

# Swallowing in moderate and severe phases of Alzheimer's disease

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## ABSTRACT

**Objective:** To characterize the problems of feeding and swallowing in individuals with moderate and severe Alzheimer's disease (AD) and to correlate these with functional aspects. **Method:** Fifty patients with AD and their caregivers participated in this study. The instruments used were: Clinical Dementia Rating (CDR), Mini-Mental State Examination, Index of Activities of Daily Living, Assessment of Feeding and Swallowing Difficulties in Dementia, Functional Outcome Questionnaire for Aphasia, and Swallowing Rating Scale. **Results:** Problems with passivity, distraction and refusal to eat were encountered in the CDR2 group. Distraction, passivity and inappropriate feeding velocity were predominant in the CDR3 group. The problems were correlated with communication, swallowing severity of AD individuals and caregiver schooling. **Conclusion:** Given the inexorable functional alterations during the course of the disease, it is vital to observe these in patients with a compromised feeding and swallowing mechanism. The present study supplies the instruments to orient caregivers and professionals.

**Key words:** swallowing disorders, Alzheimer's disease, caregivers.

## A deglutição nas fases moderada e grave da doença de Alzheimer

### RESUMO

**Objetivo:** Caracterizar os problemas de alimentação e deglutição em indivíduos com doença de Alzheimer (DA) em fases moderada e grave e correlacioná-las com os aspectos funcionais. **Método:** Participaram do estudo 50 pacientes com DA e seus 50 cuidadores. Os instrumentos utilizados foram: Estadiamento clínico da demência (CDR), Mini-Exame do Estado Mental, Índice das Atividades de Vida Diária, Questionário de Habilidades de Alimentação e Deglutição, Questionário para Avaliação da Comunicação Funcional na Afasia, Escala de Gravidade da Deglutição. **Resultados:** No grupo CDR2 foram encontrados problemas como passividade, distração e recusa do alimento. No grupo CDR3 predominou a distração, passividade e velocidade de alimentação inapropriada que se correlacionaram com comunicação, gravidade da deglutição e escolaridade. **Conclusão:** Dadas as alterações funcionais inexoráveis no curso da doença, é imprescindível a sua observação em pacientes com prejuízos na alimentação e nos mecanismos da deglutição. O presente estudo fornece instrumentos para orientar cuidadores e profissionais. **Palavras-chave:** transtornos da deglutição, doença de Alzheimer, cuidadores.

Swallowing depends on the complex sensory-motor mechanism regulated by the central nervous system, which includes voluntary and involuntary components. The neurophysiological support for swallowing, from the cortex to the bulb, has been confirmed via modern neuro-functional imaging methods<sup>1</sup>.

Throughout its development, swallowing has modified so that individuals adapt to nutritional and social necessities, which include the capacity to discriminate in order to process, in the mouth and pharynx, the different food-types of a most-diverse consistency, viscosity and volume.

The pathological alteration of this

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mechanism results in what is known as dysphagia, which can carry nutritional and social consequences, having repercussions in the individual's well-being.

The aging process, in itself, does not give rise to pathological changes in swallowing, but it is the co-morbid risk factor that leads to dysphagia. The factors causing greater difficulty or impediments to maintain independent and efficient oral feeding are the cognitive and functional conditions of the patient. They limit self-regulation, perception and control of the risk factors as well as limiting the development of compensatory strategies such as, for example, postural adjustments or swallowing and breathing coordination. These alterations are observed in Alzheimer's disease (AD), where the progressive dementia condition is prevalent in the aged.

From a clinical point of view, AD presents memory alterations that extend to other cognitive spheres. In its typical manifestation, the symptoms result from an injury to entorhinal cortex (hippocampus and bilateral parietal temporal regions). Motor deficits, in more advanced phases of the disease<sup>2</sup>, result from its expansion to the frontal regions. There are reports of difficulties in swallowing management during the initial phases, although the most expressive problems are found in the moderate and severe phases of AD<sup>3-5</sup>.

Thus, the objective of this study was to characterize the problems of feeding and swallowing in individuals with moderate and severe AD and correlate these with other functional aspects.

## METHOD

The participants were 50 individuals diagnosed with moderate (n=18) and severe (n=32) AD and their 50 caregivers, coming from the Clinical Medical Division - Geriatric Service of Clinics Hospital from School of Medicine at São Paulo University, between August 2008 and March 2009.

Patients were included, providing they had caregivers. There were no restrictions to gender, age or schooling for patients or caregivers. Individuals with mild AD and those whose caregivers administered care for less than one day per week were excluded. The study was approved by the Research Ethics Commission of Clinics Hospital at São Paulo University School of Medicine (CAPEPesq n. 0647/08) and each caregiver signed their consent to participate.

The moderate and severe groups were defined by the scores obtained during the Clinical Dementia Rating (CDR) interview and answered by the caregiver. The total amount criteria was used, and was based on observing the performance of cognitive-behavioral aspects - memory, orientation, judgment, problem solving, community relations, home or leisure activities and self-independent

care<sup>6</sup> in everyday life. To screen the cognitive aspects, the Mini-Mental State Examination (MMSE), which evaluates orientation, calculation, memory, visual-spatial and language<sup>7</sup> skills, was applied to the patient. Global functionality was analyzed via the Index of Activities of Daily Living (IADL) obtained by questioning the caregiver about aspects, such as bathing, dressing, personal hygiene, transference, continence and feeding<sup>8</sup>. Furthermore, the caregiver was given the Functional Outcome Questionnaire for Aphasia (FOQ-A)<sup>9</sup>, to evaluate communication. The questionnaire is composed of 32 items of communicating basic needs (7 questions), realization of speaking acts such as routine requests (7 questions), communication of new information (8 questions), attention/other communication skills (10 questions). To evaluate feeding and swallowing difficulties the caregiver was given the Assessment of Feeding and Swallowing Difficulties in Dementia (AFSDD)<sup>10</sup>, so as to obtain information about feeding and swallowing in patients with dementia. The AFSDD was translated into Portuguese with the addition of one frequency scale (0=never, 1=rarely, 2=sometimes, 3=frequently, 4=always). The questions in the sections about sensory impairment and dentition, mental state and behavior and Issues related to food, drink and swallowing, were answered by the caregiver. The sections of feeding situation and skills and severe swallowing problems were scored by the evaluator. The answers to the questions in the sections of sensory impairment and dentition and severe swallowing problems were classified either as a problem absent [0] or present [1]. Lastly, the situation for graduated swallowing was observed via the Swallowing Rating Scale/American Speech-Language-Hearing Association (SRS) and scored by the researcher between 0-not-testable and 7-normal swallowing, while observing a meal<sup>11</sup>.

## Statistical analysis

Initially, the impact of age and the results of the MMSE were described and verified by measure resume. The groups were compared relative to age (t-Student test) and MMSE (Mann-Whitney). The other scales were described according to the behavioral occurrences in the groups. To verify the existence of a correlation between the AFSDD items and the other scales, logistical regressions<sup>8</sup> were used with absence or presence as the answer for each item on the MMSE, SRS, IADL scales and total FOQ-A beyond the group effect.

A 5% significance level was adopted to analyze the results.

## RESULTS

The age of the 50 patients varied between 62 and 95 years (n=13 men and 37 women, mean age of 79.5±7.4

**Table 1.** Socio- demographic and cognitive characteristics of individuals with Alzheimer's disease.

Variables	Group	Average	SD	Median	Minimum	Maximum	N	p value
Age	CDR2	80.61	4.94	81	73	89	18	0.474*
	CDR3	79.25	8.41	78.5	62	95	32	
	Total	79.74	7.32	80	62	95	50	
Schooling	CDR2	3.44	4.42	3	0	15	18	0.704
	CDR3	3.91	4.72	3	0	15	32	
	Total	3.74	4.58	3	0	15	50	
MMSE	CDR2	14.61	4.27	14.5	7	23	18	<0.001
	CDR3	2.09	3.85	0	0	12	32	
	Total	6.60	7.25	6	0	23	50	

MMSE: Mini-mental State Examination; SD: standard deviation; CDR2: Clinical Dementia Rating Moderate; CDR3: Clinical Dementia Rating Severe; N: Number of the participants; \* t-student.

**Table 2.** Global (Index of Activities of Daily Living) and swallowing (Swallowing Rating Scale) functional performance.

Variables	Groups			
	CDR 2		CDR 3	
	n	%	n	%
SRS				
Graduate of commitment				
1 ( commitment maximum)	0	0	1	3.1
2	0	0	5	15.6
4	0	0	10	31.3
5	0	0	5	15.6
6	7	38.9	11	34.4
7 (normal)	11	61.1	0	0
IADL				
0 (commitment maximum)	0	0	22	68.8
1	0	0	9	31.2
4	2	11.1	0	0
5	7	38.9	0	0
6 (normal)	9	50	0	0
Total	18	100	32	100

SRS: Swallowing Rating Scale; IADL: Index Activities of Daily Living; CDR2: Clinical Dementia Rating Moderate; CDR3: Clinical Dementia Rating Severe.

years). Eighteen of the 50 patients with AD were classified as moderate (CDR2) and 32 as severe (CDR3). The 50 caregivers had age between 23 and 82 years (n=18 men and 32 women, mean age of 52.7±16.7 years) and they had between 2 and 18 years of formal schooling. Days of care provided by caregivers of the AD patients varied between 1 and 7 days per week and 76% of caregivers provided daily care.

There was no statistically significant difference between the groups, in age and schooling variables, while group CDR3 scored lower (p<0.001) (Table 1) on the MMSE.

**Table 3.** Functionality of Communication in Clinical Dementia Rating (CDR).

Variables	Groups			
	CDR2		CDR3	
	n	%	n	%
FOQ-A				
Communicating basic needs				
No	0	0	13	40.6
Yes	18	100	19	59.4
Making routine requests				
No	0	0	18	56.3
Yes	18	100	14	43.8
Communicating new information				
No	7	38.9	24	75
Yes	11	61.1	8	25
Attention/Communication skills				
No	8	44.4	25	78.1
Yes	10	55.6	7	21.9
Total	18	100	32	100

FOQ-A: Functional Outcome Questionnaire for Aphasia; CDR2: Clinical Dementia Rating Moderate; CDR3: Clinical Dementia Rating Severe.

The CDR3 group presented a lower performance on the IADL, FOQ-A and SRS than the CDR2 group (p<0.05) (Tables 2 and 3).

In the section sensory impairment and dentition of the AFSD, visual deficiency was related in the entire CDR2 group and in 22 (68.75%) of CDR3. Related to hearing, 11 (61.1%) in CDR2 needed hearing aids, and 19 (59.37%) in CDR3. Dentition problems were present in 18 (100%) in CDR2 group and in 31 (93.75%) in CDR3.

In the section mental state and behavior, compromises related to passivity were reported (5 individuals=27.8% in CDR2 and 19=59.4% in CDR3), forgetting or distraction (5=27.8% in CDR2 and 25=78.1% in CDR3); the refusal of food and drink (2=11.1% in CDR2 and 3=9.4%

**Table 4.** Clinical Dementia Rating (CDR) in assessment of feeding and swallowing difficulties in dementia.

Section	Group	Score*	Total average**
Sensory impairment and dentition	CDR2	18	1
	CDR3	31	0.96
Mental state and behavior	CDR2	41.7	2.31
	CDR3	98.19	3.06
Feeding situation and skills	CDR2	47.97	2.66
	CDR3	113.64	3.55
Issues related to food, drink and swallowing	CDR2	58.64	3.25
	CDR3	100.12	3.12
Severe swallowing problems	CDR2	0	0
	CDR3	7	0.21

AFSDD: Assessment Feeding and Swallowing Difficulties in Dementia; CDR2: Clinical Dementia Rating Moderate; CDR3: Clinical Dementia Rating Severe. \*Number of subjects who answered "yes"; \*\*Average of points from 0: absent; 1: present; 2: sometimes; 3: frequently; 4: always.

in CDR3) and feeding velocity (4=22.2% in CDR2 and 13=40.6% in CDR3).

In the section Issues related to food, drink and swallowing the most severe problem was the ingestion of specific consistencies (5=27.8% in CDR2 and 23=71.9% in CDR3), followed by delay in beginning the swallowing process (12=37.5% in CDR3) which was related only in CDR3 individuals and difficulty in relation to specific foods (2=11.1% in CDR2 and 22=68.8% in CDR3).

In the section feeding situation and skills, a meal was observed by the clinical researcher and most of the caregivers adequately supervised the feeding situation (14=77.8% in CDR2 and 22=68.8% in CDR3). Problems with positioning during the feeding were related only in the CDR3 group, 14=43.8% of the participants, just as the inability to self-feed was recognized by 22=68.8% in CDR3. Distractions with utensils was observed in 1 (5.6%) in CDR2 group and in 17 (53.3%) in CDR3 group.

In the section Severe swallowing problems the examiner did not recognize the need to investigate swallowing using a video-fluoroscope on either of the groups and, severe swallowing problems were observed in 7 (21.87%) of the individuals in group CDR3.

Upon analyzing the mean total obtained in the domains between CDR2 and CDR3, we observed that the sections mental state and behavior (3.06), feeding situation and skills (3.55). Issues related to food, drink and swallowing (3.12) a mean frequency scale above 3 a problem almost always present in group CDR3, while the section Sensory impairment and dentition (1) presented greater frequency in group CDR2 (Table 4).

On par with the descriptive aspects, it behooves analyzing how feeding and swallowing aspects correlate with functional and cognitive aspects.

In correlating the domain mental state and behavior with the other scales we found that the chance of the individual presenting a diminished consciousness reduced to 73% as the score of the SRS scale increased (OR=0.27; p=0.050), in other words, the more the individual approached normal swallowing behavior; the chance that the individual presented inappropriate feeding velocity reduced to 65% with an increase in functional communication skills, measured by FOQ-A (OR=0.35; p=0.049). The other correlations were not statistically significant (Table 5).

In the correlation items relative to issues related to food, drink and swallowing of the AFSDD with the other scales, we obtained that the chance of the patient presenting escape of saliva or food in the mouth, reduced 68% with an increase of the SRS scale (OR=0.32; p=0.035). The chance of taking into consideration how much an individual opened his mouth to offer food diminished 69% with the increase of the FOQ-A (OR=0.31; p=0.017) and the chance of the patient leaving a good part of his meal on the plate diminished 68% with an increase of the SRS scale (OR=0.32; p=0.021).

Upon correlating the situation of feeding and skills with the other scales, we obtained that the chance of the individual being distracted with other utensils diminished 62% with an increase of the score obtained on the SRS scale (OR=0.38; p=0.032). The other relations were not statistically significant.

Summarizing, the SRS supplies predictive data for most of the aspects observed on the questionnaire (Table 5).

## DISCUSSION

Many studies have been directed to the feeding problems in people with dementia, principally when there is

**Table 5.** Correlation between items of Assessment of Feeding and Swallowing Difficulties in Dementia with other scales.

Variable	Factor	OR	IC (95%)		p
			Lower	Upper	
Presents a diminished a consciouness	Group (CDR3)	0.93	0.01	157.82	0.979
	Scholing	0.87	0.71	1.06	0.165
	MMSE	0.88	0.74	1.05	0.142
	SRS	0.27	0.07	1	0.050
	ADL	1.60	0.55	4.64	0.385
	FOQ-A	0.59	0.30	1.17	0.130
Presents inappropriate feeding velocity ?	Group (CDR3)	0.42	0	35.84	0.699
	Scholing	0.70	0.50	0.96	0.029
	MMSE	0.95	0.74	1.21	0.656
	SRS	1.49	0.39	5.72	0.564
	ADL	0.42	0.15	1.20	0.105
	FOQ-A	0.35	0.12	0.99	0.049
Presents escape of saliva or food in the mouth ?	Group (CDR3)	0.02	0	194.16	0.392
	Scholing	0.96	0.81	1.15	0.687
	MMSE	0.92	0.69	1.23	0.580
	SRS	0.32	0.11	0.92	0.035
	ADL	0.65	0.11	3.91	0.637
	FOQ-A	0.84	0.37	1.89	0.673
How much an individual opened his mouth to offer food ?	Group (CDR3)	#			0.998
	Scholing	0.90	0.71	1.15	0.404
	MMSE	0.77	0.53	1.10	0.147
	SRS	1.30	0.57	3	0.532
	ADL	0.74	0.20	2.80	0.659
	FOQ-A	0.31	0.12	0.81	0.017
Leaves a good part of his a meal on the plate ?	Group (CDR3)	3.07	0.03	332.29	0.639
	Scholing	0.88	0.76	1.02	0.091
	MMSE	1.10	0.92	1.30	0.286
	SRS	0.32	0.12	0.84	0.021
	ADL	1.47	0.56	3.85	0.435
	FOQ-A	0.97	0.54	1.73	0.909
Distracts with other utensiles ?	Group (CDR3)	0.24	0	18.82	0.518
	Scholing	1.22	1	1.50	0.051
	MMSE	1	0.84	1.20	0.972
	SRS	0.38	0.16	0.92	0.032
	ADL	1.10	0.45	2.68	0.833
	FOQ-A	0.70	0.38	1.30	0.262

MMSE: Mini-Mental State Examination; SRS: Swallowing Rating Scale; IADL: Activities of Daily Living; FOQ-A: Functional Outcome Questionnaire for Aphasia; OR: Odds Ratio; IC: Confidence Interval; P: Significanc Level.

a dependence on the caregiver for the offering of food<sup>4,12</sup>. A good part of this was realized by nursing professionals, with institutionalized patients, and the most frequent themes were: ethical factors, interpretation of the feeding difficulties and satiety<sup>4</sup>, interventions and description of the feeding problems in a nutritional state. Most of the studies make use of questionnaires directed at health professionals in order to characterize the feeding situation, while few differentiate the phases of dementia and are not directed at swallowing. Bearing in mind the need to give attention to the feeding and swallowing problems in dementia and the need to obtain detailed information so as

to orient the caregivers, we have undertaken to characterize these problems in patients with moderate and severe AD (CDR 2 e 3).

In our study there was a predominance of patients in group CDR3. Mean age and schooling were similar between the two groups. Regarding the MMSE in group CDR2 there was a greater variation, while in CDR3, most presented a performance with a floor effect due to a greater severity in cognitive decline of the individual. The SRS made it possible to classify the individuals with advanced AD, according to the swallowing functionality. Group CDR2 presented better swallowing levels while the

CDR3 was distributed throughout all levels of compromise, from mild to severe.

The communication scale made it possible to identify the compromise in different contexts and then to later relate them to feeding and swallowing problems. Sandman<sup>3</sup> related feeding problems with difficulty to communicate. Athin and Noberg<sup>12</sup> highlighted the difficulties the caregiver had in interpreting the patient's behavior during a meal. Groups CDR2 and CDR3 displayed different communication inabilities. In CDR2, it was noted that the individuals demonstrated a loss of the skills that manage new information, attentional difficulties and other communication incompetence, despite that most were still able to perform them to some degree. Yet, in CDR3, the possibility for the individual to communicate basic needs was observed, albeit with some loss, as most do not routinely make requests, do not communicate new information and do not mobilize attention and other communication skills.

As to sensory impairment and dentition, all of the caregivers of group CDR3 related dentition and vision problems. The impact of these problems in skills of feeding and swallowing occur in the severe phase<sup>13</sup>, as seen in the application of the AFSDD in our study.

Relative to mental state and behavior most of the moderate-stage AD patients (CDR2) displayed passivity, distraction and refusal of food as the most frequent problems. Blandford<sup>14</sup> showed that moderate-stage dementia patients frequently present absent-minded behavior in the feeding situation. In group CDR3, related among the most frequent problems were distraction and passivity during the meal as well as inappropriate feeding velocity. Passivity could constitute a factor for generating risks as the caregiver is the one who stimulates the beginning of or the follow-through of feeding, at times ignoring the patient's swallowing timing. Refusing food can be expressed verbally or through gestures, or may even be the result of erroneously interpreting oral apraxia and an inability to voluntarily open one's mouth<sup>5</sup>. Another refusal factor is the non-understanding of the feeding situation and the caregiver's offering intention. Primitive reflexes can appear in the final stage of dementia, such as, biting the spoon during the offering which the caregiver could interpret as a refusal<sup>9</sup>. The possibility that the gesture to refuse food might be a strategy that individuals with difficulty use for protection or to obtain more time to swallow before receiving the next spoonful can also be considered<sup>10</sup>. Distraction during the meals is typically related by the caregivers of AD patients<sup>15</sup>. The person begins but becomes distracted and interrupts the meal because he forgets what he was doing. Other studies relate that in the severe phase of dementia there is a greater compromise of aspects related to food which is correlated to severity of cognitive and functional alterations<sup>14</sup>.

In the section issues related to food, drink and swallowing the caregivers of CDR2 related the difficulty of chewing and swallowing food of a certain consistency. These problems afflicted a minority of CDR2 individuals, but in high frequency. The caregivers of this group also related dentition problems, probably associated to the frequent difficulty of chewing. Maintaining the food in the oral cavity or chewing inadequacy, frequent in AD<sup>10</sup> can be manifestations of the difficulty to control food during the oral phase of swallowing. The caregivers of the severe-stage patients (CDR3) relate this as an ever-present problem, associated to the delay of the swallowing reflex activity, equally frequent in advanced dementia and can be related to oral apraxia<sup>10</sup>.

In the feeding situation and skills, where the data was obtained by the speech-therapist observing the caregiver's behavior, when offering food, in the CDR2 group as well as the CDR3 group, the caregivers performed well as the feeding supervisors. In the individuals with CDR3, who presented a greater number of problems and greater dependence, the function of the caregiver supervision was substituted by total responsibility of caregiver for the entire process of feeding.

In the characterization of swallowing problems, the final section of the questionnaire, we observed that dysfunctional dysphagia is present only in the severe phase. Aspects such as the delay in the swallowing reflex activity and problems that interfere in the feeding skill, such as positioning and the inability to self-feed were observed.

There was a negative correlation between of mental state and behavior with the other scales, of swallowing severity and consciousness level. This can be attributed to the fact that the individuals with an altered state of alert presented food stasis in the oral cavity and difficulty in the swallowing reflex activity, thereby favoring aspiration of same.

The issues related to food, drink and swallowing, escape of saliva or food in the mouth correlated positively with swallowing compromise severity. Hyper-salivation and inadequate control of food in the oral cavity has been recognized as indicators of bronchoaspiration risk<sup>16</sup>. A positive correlation was also found between the spontaneous opening of the mouth during the offering of food and communication. The dimension of the spontaneous oral opening depends on the recognition of the situation and clue integration (gnosias and praxias) common as much to primitive motor acts as to elaborate ones, such as speaking. The association between leaving a good part of a meal on the plate and dysphagia severity indicate that difficulties related to swallowing interfere in food acceptance.

A positive correlation was found between feeding situation and skills particularly, the distraction with utensils during a meal and dysphagia severity. Attention is seen as

an important cognitive aspect which contributes to the adequate duration of the oral phase of swallowing<sup>17</sup>.

Regarding the mean total obtained in the AFSDD domains, the CDR2 group presented problems in the sensory impairment and dentition section more frequently, which justifies the presence of difficulties with chewing and swallowing determinate consistencies. The CDR3 group presented problems more frequently related to mental state and behavior, situation of feeding and skills and issues related to food, drink and swallowing. Studies with feeding and swallowing questionnaires indicate that the most significant questions are related to the oral phase, independent of dementia severity<sup>18</sup>. It was possible to verify that the problems observed in sensory impairment and dentition in level 2 of CDR begin to interfere in the skills of feeding and swallowing, but they are aggravated in level 3. When swallowing is still functional (CDR2) it is understood that the caregivers have a greater perception of sensorial alterations and of teething.

Our study pointed out problems of feeding and swallowing present in the moderate as well as the severe phases, such as passivity, distraction, food refusal, difficulty to chew/swallow; with the evolution of AD, inappropriate velocity and the difficulty in feeding oneself are also present.

From this, we can verify that in advanced AD the problems of feeding and swallowing arise from the sensory-motor factors associated to cognitive alterations such as attention, memory, language, executive function and apraxia. The clinical evaluation, beginning from the point-of-view of the caregivers and speech-therapists, unveil the need for information, education and support for the caregivers, in order that they can guarantee adequate and safe feeding to the patients.

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