Swallowing in behavioral variant frontotemporal dementia

Deglutição na variante comportamental da demência frontotemporal

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ABSTRACT

Background: Swallowing and feeding problems may occur with the progression of behavioral variant frontotemporal dementia (bvFTD) and can impair the anticipatory and oral preparatory phases of swallowing. Objective: To characterize swallowing problems and the feeding situation of patients with bvFTD and to correlate the swallowing problems with functionality, executive functions, cognitive and behavioral features. Methods: Consecutive outpatients with bvFTD in mild, moderate and severe dementia stages were recruited along with their caregivers. Patients and caregivers were screened with the following scales: "Mini-Mental State Examination", "FTLD-modified Clinical Dementia Rating", "Neuropsychiatric Inventory", "Frontal Assessment Battery", "Index of Independence in Activities of Daily Living", "Swallowing Rating Scale" and "Assessment of Feeding and Swallowing Difficulties in Dementia". Results: Overall, thirty patients with bvFTD were included along with their caregivers. Patients with bvFTD showed feeding and swallowing difficulties such as: messy to eat, passivity, coughing and choking, difficulty with some food consistencies and with specific food. Swallowing problems in bvFTD correlated with impaired functionality (p<0.05) and cognition (p<0.05), executive dysfunction (p<0.01) and behavioral features (p<0.01). Caregivers had great difficulty in managing the feeding situation during mealtime, with different characteristics in each dementia stage. Conclusion: Patients with bvFTD had inappropriate speed eating, passivity, coughing and choking starting in the mild dementia stage, and these problems worsen in the severe stage. Such difficulties affected caregiver performance during mealtime. The correlations indicated that swallowing difficulties tend to follow cognitive and behavioral decline in patients with bvFTD.

Keywords: Frontotemporal Dementia; Deglutition Disorders; Feeding Behavior; International Classification of Functioning, Disability and Health; Cognition Disorders.

RESUMO

Introdução: Os problemas na situação de alimentação e deglutição podem ocorrer com a progressão da variante comportamental da demência frontotemporal (DFT-vc) e alterar as fases antecipatória e preparatória oral da deglutição. Objetivo: Caracterizar os problemas de deglutição e a situação de alimentação de pacientes com DFT-vc e correlacionar os problemas de deglutição com a funcionalidade, funções executivas, aspectos cognitivos e comportamentais. Métodos: Foram recrutados pacientes ambulatoriais com DFT-vc nas fases leve, moderada e grave da demência, e seus respectivos cuidadores. Os pacientes e cuidadores foram avaliados com as escalas: "Mini-Exame do Estado Mental", "Mini-Exame do Estado Mental Grave", "Escala de Avaliação Clínica da Demência Modificada – DFT", "Inventário Neuropsiquiátrico", "Bateria de Avaliação Frontal", "Índice de Independência nas Atividades da Vida Diária", "Escala Funcional de Avaliação da Deglutição" e "Avaliação das Dificuldades de Alimentação e Deglutição na Demência". Resultados: Foram incluídos 30 pacientes com DFT-vc, e seus cuidadores. Pacientes com DFT-vc apresentaram dificuldades de alimentação e deglutição como: confusão na alimentação, passividade, tosse e asfixia, dificuldades com algumas consistências alimentares e alimentos específicos. Problemas de deglutição na DFT-vc correlacionaram-se com funcionalidade prejudicada (p<0,05) e cognição (p<0,05), disfunção executiva (p<0,01) e características comportamentais (p<0,01). Os cuidadores tiveram grande dificuldade em gerenciar a situação de alimentação diante de

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diferentes problemas em cada fase da demência. Conclusão: Pacientes com DFT-vc apresentaram velocidade de alimentação inapropriada, passividade, tosse e engasgos já na fase leve da doença, com piora na fase grave. As correlações indicaram que as alterações de deglutição tendem a seguir o declínio cognitivo e comportamental na DFT-vc.

Palavras-chave: Demência Frontotemporal; Transtornos da Deglutição; Comportamento Alimentar; Classificação Internacional de Funcionalidade, Incapacidade e Saúde; Transtornos Cognitivos.

INTRODUCTION

Swallowing is a complex and synchronized neuromuscular process during feeding that includes sensory and motor aspects. It starts with voluntary mechanisms that are highly dependent upon cognition, language, behavior and funcionality; therefore, swallowing consists on the following five phases¹: the first phase (anticipatory) precedes the food in the oral cavity; the second phase (oral preparatory) is related to the preparation of the bolus with oral motor acts; the third phase (oral phase) is characterized by the backward movement of the tongue for oral ejection of food; the fourth (pharyngeal) and the fifth phases (esophageal) are involuntary. The voluntary phases of swallowing (anticipatory, oral preparatory, and oral) are also influenced by functional, cognitive and behavioral aspects that can result in dysphagia and malnutrition²³.

Behavioral variant frontotemporal dementia (bvFTD) is a clinical syndrome characterized by progressive changes in behavior and personality, whereas at least three of the following clinical features must be present: early disinhibition, early apathy, loss of empathy for others, overeating, compulsions, and frontal executive loss; these features may occur in isolation or in addition to executive dysfunction^{4,5,6,7}. Dysphagia is common in neurodegenerative diseases^{2,3}. Feeding problems previously described in bvFTD include loss of social graces when eating, eating quickly, increased appreciation of sweet foods, hyperphagia, and hyperorality^{8,9}. Several studies have assessed feeding behavior in bvFTD, but there is little information regarding swallowing problems^{8,9,10}, and no description of the feeding situation of these patients with their caregivers.

In view of the well-known clinical features of patients with bvFTD, particularly regarding the pattern of neuropsychiatric symptoms, we hypothesized that swallowing and feeding would have peculiar characteristics in this dementia syndrome in comparison with other neurodegenerative diseases. Herein, our aims were to characterize feeding and swallowing features in patients with bvFTD in mild, moderate and severe dementia stages, and to correlate ensuing swallowing problems with functionality, executive dysfunction, and cognitive and behavioral features.

METHODS

In this uncontrolled cohort, outpatients with bvFTD⁴ were consecutively recruited from the Behavioral Neurology Section of Hospital São Paulo, Universidade Federal de São

Paulo (UNIFESP), and from the Neurology Service of Hospital das Clínicas, Universidade de São Paulo (USP), from March 2012 to September 2013 (19 months). Diagnosis of bvFTD was based on the international consensus research criteria for behavioral variant frontotemporal dementia⁴. All patients and their caregivers were evaluated by neurologists with expertise in neurocognition and dementia, and by a speech therapist. Patients with previous history of stroke, Parkinson's disease, Parkinson-plus syndromes, and neuromuscular diseases would be excluded from the study. All patients had a magnetic resonance exam to evaluate mostly the presence of orbitofrontal and/or anterior temporal atrophy⁴.

Neuropsychiatric assessment

We employed the Mini Mental State Examination (MMSE)¹¹ for global cognitive assessment, along with the Severe Mini Mental State Examination (SMMSE)¹² for moderately and severely impaired patients.

The Index of Independence in Activities of Daily Living (ADL)¹³ was used for caregiver assessment of the following sociobiological functions: bathing, dressing, toileting, transfer, continence and feeding, with index total scores ranging from 0 (severe functional impairment) to 6 (preserved functionality).

The Frontal Assessment Battery (FAB)¹⁴ was employed for screening of executive dysfunction, consisting on six subtests that evaluate the following aspects: similarities, lexical fluency, motor series, conflicting instructions, go/no-go and prehension behavior. The maximum score for each subtest is 3 points, which a maximum total score of 18.

The 12-item Neuropsychiatric Inventory $(NPI)^{15}$ was employed for caregiver assessment of behavioral features, including frequency, severity and caregiver distress for each item.

Assessment of dementia severity

Dementia stages were assessed by way of a structured interview with the caregiver using the FTLD-modified Clinical Dementia Rating¹⁶ (CDR) — scores were CDR=1 (mild stage), CDR=2 (moderate stage), or CDR=3 (severe stage), based on observation of the following cognitive-behavioral aspects: memory, orientation, judgment, problem solving, community affairs, home and hobbies, personal care and language, language and behavior, and comportment and personality.

Assessment of swallowing and feeding situation

A face to face interview with all patients and their caregivers was conducted by a speech therapist. To characterize

feeding and swallowing, the questionnaire Assessment of Feeding and Swallowing Difficulties in Dementia (AFSDD)^{2,17} was used, consisting on five sections. Three sections (sensory impairment and dentition; mental state and behavior; and issues related to food, drink and swallowing) were answered by caregivers. Two sections (feeding situation and skills; severe swallowing problems) were answered by the speech therapist. Caregivers were asked to rate the frequency for each symptom (0=never; 1=rarely; 2=sometimes; 3=frequently; 4=always). In the section entitled "sensory impairment and dentition", the caregiver was asked about vision problems, hearing loss and dentition problems. In the section entitled "mental state and behavior", the anticipatory phase of swallowing was investigated, which is affected by behavioral aspects such as agitation, passivity, appetite abnormalities and sleep disturbances. Caregivers answered questions about eating behaviors, such as inappropriate feeding speed, passivity, agitation and distraction in feeding situations. Aspects of the oral preparatory phase and the oral phase of swallowing, such as difficulty with food consistency and drooling saliva or food by mouth, were investigated in the section "issues related to food, drink and swallowing". In the section "feeding situation and skills", the speech therapist observed how patients were fed along with their caregivers. In the section "severe problems of swallowing", the evaluator concluded whether the patient had severe swallowing problems and whether there was any need of additional examinations.

Assessment of swallowing functionality

Functional swallowing was graded according to the Swallowing Rating Scale of the American Speech-Language-Hearing Association (SRS)¹⁸ with scores from 1 to 7, with score=1 corresponding to severe dysphagia and score=7 corresponding to normal swallowing.

DATA ANALYSIS

Continuous data for each variable were first compared with the normal curve by distance test using the Kolmogorov-Smirnov test and categorized as non-parametric. The non-parametric data were represented by median, lower quartile (25th percentile) and upper quartile (75th percentile), while independent groups were compared by way of the Mann-Whitney test.

Spearman rank-order correlation coefficients were employed to assess correlations between variables. The threshold of significance was set at p<0.05.

Ethical considerations

This study was approved by the Ethics Committee of Hospital das Clínicas, USP, according to the registration number 51762. All invited patients and their legal representatives agreed to participate on the research and signed the Informed Consent Form before the evaluation.

RESULTS

A total of 30 patients and their 30 caregivers participated in the study.

Of 30 patients (10 men and 20 women), 14 (46%) were classified as mild stage, 8 (27%) as moderate stage, and 8 (27%) as severe stage of dementia. The description of characteristics of patients and caregivers may be found in Table 1.

The median value of MMSE was 16 (9–21) and of CDR was 2 (1–3) (Table 2). According to Table 2 and to Figure 1, the most frequent behavioral features of all patients were: apathy (range of frequency: 2–4), appetite and eating disorders (range of frequency: 0–4), abnormal sleep (range of frequency: 0–3), and agitation (range of frequency: 0–4). Regarding the SRS, we observed score=7 (normal swallowing) in seven (23%) patients with bvFTD.

Table 3 showed that several aspects influenced the anticipatory and oral preparatory phases of swallowing (according to the sections of the questionnaire AFSDD) such as drowsiness, restlessness, distractibility, passivity,

Table 1. Characteristics of patients and caregivers.

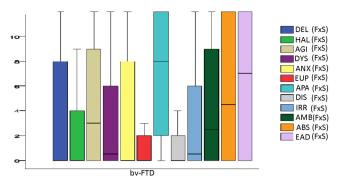
bvFTD	Median	25%	75%
Time since onset of symptoms (years)	4.5	3	7
Time since diagnosis (years)	2	2	4
Time of untreated disease (years)	1	1	3
Patient age (years-old)	66	60	70
Education of the patient (years)	5	4	9
Caregiver age (years-old)	56	42	64
Education of the caregiver (years)	10	4	14
Care time in personal daily life activities (hours per day)	2	0	4
Care time in instrumental daily life activities (hours per day)	4	1	6
Caregiver residing with the patient	1	1	1
Number of caregivers	1	1	3
Percentage of contribution in the care	5	3	5
MMSE	16	9	21
CDR	2	1	3
FAB similarities	1	0	1
FAB lexical fluency	1	0	3
FAB motor series	0	0	2
FAB conflicting instructions	0	0	2
FAB go/no-go	1	0	2
FAB prehension behavior	3	3	3
ADL	6	2	6
SRS	6	6	7

bvFTD: behavioral variant frontotemporal dementia; MMSE: Mini Mental State Examination; CDR: FTLD-modified Clinical Dementia Rating; FAB: Frontal Assessment Battery; ADL: Index of Independence in Activities of Daily Living; SRS: Swallowing Rating Scale of the American Speech-Language-Hearing Association.

Table 2. Descriptive results for neuropsychiatric symptoms.

bvFTD	Median	25%	75%
Delusions			
S	0	0	2
F	0	0	3
CD	0	0	3
Hallucinations			
S	0	0	1
F	0	0	2
CD	0	0	0
Agitation			
S	2	0	3
F	2	0	4
CD	0	0	3
Dysphoria	· ·	0	Ü
S	1	0	2
F	1	0	3
CD	0	0	2
Anxiety	U	U	Z
S	0	0	3
F			
CD	0	0	4
	U	U	Z
Euphoria	0	0	1
S F	0	0	1
	0	0	2
CD	0	0	1
Apathy	0	4	0
S	3	1	3
F	4	2	4
CD	0	0	2
Disinhibition			
S	0	0	1
F	0	0	1
CD	0	0	0
Irritability			
S	1	0	3
F	1	0	3
CD	0	0	2
Aberrant motor behavior			
S	1	0	3
F	1	0	4
CD	0	0	2
Abnormal sleep			
S	2	0	3
F	3	0	4
CD	0	0	2
Eating disorders			
S	2	0	3
F	4	0	4
CS	0	0	2

bvFTD: behavioral variant frontotemporal dementia; S: severity; F: frequency; CD: caregiver distress.



DEL-delusions; HAL-hallucinations; AGI-agitation; DYS-dysphoria; ANX-anxiety; EUP-euphoria; APA-apathy; DIS-disinhibition; IRR-irritability; AMB-aberrant motor behavior; ABS-abnormal sleep; EAD-eating disorders; bv-FTD-behavioral variant frontotemporal dementia; S-severity; F-frequency. Figure 1. Graphic representation of scores for each behavioral domain of the Neuropsychiatric Inventory (frequency times severity).

Table 3. Descriptive results for Assessment of Feeding and Swallowing Difficulties in Dementia scores.

bvFTD	Median	25%	75%
Mental state and behavior			
Sleepiness	0	0	0
Agitation	0	0	4
Distraction	2	0	4
Passivity	4	0	4
Refusal of food	0	0	2
Inappropriate speed eating- too fast	2	0	4
Inappropriate speed eating- too slow	0	0	0
Oral exploration of objects	0	0	1
Feeding situation and skills			
Inappropriate supervision	0	0	2
Inappropriate position	0	0	0
Dependent to eat	0	0	2
Eat from caregiver plate	0	0	0
Distraction with utensils	0	0	3
Messy to eat	1	0	3
Mixing courses	0	0	0
Severe caregiver	0	0	0
Caregiver not use gentle tone of voice	0	0	0
Caregiver not encouraging	0	0	4
Stress situation	0	0	0
Feeder does not approach	0	0	2
Issues related to food, drink, and swallowing			
Drooling saliva or food	0	0	2
Tongue weakness	0	0	0
Difficulty with consistencies	3	0	4
Delayed swallow	0	0	3
Coughing and choking	2	0	4

Continue...

Table 3. Continuation.

bvFTD	Median	25%	75%
Wet voice quality after swallowing	0	0	0
Multiple swallows	0	0	1
Difficulty with specific food	4	0	4
Difficulty with correctly opening the mouth	0	0	3
Does not recognize temperature	0	0	0
Left greater portion of food in the plate	0	0	3
Does not recognize tastes	0	0	4
Left food in the mouth	0	0	2

bvFTD: behavioral variant frontotemporal dementia; AFSDD: Assessment of Feeding and Swallowing Difficulties in Dementia.

improper speed during feeding, delayed triggering of swallowing, and accumulation of food in the mouth, resulting in coughing and choking. Swallowing and feeding problems most often observed were: passivity (range: 0–4) in "mental state and behavior", messy to eat (range: 0–3) in "feeding situation and skills", problems with certain foods (range: 0–4) and problems of food consistency (range: 0–4) in "issues related to food, drink and swallowing". Only one patient in the severe dementia stage had severe swallowing problems.

Visual impairment was reported in 90% of patients, and dental problems were reported in 77% of patients. Caregivers reported hyperphagia in 28% and hyperorality in 20% of patients.

There was significant association (r>0.5) and good correlation (p<0.05) of MMSE, SMMSE, ADL, CDR and FAB with AFSDD (Table 4), and significant association (r>0.5) and good correlation (p<0.01) between sum of NPI items and the section "mental state and behavior" of AFSDD (Table 5).

DISCUSSION

In the current study, we reported the feeding situation between caregivers and patients with bvFTD, and correlated the swallowing abnormalities with behavioral, cognitive and functional aspects within and among different stages of this dementia syndrome.

Most of the caregivers who accepted to participate were spouses, sons or daughters of our patients, and lived with them (Table 1). Even though most caregivers contributed to almost 100% of the care of our patients, we noticed frequent caregiver difficulties when managing feeding, an aspect that may increase the risk of choking, the time of food in the mouth, and the risk of aspiration. We believe that this is due to cognitive and behavioral impairments, as well as the pattern of dependence for activities of daily living.

Table 4. Correlations of Mini Mental State Examination, Severe Mini Mental State Examination, Index of Independence in Activities of Daily Living, FTLD-modified Clinical Dementia Rating and Frontal Assessment Battery with Assessment of Feeding and Swallowing Difficulties in Dementia.

bvFTD		AFSDD- FSS*	AFSDD- IFS*
	Correlation coefficient	-0.626	
MMSE*	Significance (2-tailed)	<0.001	
	n	30	
	Correlation coefficient	-0.689	
SMMSE*	Significance (2-tailed)	0.040	
	n	9	
	Correlation coefficient	-0.768	-0.593
ADL*	Significance (2-tailed)	<0.001	0.001
	n	30	30
	Correlation coefficient	0.524	0.402
CDR	Significance (2-tailed)	0.003	0.028
	n	30	30
	Correlation coefficient	-0.642	
FAB*	Significance (2-tailed)	<0.001	
	n	30	

bvFTD: behavioral variant frontotemporal dementia; AFSDD: Assessment of Feeding and Swallowing Difficulties in Dementia; FSS: feeding situation and skills; IFS:Issues related to food, drink, and swallowing; MMSE: Mini Mental State Examination; SMMSE: Severe Mini Mental State Examination; CDR: FTLD-modified Clinical Dementia Rating; FAB: Frontal Assessment Battery; ADL: Index of Independence in Activities of Daily Living; SRS: Swallowing Rating Scale of the American Speech-Language-Hearing Association.

Table 5. Correlations of neuropsychiatric symptoms of Neuropsychiatric Inventory with domains of Assessment of Feeding and Swallowing Difficulties in Dementia.

bvFTD test parameters (n=30)		AFSDD- FSS total score	AFSDD- IFS total score
Euphoria (F X S)	Correlation coefficient		0.374
	Significance (2-tailed)		0.042
Euphoria - CD	Correlation coefficient		0.408
	Significance (2-tailed)		0.025
Aberrant motor behavior (F X S)	Correlation coefficient	0.387	0.444
	Significance (2-tailed)	0.034	0.014
Abnormal sleep - CD	Correlation coefficient	0.374	
	Significance (2-tailed)	0.042	
Eating	Correlation coefficient		0.589
disorders - CD	Significance (2-tailed)		0.016
NPI total scores	Correlation coefficient		0.423
	Significance (2-tailed)		0.020

bvFTD: behavioral variant frontotemporal dementia; AFSDD: Assessment of Feeding and Swallowing Difficulties in Dementia; FSS: feeding situation and skills; IFS: Issues related to food, drink, and swallowing; NPI: Neuropsychiatric Inventory; S: severity; F: frequency; CD: caregiver distress.

^{*}Total test score.

According to caregiver reports, 90% of our patients had visual impairment. In the feeding situation, visual impairment may affect the information about what type of food is being offered or eaten, lead to inappropriate use of cutlery and impair hand-to-mouth movements; thus, the amount of food may be too much for chewing at once, and result in coughing and choking.

Apathy and lack of initiative may interfere with swallowing, considering that more than half of all patients who presented passivity during feeding also presented chewing problems, coughing and choking. Lack of initiative and low engagement during feeding may affect the anticipatory phase of swallowing, while patients eating too slow when apathetic may have increased oral transit time, thus affecting the preparatory oral and oral phases as well, possibly resulting in choking episodes. Furthermore, disorganized initiation or maintenance of the feeding situation were more prevalent when more cutlery was available to patients.

Patients with bvFTD had different swallowing feature profiles in different dementia stages. Passivity and inappropriate speed ("eating too slow") predominated in the severe dementia stage. Half of all patients with passivity in the feeding situation had dysphagia (chewing problems and choking), probably because passivity influenced the anticipatory and oral preparatory phases. Instead, inappropriate speed ("eating too fast") and agitation predominated in the moderate stage of bvFTD causing cough and choking. Aspects such as passivity and eating too slow may also happen in the mild dementia stage, though less frequently than in the severe dementia stage.

Our study is consistent with published data showing that patients with bvFTD have feeding problems, but we found that these patients have more swallowing difficulties than what is clinically reported in usual situations. Previous studies reported problems such as hyperphagia, hyperorality, changes in feeding preferences and appetite, whereas swallowing changes would be rare^{8,9,10}. Our study reported hyperphagia, hyperorality, altered mental status during feeding, and swallowing difficulties starting from the mild dementia stage. Our former studies^{2,3} regarding swallowing in Alzheimer's disease and primary progressive aphasia also showed the importance of investigating swallowing difficulties with caregivers. In moderate and severe stages of Alzheimer's disease², Correia et al. observed difficulties such as passivity, forgetting or distraction, and eating too slow, besides difficulties when swallowing specific food and delays in the early phases of swallowing. However, in the present study, we observed that caregivers of patients with bvFTD were distressed when dealing with swallowing difficulties in all dementia stages. The burden of neuropsychiatric symptoms starting from the mild stage of bvFTD may lead to more hardness for caregivers to deal with feeding and swallowing difficulties. Nevertheless, in patients with

primary progressive aphasia³, Marin et al. reported multiple swallows and drooling of saliva, particularly in the semantic variant, but these features were not frequently observed in our patients with bvFTD.

Ikeda et al.8 investigated swallowing in 91 patients who were allocated into three groups: bvFTD (n=23), semantic variant primary progressive aphasia (n=25) and Alzheimer's disease (n=43). The mean age of these groups was, respectively: 61, 65 and 68 years. Six participants with bvFTD were institutionalized. A questionnaire comprising 36 questions to be answered by caregivers was used to assess swallowing problems. The questionnaire presented five domains: swallowing problems, change in appetite, food preference, eating habits, and other oral behaviors. The authors found rare swallowing problems in the bvFTD group, and suggested that dysphagia in bvFTD tends to develop in later dementia stages. Our results were different from those, and one possible reason for this discrepancy is that we employed a more detailed evaluation that included the observation of feeding behaviors, suggesting the need for a thorough assessment of swallowing in patients with bvFTD.

In the literature, the main behavioral aspects reported in bvFTD are: apathy, anxiety, psychomotor agitation and feeding disorders ^{19,20,21}. In our study, the most evident ones were apathy, feeding disorders and sleep disorders. The fact that most of our patients were in the mild dementia stage might have affected such results

The correlations observed between the section "feeding situation and abilities" of AFSDD and the instruments MMSE, SMMSE, ADL, CDR and FAB (p<0.05) showed that cognitive aspects, functional abilities, severity of disease and executive dysfunction can influence the feeding situation. These aspects led to the conclusion that swallowing difficulties tend to follow cognitive and behavioral decline in patients with bvFTD.

Limitations of this study include its cross-sectional nature with a relatively small sample and no randomization. In future studies, the use of a thorough battery of neuropsychological tests for memory and visuospatial skills along with objective exams for assessment of swallowing (such as fluoroscopy with barium) could provide more information to objectively assess these features of patients with bvFTD. Nevertheless, it should be noted that patients with dementia might not collaborate with exams such as videofluoroscopy and videoendoscopy, which is why we suggest that proper indication should be individualized so as not to mask the actual patterns of swallowing of each patient. In spite of these caveats, clinical assessment of dysphagia was well documented, and added important information to the relatively scarce literature on the subject, particularly by considering the feeding situation between caregivers and patients with bvFTD.

In summary, swallowing and feeding problems were present in different stages of bvFTD, with different characteristics in each stage. This study should alert healthcare professionals not only about the prevalence of swallowing difficulties starting in the mild stage of bvFTD but also on the need for orientation programs for caregivers, so that therapy can be established for improvement and to prevent complications.

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