cognitive or functional abilities.

OD assessment

A V-VST (Supplementary data 1) was systematically performed by two trained nurses within the last three days of hospitalization in patients meeting the inclusion criteria. The nurse checked the correct sitting position of the patient and prepared three glasses of water of three different viscosities water-, nectar- and pudding-like by using a thickening powder (Gelodiet®). Then, patients drank three volumes (5, 10 and 20 ml) of nectar-like liquid, followed by pudding- or water-like liquid depending on the results of the nectar phase assessment. At each step, the nurse assessed the signs of OD, such as cough, humid voice, residual product in the mouth or in the pharynx, more than 3% decrease in oxygen saturation, or drooling. Based on the V-VST assessment, a texture adaptation of liquid with a thickening powder for every kind of liquid (water, tea, coffee, milk, wine, orange juice) was proposed by the nurse and validated and prescribed by the geriatrician in charge of the patient at discharge.

Family caregiver education

The main family caregiver of the patient received a theoretical and practical training session about OD and TMF in the last 48 hours before the patient was discharged to home. After informing the caregiver about patient's OD detected by the V-VST, a qualified nurse performed the training of the caregiver with three main objectives:

- General information about OD and its risks and consequences, based on paper (Supplementary data 2) and video supports
- Practical education and training about liquid texture adaptation and use of the thickening powder, individualized for each patient according to the conclusion of the V-VST
- Education about the general prevention of OD not based on TMF, including correct positioning of the patient, the use of appropriate glasses, a quiet environment during

mealtimes and a delay of time estimated at 30 minutes before going to sleep after the mealtime

Educational support materials created by the nurses and validated by a geriatrician and the geriatric resident were used during these sessions and given to the family caregiver to summarize the advice. The educational session lasted 25 to 45 minutes. Nurses answered all questions of the family caregiver about OD, and the geriatrician supplemented the information if necessary.

Data collection

Our study was performed according to the COREQ criteria for qualitative study, as shown in Supplementary data 3.

Before obtaining the consent of the family caregivers, the qualified nurses explained the purpose of the study. Data were collected using a researcher-developed interview guide reviewed and validated by the geriatrician and the geriatric resident. After the hospital's discharge of the patient and the information session, the main caregiver was called two weeks later by one of the qualified nurses. This nurse conducted a semistructured, in-depth phone interview in French. The interviews focused on the main questions defined previously (Supplementary data 4 and 5) and continued until the data were saturated. There was a semiquantitative assessment about the adherence of caregivers and patients to the TMF, which went from 0 to 5 (0 = no adaptation at all; 1 = adaptation once a day; 2 = twice a day; 3 = three times a day; 4 = almost always; 5 = adaptation of every drink).

Family caregivers were encouraged to self-direct the content of the interview: strategies such as silent attention, reflection, probe, and direct questions were used to encourage rich descriptions. Interviews were tape-recorded with participants' permission. Field notes were

taken throughout the phone interviews to record the answer sequence, the key phrases, and contextual data such as nonverbal behaviors.

The geriatric resident collected all the preliminary data (transcripts and field notes), then he guided and supplemented the field notes to record the interview as faithfully as possible. The geriatrician did the same. All of them (geriatrician, geriatric resident, and nurses) then discussed and compared the interview transcripts and field notes so that the data collected were as complete as possible.

Data analysis

We based the analysis of our data on an interpretive phenomenological approach (IPA), which attempts to understand the participants' lived experiences through description and interpretation. We immersed ourselves in the collected data through reading and rereading the transcripts (the two nurses, the geriatric resident and the geriatrician), and making notes of any thoughts, reflections, and understandings that emerged as a result of this interaction with the data. We followed these steps:

1. Each transcript and notes made by the two nurses during the live phone interviews was read and reread. On the second reading, important words, phrases, and references were highlighted and noted.
2. The transcripts were read once again; emerging codes based on our preliminary interpretations were recorded and potential connections between them identified. Connected codes were grouped together, resulting in a number of preliminary themes for each transcript.
3. The preliminary themes were then compared for similarities and differences. This comparison resulted in the development of a smaller number of refined themes. All data were accounted for. No data were deemed inappropriate or discarded from analysis.

4. These refined themes were then further clustered, leading to the development of overarching superordinate themes, which were representative of all transcripts and which had a number of associated subcategories.
5. Finally, all the extracts from each of the transcripts and written notes were recorded under the three main identified themes. Any disagreements in coding or analysis were resolved through discussion among the two nurses, the resident, and the geriatrician.

Results

Proportion of patients truly appropriate to TMF

One hundred eighty-one patients were hospitalized during the inclusion period. Thirty-three (18%) died before discharge; 25 (14%) were discharged to a rehabilitation center; 22 (12%) to a nursing home; and 6 (3%) to another hospital. Among the 95 (52.5%) patients discharged to home, 66 (36.4%) had a normal V-VST and 6 (3%) had no V-VST noted in the electronic medical records because it was not feasible or missing.

Among the patients discharged to home with a pathological V-VST, 3 (1.5%) did not have family caregivers. None of these patients had sufficient cognitive or functional abilities to prepare TMF on their own. Twenty (11%) patients had a family caregiver, who was present daily at home for 18 patients.

Thus, 18 patients (9.9%) were truly appropriate to TMF at home during the inclusion period (Figure 1).

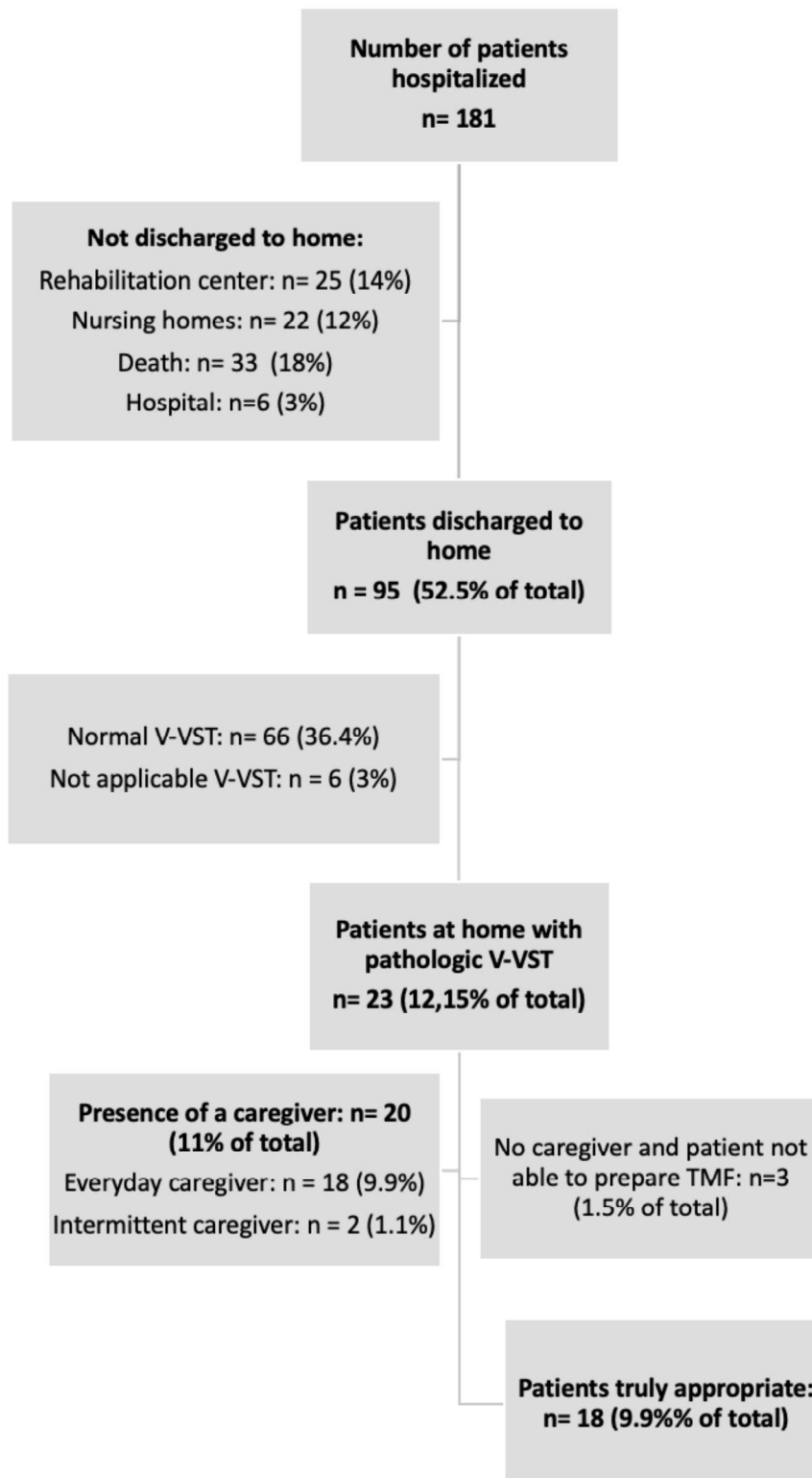


Figure 1. Flow chart of patients excluded by the study. V-VST: Volume-Viscosity Swallowing Test

Qualitative study

Eight patient-caregiver dyads were included in the qualitative study. Patients had a mean age of 89.4 (84–100) years old and three of them were males. Detailed characteristics of patients and family caregivers are described in table 1 and table 2. All patients had dementia or cognitive impairment (mild to moderate). Three patients had depression. All patients were dependent: 1 patient had an ADL score of 4.5, 3 had an ADL score of 3.5, 1 an ADL score of 3, 1 an ADL score of 2, and 2 an ADL score of 1. Texture adaptation proposed by the nurse was nectar-like for all patients.

Caregivers were the children of patients (n = 5) or spouse (n = 3). Sometimes, children and parents were present at the same time, either at the educational step or as a secondary caregiver. Four family caregivers lived with the patient and the others were present at mealtime.

The level of adherence to the thickened liquids was low or absent in 5 patients (3 patients with a score of 0/5, 1 with 1/5, and 1 with 2/5); mild in 1; and excellent in 2 of them.

Patients	Age (years old)	Sex	Main diagnosis of hospitalization	Comorbidities	Dementia or Minor cognitive impairment	ADL	V-VST result
P1	84	F	Aspiration pneumonia, Acute Heart Failure, Acute Kidney Injury	DMLA, Depression, Stroke	YES	1/6	Nectar
P2	100	M	Community Acute Pneumonia, Acute Heart Failure	Falls	YES	3.5/6	Nectar
P3	84	F	Fall, dehydration, restrictive respiratory impairment	Stroke	YES	3/6	Nectar
P4	91	F	Pneumonia, Acute Heart Failure	Arthrosis	YES	3.5/6	Nectar
P5	95	F	Fall, dehydration, Acute Kidney Injury	Falls	YES	3.5/6	Nectar
P6	85	M	Fall, Acute Heart Failure	Epilepsy, Depression	YES	1/6	Nectar
P7	92	F	Aspiration pneumonia	COVID	YES	4.5/6	Nectar
P8	88	M	Aspiration Pneumonia	Stroke	YES	2/6	Nectar

Table 1: Main characteristics of included patients

Caregivers	Type	Days/week	Level of adherence	Educational session
C1	Husband	24H/24 and 7/7 days	0/5	Motivation, Good explications, Sensibilization, more details in the paper support
C2	Son	6H/24 and 7/7 days	0/5	Motivation
C3	Daughter +Healthcare providers	3H/24 and 7/7 days	3/5	Knowledge already acquired, sensibilization to the other compensatory strategy as adapted glasses or hyper-protein drinks
C4	Son	24H/24 and 7/7 days	1/5	Good explications, sensibilization to dysphagia and other compensatory strategy as adapted glasses or hyper-protein drinks
C5	Daughter	2H/24 and 3/7 days	2/5	Good explications, sensibilization to dysphagia
C6	Wife + Daughter	24H/24 and 7/7 days	5/5	Good explications, sensibilization to dysphagia
C7	Son + his wife	1H/24 and 7/7 days	1/5	Good explications, sensibilization to dysphagia
C8	Wife	24H/24 and 7/7 days	5/5	Good explications, sensibilization to dysphagia

Table 2: Main characteristics of family caregivers of included patients

Qualitative analysis

Analysis of the telephone interview transcripts revealed that family caregivers' feelings and experiences regarding OD and TMF could be categorized in three main themes with subcategories.

Theme 1: Family caregiver empowerment

Most of the caregivers stated a better knowledge of OD, TMF, and prevention strategies of OD. They described feeling an empowerment about OD because of the educational session and thus seemed better able to take care of the patient.

1. Improvement in knowledge about OD with educational session

Family caregivers noted the benefit of the educational session in improving their knowledge about OD. They enjoyed the paper and video support materials shared by the qualified nurse, along with the practical training. They also pointed out that this training put words to situations they had already experienced:

(C4) "Thanks to the video and paper support, I learned something which I did not know."

(C6) "I did not expect that dysphagia could cause all these impairments."

(C2) "It's really interesting because I have already noticed some difficulties eating meat in my father....This is why I cut it in small pieces for him."

(C8) "It was really interesting. Thank you very much."

2. Positive aspect of other preventive strategies than thickening powder

The preventive strategies for OD, which were illustrated in the educational step, have been well accepted by the caregivers. Many caregivers tried to apply all these strategies daily, not only the adaptation of texture. They were enthusiastic about many of these strategies:

(C4) *“I have bought the glass for dysphagic people and it was really useful, easy to use.”*

(C3) *“I try to respect the time delay between the meal and the sleeping time, in order to cut off the cough postmeal in my mother.”*

3. Sensibilization about the risk of OD

One caregiver was already trained to the TMF. Other family caregivers were sensibilized to the subject thanks to the educational session. They got conscious of the severity of OD and shared it with other people who took care of patients at home to minimize the global risk as much as possible:

(C5) *“I see that this (OD, n.d.r.) could be really dangerous for my mom.”*

(C3) *“I have already known all about dysphagia and I had already coped with TMF.”*

4. Relationship with other caregivers

The presence of different people at home for helping patients in daily activities was particularly challenging for the trained family caregivers. With their empowerment, the family caregiver became more aware of the errors or the lack of knowledge of the other caregivers, even professional. This could lead to relationship difficulties or a loss of confidence. Some family caregivers stated that other caregivers were not really involved in the preparation of TMF for different reasons, such as lack of training or lack of time:

“(C3) I have seen that the other caregivers are not afraid of OD or that they do not have enough time to spend in the preparation.”

(C7) “The nurse who help us, she put five teaspoons of thickening powder in the glass.”

Some caregivers tried to inform and sensibelize the other caregivers to OD:

(C4) “I will inform the others immediately in order to change our habits.”

Theme 2: Experience and perception about thickening powder

The main strategy proposed to adapt the texture of liquid was the use of thickening powder. A practical situation was part of the educational session, allowing the family caregiver to prepare a nectar-like liquid and perceive the main characteristics of the product. Family caregivers reported the poor organoleptic properties of thickened liquids and their consequences and some practical problems such as complex preparation or difficulties in finding the thickening powder.

1. Organoleptic properties

The most important feature reported by caregivers, according to the patient’s opinion, was the aspect of the thickened liquids. It was so far from the classical aspect of their daily drinks that it was impossible to accept.

a. Taste and texture

Caregivers confirmed that patients were not satisfied by the texture or taste of the thickened liquids. In addition, the caregivers themselves were repulsed by the presentation of the thickened liquid:

(C2) “It doesn’t have a good aspect... it has a gluing aspect.”

(C4) “There are residues in the bottom of the glass.”

(C3) *“The glasses are unclean because of the powder....It is gross: I would never taste it.”*

(C2) *“The wine doesn’t have the same taste.”*

(C3) *“You know, the taste of thickened water is bitter, like a medical drug.”*

b. Effect of heat on thickened liquid texture

Taste and texture depend on the temperature of the drinks. Due to the chemical and physical characteristics of the thickening powder, the texture and power of agglomeration were different and even challenging when hot drinks were prepared:

(C3) *“The coffee doesn’t have the same taste and, when it is hot, is not really good.”*

(C4) *“When I prepare the hot milk for breakfast, it doesn’t have the same consistency of thickened water; it is thicker.”*

2. A consequence of the organoleptic properties of thickened liquids: dehydration

During the educational session, some caregivers were initially optimistic about the success of reducing OD by thickening liquids. However, they were discouraged by one of the consequences of this texture adaptation: some patients reduced their fluid intake and thus became dehydrated. This was one of the main causes of stopping the adaptation of the liquids’ texture:

(C2) *“I have seen that my father drinks directly by the bottle.”*

(C7) *“My husband was drinking less and less.”*

(C3) *“We had to end the thickening of liquid cause my mother was hospitalized for dehydration.”*

(C3) "I saw that my mom was dehydrated."

3. Cost and difficulty to find the thickening powder

Some caregivers reported difficulties finding the correct thickening powder. Educational sessions at the hospital were performed with one brand of powder (Gelodiet®), but in pharmacies the reimbursed prescribed powder was of a different brand (Nestlé®), when available. However, some caregivers were disposed to buy the other one rather than not thickening the liquids:

(C3) "It was tiring to find the prescribed thickening powder: I had to look in all the pharmacies of the city."

(C2) "I think that I can afford the cost of the powder (concerning the unreimbursed one)."

4. Preparation's difficulties

The preparation of thickened liquids was challenging for all caregivers. In most cases, the lack of time due to daily personal activities was the main problem. In some cases, the preparation itself was too complicated to accomplish.

a. Time to prepare

The family caregiver's personal life had an impact on the preparation of the thickened liquids. Their daily job schedule did not allow them enough time to either prepare the thickened liquids or assure that the patients got them correctly:

(C4) "I had a busy day and I didn't have enough time for this stuff."

b. Difficulties in preparing the thickened liquid

Some family caregivers stated that, despite the educational session, the thickened liquids remain difficult to prepare. Some of them suggested that this should be done by a health professional:

(C4) “I think that there is a problem with the powder....I think that it is something which should be done in the medical domain only.”

(C1) “The mix between the thickening powder and the liquids is too complicated to me.”

Theme 3: Change in patient-caregiver relationship

Another main theme stated by the family caregivers was the effect of OD management on their relationship with the patient. In fact, some conflicts and worries have arisen due to OD and TMF.

1. Family arguing

The advantage of knowing each other for a long time is that caregivers come to know the limits of the patients, anticipating them or going beyond using the right tools.

a. Insisting

The patient-caregiver dyad who experienced the best adherence to thickened liquids reported that this was possible because of persisting:

(C6) “Even if it was hard to accept initially, we have persisted and we have seen the benefits of all of the compensatory strategies, even the thickening powder. We will buy the other one (N.D.R: thickening powder not reimbursed) to try it, too.”

b. Predicted and not spontaneous attitude

Nevertheless, most of the caregivers were not so optimistic about the discipline and acceptance of their siblings. During the educational session, they[is 'they' the caregivers or the siblings?] clearly expressed their doubts about the spontaneous acceptance by the patients:

(C1) "I know my wife: she will never accept all this stuff."

(C2) "I will try but it will be a bit complicated for my father; you know, he has a strong character."

(C1) "My wife had never done it by herself....She prefers to drink mineral water."

2. Deterioration of the patient-caregiver's relationship

Many caregivers noted the opposition of patients to thickened liquids and thus the deterioration of the familial relationship. This could lead to an absence of social interaction and aggressiveness or to an impaired mood:

(C1) "She was not speaking with me anymore."

(C1) "She was aggressive verbally and physically with me and the others."

(C3) "She cried during teatime."

(C3) "She is sad about the TMF."

All of these reactions had an emotional impact on family caregivers, who ended up worrying:

(C4) "He has no wish to drink this stuff."

(C7) "My husband was drinking less and less."

(C3) "I saw that my mom was dehydrated."

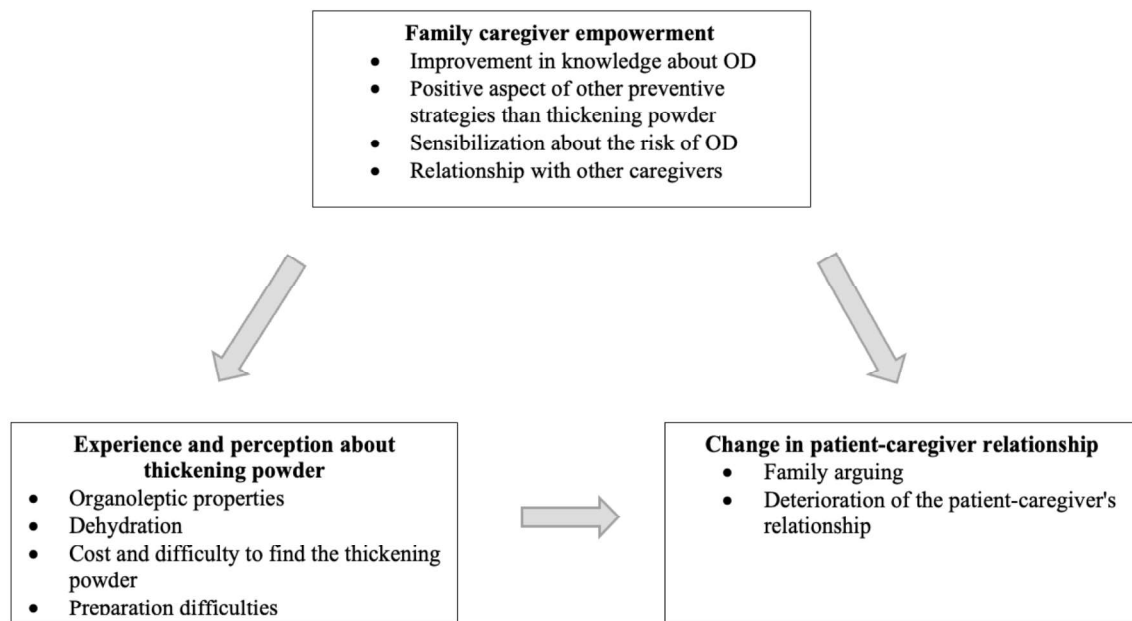


Figure 2. Themes and main categories of family caregivers' experiences about OD and thickened liquids. OD: Oropharyngeal Dysphagia

Discussion

This qualitative study focused on family caregivers, who are the first line of managing OD at home, and on the main strategy to prevent OD: thickening the liquids. We demonstrated that education about OD is welcome and useful for family caregivers, but that thickened liquids are not well accepted and can lead to medical problems, such as dehydration, and to the deterioration of the patient-caregiver relationship. We also showed that only a small proportion of patients are truly suitable for this preventive intervention after being discharged from an acute geriatric ward to home.

In fact, many of our patients are discharged to a nursing home or a rehabilitation ward. Among patients discharged to home, most of them are old and have a high prevalence of dementia or mild cognitive impairment, dependency, or loss of autonomy. Thus, they are bad candidates for a training session and are not able to prepare TMF by themselves. Consequently, the family caregiver must be present at each meal to prepare the thickened liquids, which further limits the number of patients suitable for TMF. This could explain why most of the existing studies focused on patients with OD discharged to a nursing home or on younger populations with one main disease, such as stroke or Parkinson's disease, and were thus able to prepare TMF themselves (41,42). We focused on geriatric patients because they have a different profile from patients with OD related to one main cause. The OD onset is brutal in patients with stroke, which calls for a rapid and intense process of coping and a significant level of compliance with the preventive treatment (43). Moreover, OD frequently represents one of the main problems of the patient with stroke (44). Conversely, geriatric patients have different medical, psychological, and social conditions that could be impacted by the OD. Thus, OD is more insidious and is not always the highest priority for the patient. In addition, family caregivers are sometimes not aware of OD (45).

The adherence to the liquid thickening proposed was low. Except for two participants, all participants were reluctant to change their habits and drink thickened liquids. This is in accordance with other, larger studies, in which the acceptance of thickened liquids was low, as in patients with stroke, leading to health complications like dehydration (46).

We did not include patients discharged to a nursing home or rehabilitation ward, because the people preparing and giving the TMF to patients unable to do it themselves are health professionals and thus have a different level of experience and knowledge about OD. We chose to focus on the family caregiver perception about OD, which has been less investigated than that of nurses (40). We used a qualitative methodology because this type of study is more appropriate to describe the perceptions and experiences of a population.

First, the educational training session about OD and preventive strategies made by the qualified nurses was really appreciated. Thanks to the supportive materials, everyone was more conscious of the problem of OD in general and its direct consequences. In addition, The session helped them recall some details or episodes of OD which had been already noticed at home but not correlated to the severity of the condition. There are several studies about the impact of training of main caregivers of patients affected by OD after a stroke, which showed that caregivers pay more attention on how to manage OD to limit deadly complications like aspiration pneumonia (47,48). Thus, the educational session resulted in the empowerment of the family caregiver, with a better comprehension of OD, a better adherence to preventive strategies, and a better knowledge of the risk. However, it also had an impact on the relationship with other caregivers because the family caregiver became more aware of the errors or the lack of knowledge of the other caregivers, even professionals, about OD management. This could lead to relationship difficulties and increase the psychological burden of caregivers. The knowledge and training about OD

management leads to the empowerment of family caregivers but also to a more guilty feeling when the patient makes an adverse event secondary to the OD (47,49).

Second, whereas all the other preventive strategies of OD were well accepted, the thickening of liquids and its application in everyday life were difficult. Family caregivers thickened the liquids but faced practical or relationship difficulties, leading to the discontinuation of this preventive intervention. In fact, most of the family caregivers did not have difficulty preparing the thickened liquid, but the texture and the taste of the preparation was not accepted by the patients. Probably the new way of drinking and self-consciousness about their OD contribute to the low rate of acceptance of thickened liquids by the patients. Some previous studies demonstrate the poor adherence to TMF related to their organoleptic properties, which affect the sensory and hedonic expectation of participants (50). However, these kinds of studies were conducted with healthy volunteers, able to express their opinion in a sophisticated way, which is not applicable to our population because of cognitive impairment. Moreover, two participants stated that the use of thickening powder has induced a spontaneous reduction in drinking liquids or dehydration. This is in accordance with previous studies showing a decrease in hydration when thickened liquids are used, due to their lower palatability and poor taste (34,42). A nonoral hydration support, such as intravenous, is often necessary in order to limit the dehydration (51). However, these studies have been performed in younger patients with OD related to stroke or to a single disease but not on a poly-pathologic population. Beyond the risk for the patient, this complication could lead to a feeling of guilt in the family caregiver. In fact, they are faced with a dilemma: balancing the risk of dehydration with the desire to prevent aspiration pneumonia and death-related risk (52). This dilemma was very apparent in the most frequent sentiment described by caregivers about OD management—“*I do whatever it takes*”—stressing the psychological impact of OD on caregivers (40).

The third theme of our finding was focused on the change in the patient-caregiver relationship. To avoid family conflict or accentuation of depression symptoms, some caregivers preferred to reduce or discontinue the adaptation of liquid texture. Many different reactions were observed in patients: sadness, depression, aggression. These reactions have already been observed and described in other studies (53). This deterioration in the patient-caregiver relationship may be deleterious for the patient and also for the family caregivers by increasing their burden of disease. As described in the theory of dyadic illness management (54), the patient and their caregiver must be considered as a single unit of care, and the health of patient and caregiver is interdependent. This theory was reported also by a recent study about the impact on the quality of life of dyad Parkinson's patients and their caregivers (55). The study showed that the degradation of the patient's quality of life and the emotional impact on caregivers were affected by the severity of OD.

Limits of the study

Our study has some limits. First, our population is small and we did not reach saturation of the data. Thus, we will continue the inclusion of dyad until reaching this saturation. Second, we did not explore the difference between the two brands of thickening powder (Nestlé® and Gelodiet®) available. This could create a difference in the perception of the patient and the family caregivers about thickened liquids. Third, the diagnosis of OD was based on the V-VST and not confirmed by other instrumental methods. Fourth, some family caregivers who attended the educational session were not the only caregivers or did not live with the patient at home, and thus could not always control the thickening of liquids.

Conclusion

Our study demonstrates that few patients are truly appropriate to TMF at home when they are discharged from an acute geriatric ward. Family caregivers experienced many difficulties related to thickened liquids, including a deterioration in their relationship with the patient. However, this study highlights the benefit of the educational training session about OD, particularly to present other preventive strategies of OD. Our results suggest not systematically prescribing thickening powder for patients with OD on discharge from hospital to home because of the medical, social, and psychological consequences. Further qualitative studies are needed to define the place of thickening powder at home for elderly patients affected by OD.

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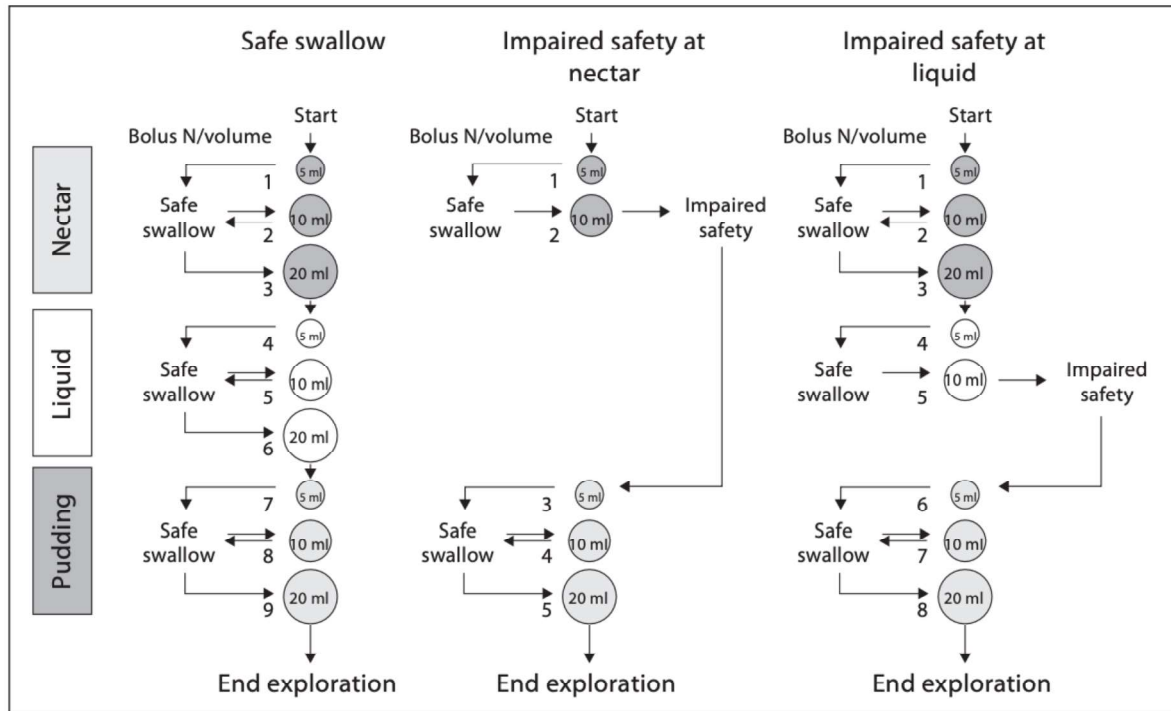
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Supplementary data

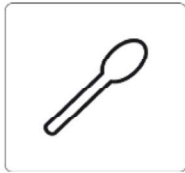
Supplementary data 1



Supplementary data 1: V-VST short algorithm. Left diagram: patients with safe swallow completed the pathway. Middle diagram: representative pathway for patients with impaired safety at 10 ml nectar. Right diagram: representative pathway for patients with impaired safety at 10 ml liquid (17).

TEXTURE NECTAR

1 cuillère-mesure pour 1 verre d'eau :



+



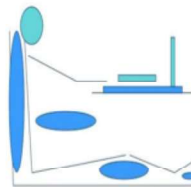
Ne pas donner à boire avec :



Verre adapté :



L'installation :



Supplementary data 3

Domain 1: Research team and reflexivity		
Personal Characteristics		
Interviewer/facilitator	Which author/s conducted the interview or focus group?	p. 23-25
Credentials	What were the researcher's credentials? E.g. PhD, MD	p. 23-25
Occupation	What was their occupation at the time of the study?	p. 23-25
Gender	Was the researcher male or female?	
Experience and training	What experience or training did the researcher have?	
Relationship with participants		
Relationship established	Was a relationship established prior to study commencement?	
Participant knowledge of the Interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	p. 23-24
Domain 2: study design		
Theoretical framework		
Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	p. 23-24
Participant selection		
Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	p. 27
Method of approach	How many people refused to participate or dropped out? Reasons?	
Sample size	How many participants were in the study?	p. 27
Non-participation	How many people refused to participate or dropped out? Reasons?	
Setting		
Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	p. 24-26
Presence of non-participants	Was anyone else present besides the participants and researchers?	
Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	p. 30-31
Data collection		
Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	p. 53-54
Repeat interviews	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	Did the research use audio or visual recording to collect the data?	p. 24-25
Field notes	Were field notes made during and/or after the interview or focus group?	p. 24-25
Duration	What was the duration of the interviews or focus group?	20-40 min
Data saturation	Was data saturation discussed?	
Transcripts returned	Were transcripts returned to participants for comment and/or correction?	
Domain 3: analysis and findingsz		
Data analysis		
Number of data coders	How many data coders coded the data?	four
Description of the coding tree	Did authors provide a description of the coding tree?	
Derivation of themes	Were themes identified in advance or derived from the data?	both
Software	What software, if applicable, was used to manage the data?	
Participant checking	Did participants provide feedback on the findings?	
Reporting		
Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	p. 32-38
Data and findings consistent	Was there consistency between the data presented and the findings?	yes
Clarity of major themes	Were major themes clearly presented in the findings?	yes
Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	p. 32-38

Supplementary data 3: COREQ criteria

TROUBLES DE LA DEGLUTITION

QUESTIONNAIRE ENTRETIEN POST HOSPITALISATION

IDE :

Date de sortie du patient :

Date du questionnaire :

Résultat VVST :

Étiquette patient

1. A quelle fréquence avez-vous appliqué l'adaptation des textures ?

Jamais	Rarement	Parfois	Souvent	Toujours
0	1	2	3	4

Total : /4

2. Quel(s) repas avez-vous adapté(s) ?

Petit déjeuner	Café matinal	Déjeuner	Goûter	Dîner

Total : /5

3. Quel était le liquide le plus difficile à adapter et pourquoi ?

Liquides	Problème(s)
Eau plate	- -
Boisson gazeuse	- -
Jus de fruit	- -
Café	- -
Thé	- -
Chocolat chaud	- -
Vin	- -
Alcool pétillant	- -
Autre(s)	- -

4. Avez-vous arrêté d'adapter les textures ? Oui / Non
Si oui, quand et pourquoi ?
5. En dehors des repas auxquels vous étiez présents, avez-vous remarqué que votre proche n'avait pas respecté les consignes données ? (Bouteille d'eau ouverte, tasses ou verres utilisés, ...)
6. Votre proche a-t-il spontanément respecté les consignes données ?
7. Quelle a été la situation la plus difficile pour vous et votre proche ?
 - Prise des médicaments :
 - Repas en famille :
 - Conflits :
 - Autre(s) :
8. Au niveau organisation, avez-vous eu des difficultés ? (Déplacements, adaptation de la texture, temps demandé, ...)
9. Quel a été votre ressenti global sur l'adaptation des textures liquides ?
 - Préparations compliquées ? :
 - Ressenti personnel :
 - Aspect et consistance des liquides proposés :
 - Point(s) positif(s) :
 - Point(s) négatif(s) :
10. La formation pour apprendre à adapter les textures vous a-t-elle semblé adaptée pour la prise en charge de votre proche ?
11. Comment pourrions-nous améliorer la formation que vous avez reçue ?
12. Nouvelle(s) question(s) :

Résumé

Introduction : Les troubles de la déglutition oropharyngées (TDO) sont fréquents chez les sujets âgés. Ce syndrome gériatrique compromet la sécurité et/ou l'efficacité de la déglutition. Les TDO peuvent être détectés par le volume-viscosity swallowing test (V-VST).

L'installation et l'épaississement des liquides font partie de la prévention des complications des TDO. Chez les patients âgés, les aidants familiaux sont en première ligne de la gestion des TDO et de l'épaississement des liquides. Néanmoins, le bénéfice à long terme de cette adaptation est controversé. Notre objectif était d'évaluer qualitativement la perception concernant l'épaississement des liquides des aidants familiaux de patients âgés avec TDO. La proportion des patients âgés avec des TDO vraiment éligibles à l'épaississement des liquides quotidien à domicile a été également évaluée.

Patients et Méthodes : cette étude qualitative a inclus les aidants familiaux et les patients avec des TDO hospitalisés dans le service de médecine gériatrique aigüe. Les TDO ont été dépistés par le V-VST. Les patients vraiment éligibles à l'épaississement des liquides à domicile étaient ceux ayant des capacités fonctionnelles et cognitives préservées ou ceux ayant un aidant familial présent à domicile quotidiennement. Les aidants familiaux ont été formés aux TDO et à l'épaississement des liquides. Les données qualitatives sur le ressenti des aidants sur les TDO ont été évalués par entretiens téléphoniques 2 semaines après le retour à domicile. Les critères COREQ ont été utilisés. Les participants ont été interrogés jusqu'à saturation des données et les entretiens ont été analysés par analyse qualitative des contenus.

Résultats : 181 patients ont été hospitalisés entre janvier et mars 2022. 23 patients sortis à domicile avaient un V-VST pathologique. 18 étaient vraiment éligibles à l'épaississement des liquides en raison de la présence quotidienne d'un aidant familial. 8 dyades patient-aidant familial ont été inclus dans l'étude qualitative. Les thématiques identifiées par l'analyse qualitative des données ont été regroupées en 3 catégories principales : l'amélioration de l'expérience des aidants familiaux, le ressenti sur l'épaississant des liquides et le changement du rapport patient-aidant.

Conclusions : cette étude confirme les difficultés des aidants familiaux concernant l'épaississement des liquides à domicile. Ces résultats suggèrent qu'une meilleure formation des aidants aux TDO est nécessaire plutôt que la prescription systématique d'épaississant.

Mots clés : troubles de déglutition, épaississement des liquides, perception.