

QUALITY OF LIFE IN DYSPHAGIA IN PARKINSON'S DISEASE: A SYSTEMATIC REVIEW

Qualidade de vida em disfagia na doença de Parkinson: uma revisão sistemática

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ABSTRACT

Parkinson's disease can cause problems with swallowing at any stage of the disease because of movement dysfunctions. Despite various symptoms, normally the initial swallowing alterations associated with Parkinson's Disease go undiagnosed and can damage quality of life. However, instruments for assessing the effects of quality of life in dysphagia are yet to be studied systematically. The objective of this systematic review was to analyze the adequacy of the Dysphagia's Quality of Life questionnaire in assessing Parkinson's disease. Articles examining both men and women were included, whereas those assessing treatment or that examined patients with Parkinsonism, or another form of disease, were excluded. Thirty articles were included after searches through Bireme, Pubmed and Capes' Databank of Theses. The Jadad Scale was used to assess them, with some modifications. Both articles showed that the Dysphagia's Quality of Life questionnaire is a secure and relevant instrument for assessing Parkinsonian swallowing alterations, except during sleep. Besides, it can indicate a general quality of life understanding. Thus, the use of the questionnaire helped assess quality of life in dysphagia in Parkinson's disease subjects.

KEYWORDS: Parkinson Disease; Quality of Life; Deglutition; Deglutition Disorders; Scales

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■ INTRODUCTION

Parkinson's Disease (PD) can lead to problems with swallowing in between 31%-100% of individuals, at any time during disease^{1,2} progression. Normally, the disturbance is linked with bulbar structure dysfunction affecting movements, with possible tongue tremor, food bolus flow weakening, prolonged time during bolus transit, delayed swallowing reflex, poor palate elevation, weakening of epiglottis motility, regurgitation, tracheal penetration and aspiration^{1,3}.

Aspiration pneumonia is considered the main disturbance that provokes morbidity and mortality in PD³. But, other pulmonary and nutritional complications are also responsible for morbidity-mortality^{4,5}. A description of this was presented by James Parkinson in 1817, revealing a typical case of one patient, who suffered from a severe feeding difficulty

with both solid and liquid food and was only able to eat a pasty diet and consequently lost weight⁶.

Despite all these clinical symptoms, a parkinsonian individual's initial alterations in swallowing – also called dysphagia – are normally undetected. By the time the patient starts worrying about swallowing difficulties, frequently dysphagia is already in an advanced stage^{6,7}, with a functional decline able to critically damage quality of life (QL).

Thus, an early swallowing functioning assessment in PD is necessary, as well as measuring its impact on quality of life, to promote better results from the use of therapeutic resources and optimize treatment^{8,9}.

Some swallowing assessment methods for PD exist in the literature, like videofluoroscopy, endoscopy, ultrasonography, manometry, electromyography, scintigraphy and surface electromyography^{10,11}. However, none of them can determine if swallowing dysfunctions impact the quality of life of parkinsonian individuals. Therefore, our objective in this systematic review was to determine if the Swallowing Quality of Life questionnaire (SWAL-QOL) is appropriate for assessing swallowing in an individual with Parkinson's Disease.

■ METHOD

This systematic review results from the need to investigate the usefulness of applying the Swallowing Quality of Life Questionnaire (*Quality of Life in Swallowing Disorders* – SWAL-QOL) in subjects with Parkinson's Disease, with the main question being: is the Swallowing Quality of Life Questionnaire (SWAL-QOL) an adequate instrument for assessing swallowing in subject with Parkinson's Disease?

SWAL-QOL data were considered main result in assessing swallowing quality of life in Parkinson's disease. Three researchers developed the study, two of which (DC and MGWS) initially searched for data randomly and independently. The third (OGL), considered a reviewer, was consulted in cases of discrepancy to set agreement in ideas. First, data

collection forms were standardized and elaborated for the research.

A research protocol closely followed by researchers was developed. Articles with humans, both male and female adults and senior citizens, were inclusion criteria. Those having people with parkinsonian syndromes were excluded. The search was conducted between January-February 2010. There was no restriction as to language, publication year or study design, as descriptors were chosen based on the DeCS/MeSH list.

The followings descriptors were from DeCS list: Parkinson Disease, Quality of Life, Deglutition, Dysphagia. And from MeSH: Parkinson Disease, Quality of Life, Swallowing, Deglutition, Deglutition disorders.

Keywords other than DeCS/MeSH descriptors found in articles from the search, non-existent in reference lists, were also used and helped in extending the search (Parkinson's, Parkinson, Parkinsonian, Swallowing, Swallow, Dysphagia). Selected article references were analyzed to find other studies possibly excluded during electronic search.

A comprehensive strategy was used in this research, involving determinations made prior to consultation and the use of more than one portal and several databases, including those unpublished like theses and dissertations.

The portals Bireme (Medline, Lilacs, Ibecs, Scielo, Cochrane Library, among others from this source), Pubmed and Capes theses databank were used during research. The research strategy followed instructions given by Castro *et al*¹¹, Dickersin, *et al*¹² and Cochrane Collaboration.

All collected articles were organized into tables and assessed for included or excluded condition, according to the eligibility criteria. For evaluation of the items included applied to Jadad scale, with modification, where each generates a positive response point in the scale, which results in the evaluation of points 0-5 (Table 1).

The statistical tests used in the included studies are described in Table 2.

Table 1 – Modified Jadad Scale for assessment of included studies

Questions	Grading	
	Plowman-Prine, 2009.	Leow, 2009.
1. The study was described as randomized?	1	1
2. The randomization was described and is adequate?	1	1
3. They were comparisons and results?	1	1
4. Comparisons and results were described and are adequate?	1	1
5. Losses and exclusions were described?	0	1
Total	3 points	5 points

■ REVIEW OF LITERATURE

When applying item 4 (Figure 1) in the research 30 Pubmed and 13 Bireme potentially relevant articles were found and saved for analysis. Of these, all the latter were repeated in the result obtained searching Pubmed, thus 30 articles remained for analysis. A total of 28 articles fell short of the inclusion criteria

and were excluded. Only the remaining 2 had their references analyzed with no other inclusions (Figure 2).

The selected articles were: Plowman-Prine EK, *et al*³; and, Leow LP, *et al*⁴. The characteristics of both studies included in this systematic review are presented in Table 2.

1. (*Parkinson's or Parkinson or Parkinsonian*)
2. (**Quality of Life**)
3. (*Swallowing or Swallow or **Deglutition or Deglutition Disorders or Dysphagia***)
4. #1 and #2 and #3

In bold, descriptors from DeCS/MeSH list

Figure 1 – Expressions used for the search

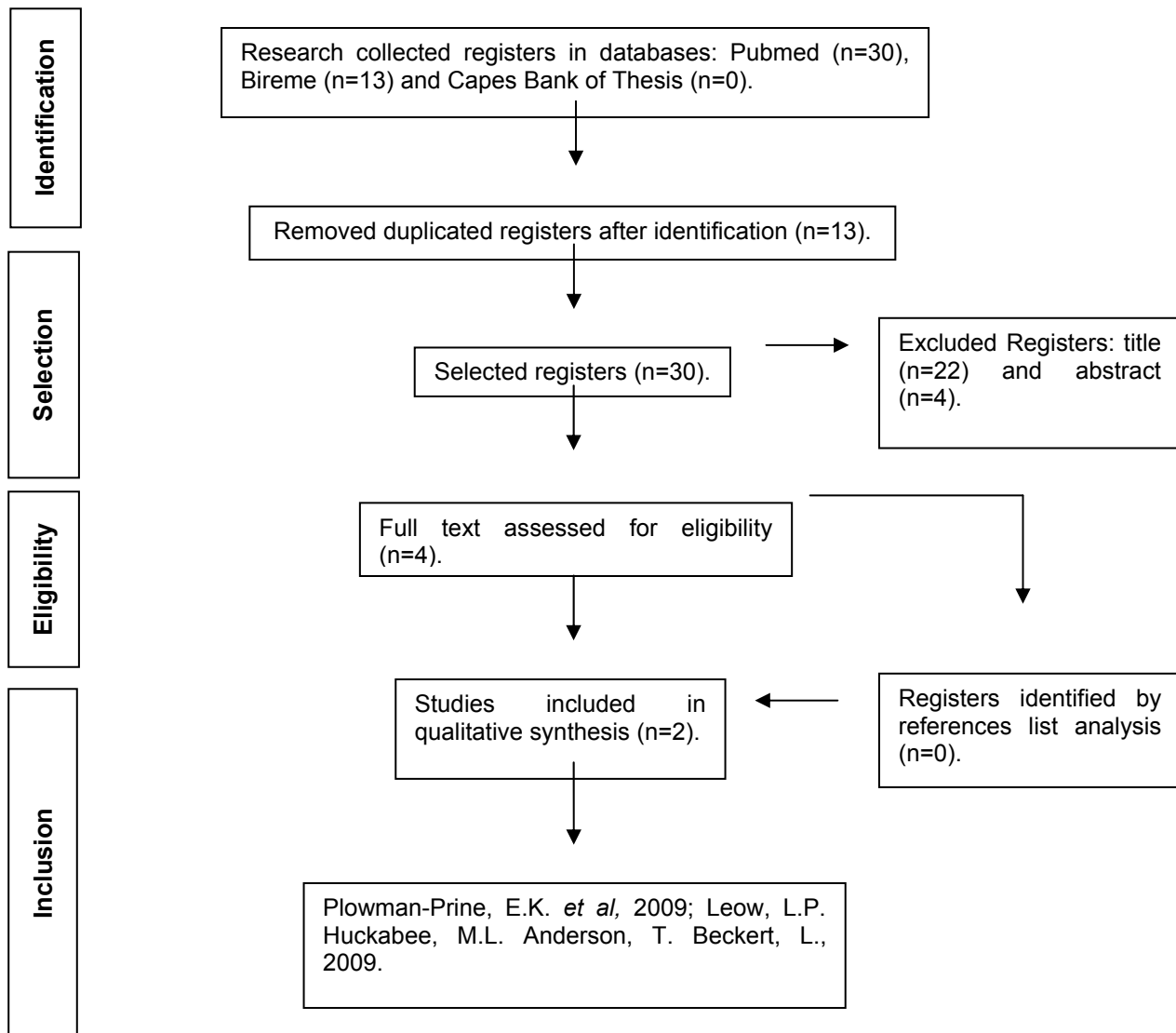


Figure 2 – Search and studies selection of a systematic review following Cochrane Collaboration

A total of 68 individuals with idiopathic PD, an average age of 67 and without gender distinction were chosen. The study by Leow LP, *et al* (2009) was the only one with a control group of 16 healthy elderly patients with an average age of 73 years, with 8 of them male.

All studies used both the Hoehn & Yahr Scale to check disease stage, and the SWAL-QOL questionnaire to assess quality of life in deglutition. The study by Plowman-Prine EK, *et al* (2009) was the only one that accompanied patients with Parkinson's disease over a period of years and used other instruments, like the Parkinson's disease-39 Questionnaire (PDQ-39), the Unified **Parkinson's Disease** Rating Scale (**UPDRS**) and the Beck Depression Inventory (BDI).

In the study by Plowman-Prine EK, *et al* (2009), (Table 3), 36 parkinsonians were assessed and classified as either dysphagic (9 individuals) or non-dysphagic (27 individuals) for statistical analysis. This classification was determined following SWAL-QOL questions 11 and 12 that checked the consistency of both liquids and solids swallowed, and from a diagnosis based on history and clinical exam that verified the integrity of movements of lips, tongue, pharynx and larynx.

The dysphagic group received lower scores in all SWAL-QOL domains, except Sleep, and had average scores equivalent in all groups for Feeding Desire. There were major differences between both dysphagic and non-dysphagic groups regarding Mental Health and Social Function¹³.

Table 2 – Characteristics of 2 articles included in systematic review

First author and year of publication	Plowman-Prine, 2009.	Leow, 2009.
Study Design	-----	Prospective, cross-cut.
Study's Objectives	Assess quality of life in swallowing in IPD; link IPD, duration and seriousness with SWAL-QOL questionnaire; check relations between quality of life in swallowing, with general quality of life and depression.	Assess dysphagia impact in quality of life with ageing and individuals with PD, using SWAL-QOL questionnaire.
Population, Age and/or PD duration	36 PD; 43 to 85 years old; 1 to 28 years of PD duration.	16 healthy young adults (8 men; average age 25 years old); 16 healthy senior citizens (8 men, average age 73 years old); and, 32 PD (average age 68 years old).
Instruments	HY, SWAL-QOL, PDQ-39, UPDRS and BDI.	HY and SWAL-QOL.
Comparisons Made	Between non dysphagic and dysphagic parkinsonians: 1- Total SWAL-QOL and domains (only significant in Mental Health domain and Social Function); 2- Total SWAL-QOL and PDQ-39 (significant negative correlation); 3- Total SWAL-QOL and HY (insignificant correlation); 4- Total SWAL-QOL I and PD duration (insignificant correlation); 5- Total SWAL-QOL and UPDRS (insignificant correlation); 6- Total SWAL-QOL and BDI (significant negative correlation).	1- Between Young adults and healthy senior citizens (only significant in Symptoms Frequency domain). 2- Between healthy senior citizens and parkinsonians (significant in all domains, but Sleep). 3- Between parkinsonians in early and late stage (only significant in Food Selection, Feeding Duration and Feeding Desire domains).
Statistical Analysis	1- U Test Mann-Whitney: SWAL-QOL and total domains. 2- Spearman correlation analysis: SWAL-QOL and total PDQ-39; SWAL-QOL and total HY; SWAL-QOL and total duration of PD; SWAL-QOL and total UPDRS on and, SWAL-QOL and total BDI.	1- T test: in comparisons between young and older adults healthy, healthy elderly parkinsonian and parkinsonian patients in early and late stage. 2- Levene test: for equality variance calculated for all groups t tests.
Modified Jadad Scale Grading	3 points	5 points

Legend: PD – Parkinson Disease; IPD – idiopathic Parkinson's Disease; SWAL-QOL – Quality of Life in Swallowing Disorders; HY – Hoehn & Yahr; PDQ-39 – Parkinson's Disease Questionnaire-39; UPDRS – Unified Parkinson's Disease Rating Scale; BDI – Beck Depression Inventory.

Table 3 – Plowman-Prine (2009) SWAL-QOL article results

	PD Non-dysphagic Mean±SD	PD Dysphagic Mean±SD	<i>p</i>	PD General Mean-SD
Burden	67 ± 24	43 ± 19	0.019	62 ± 25
Eating duration	65 ± 29	45 ± 35	0.134	61 ± 31
Eating desire	77 ± 27	73 ± 31	0.483	76 ± 27
Symptom frequency	63 ± 15	49 ± 16	0.087	60 ± 31
Food selection	71 ± 28	56 ± 20	0.141	67 ± 27
Communication	54 ± 32	44 ± 30	0.360	52 ± 32
Fear	70 ± 21	52 ± 26	0.220	65 ± 23
Mental health	70 ± 24	33 ± 24	0.002*	61 ± 28
Social functioning	75 ± 23	41 ± 21	0.002*	68 ± 27
Sleep	58 ± 31	67 ± 31	0.419	60 ± 26
Fatigue	48 ± 26	45 ± 28	0.804	47 ± 26
Total Grading	NP	NP	NP	NP

Legend: PD – Parkinson Disease; NP – not presented. *Significant difference between dysphagic and non-dysphagic groups after multiple test adjustment. Results numbers were rounded to facilitate visualization.

No significant connection existed between PD duration and SWAL –QOL total score ($r_s = -0.02$, $P = 0.93$); disease stage (Hoehn and Yahr) and SWAL-QOL total score ($r_s = -0.10$, $P = 0.59$); or UPDRS specific deglutition item and SWAL-QOL total score ($r_s = -0.12$, $P = 0.50$)¹³.

A major negative correlation between both PDQ-39 total score and SWA-QOL ($r_s = -0.56$, $P = 0.000$) was found when analyzing general quality of life and quality of life in swallowing. Thus, a correlation analysis with multiple test adjustment was performed between SWAL-QOL domains and general quality of life (Fatigue, $r_s = -0.57$, $P = 0.000$; Food selection, $r_s = -0.52$, $P = 0.001$; Social Function, $r_s = -0.51$, $P = 0.002$; and, Communication, $r_s = -0.48$, $P = 0.004$)¹³. Next, the relationship between both quality of life in deglutition and depression was assessed, finding a significant negative correlation between SWAL-QOL and BDI ($r_s = -0.48$, $P = 0.003$)¹³.

The study by Leow LP, *et al* (2009), (Table 4) had already compared and analyzed total score and domains of individuals with PD SWAL-QOL against a control group made of healthy senior citizens. Furthermore, it analyzed the total score and SWAL-QOL domains of 32 parkinsonians divided into two groups of 16 subjects, with determined disease stage (\leq stage 2, early stage, and \geq stage 2.5, final stage), (Table 5).

In the first comparison, between parkinsonians and the control group, there were significant differences in the scores for all SWAL-QOL domains, except Sleep. In the second between both groups

with PD, there were significant differences in the scores for domains about Food Selection, Feeding Desire and Food Duration, as well as in the SWAL-QOL¹⁴ general score.

Plowman-Prine EK, *et al* (2009) concluded their study with the hypothesis that quality of life in deglutition, is closely related to general quality of life of health (PDQ-39), mainly in specific domains like Food Selection, Social Function, Communication and Fatigue. Additionally, these authors mentioned that the score found in SWAL-QOL can reveal the understanding of the general quality of life in parkinsonians.

Plowman-Prine EK, *et al* (2009) mention that the literature is highly focused on physiological aspects of swallowing in PD, while the SWAL-QOL questionnaire turned out to be both a relevant and efficient instrument to be considered by clinic professionals during dysphagia manifestations, mainly for understanding the psychosocial functioning of individuals with PD. Our results also point out the necessity for both neurologists and phono-audiologists to closely work with mental health professionals in the treatment of parkinsonians with dysphagia.

These results point out the need for specialized rehabilitation to use treatment strategies that maximize social functioning, minimize the burden on the patient and improve mental health¹³.

As Plowman-Prine EK, *et al* (2009) conducted a retrospective study with a convenient sample, their data do not provide investigation elements for the psychosocial impact of dysphagia in the general population.

Table 4 – Leow (2009) SWAL-QOL article results – Control group and PD

	Control	PD	p
Burden	98 ± 6	72 ± 20	0.001*
Eating duration	94 ± 14	71 ± 27	0.005*
Eating desire	99 ± 3	87 ± 14	0.01*
Symptom frequency	91 ± 10	70 ± 17	0.001*
Food selection	98 ± 7	77 ± 21	0.002*
Communication	93 ± 14	71 ± 19	0.004*
Fear	98 ± 8	83 ± 15	0.007*
Mental health	100	76 ± 18	0.001*
Social functioning	100	76 ± 26	0.002*
Sleep	81 ± 25	77 ± 21	0.65
Fatigue	87 ± 14	63 ± 17	0.002*
Total Grading	94 ± 6	75 ± 13	0.001*

Legend: PD – Parkinson Disease. *Significance of $P \leq 0.05$ determined by *t* test independent sample. Results numbers were rounded to facilitate visualization.

Table 5 – Leow (2009) SWAL-QOL article results – Groups with PD

	PD Early Stage (≤ stage 2)	PD Late Stage (≥ stage 2.5)	p
Burden	86 ± 16	76 ± 20	0.122
Eating duration	82 ± 16	59 ± 28	0.010*
Eating desire	96 ± 8	86 ± 15	0.037*
Symptom frequency	81 ± 13	70 ± 19	0.072
Food selection	92 ± 14	78 ± 16	0.014*
Communication	74 ± 29	67 ± 23	0.448
Fear	89 ± 12	82 ± 16	0.173
Mental health	88 ± 15	77 ± 20	0.087
Social functioning	87 ± 14	78 ± 28	0.251
Sleep	76 ± 23	66 ± 22	0.204
Fatigue	69 ± 22	59 ± 18	0.181
Total Grading	84 ± 11	73 ± 14	0.018*

Legend: PD – Parkinson Disease; Early Stage – Hoehn & Yahr ≤ stage 2; Late Stage – Hoehn & Yahr ≥ stage 2.5. *Significance of $P \leq 0.05$ determined by *t* test independent sample. Results numbers were rounded to facilitate visualization.

Conclusions by Leow LP, *et al* (2009) suggest that because parkinsonians received reduced grades in all domains, but sleep, dysphagia is serious and capable of reducing quality of life significantly. They also point out that not all SWAL-QOL domains are related to PD seriousness. Finally, they suggest that the decrease in Food Desire, linked with both difficulties in Foods Selection and extended time to feed have major implications for maintaining parkinsonians nutritional state, especially those in a more advanced stages.

Though the protocol of this systematic review did not exclude works without a control group for data

analysis, only the study by Plowman-Prine EK, *et al* (2009) eliminated that type of sample, developing its data comparison between distinct parkinsonians groups with or without dysphagia. It remained clear in all works that samples were obtained by convenience, which can result in a biased selection.

The study design was only presented in the research by Leow LP, *et al* (2009), indicating the study was prospective and transversal. Meanwhile, eligibility criteria were shown in both works.

None of the studies described the sex of individuals with PD, nor mentioned whether data between sexes were insignificant, which would

justify its absence. Yet, the age parameter was revealed in both works.

The research by Plowman-Prine EK, *et al* (2009) was the only one to consider PD duration (in years), whereas the disease severity was analyzed in all studies using the Hoehn & Yahr Scale. But, no work showed which version of this instrument was used, important since both an original and a modified^{15,16} version exist.

The work by Plowman-Prine EK, *et al* (2009) was the only one to disclose the measurement values of the instruments applied, even of SWAL-QOL. Yet, it described the instrument composition as having 10 domains (weight, time to feed, desire to feed, food selection, communication, fear, mental health, social function, sleep and fatigue) and included the measuring result and other work selections in its results table (table 2 of original article) with 11 domains, but does not display the SWAL-QOL total score for any of the studied groups (dysphagic and non-dysphagic).

In the original version of the SWAL-QOL validation, created by MacHorney CA, *et al* (2002)¹⁷, the 11 domains are well presented, which confirm any content analyzed in the study by Leow LP, *et al* (2009). Our work discloses the total average scores for SWAL-QOL for all groups.

During the application of the SWAL-QOL questionnaire, Plowman-Prine EK, *et al* (2009) used data from questions 11 and 12 as one of the requirements for classifying parkinsonians as with or without dysphagia, because the questions were elaborated to identify food consistency. The group without dysphagia showed no restriction in swallowing solids and liquids, whereas the one with dysphagia needed restricted diet (answering questions with items "b", "c", and "d"), feeding with heavy liquids, tender foods easy to chew and pasty foods.

These characteristics are associated with studies which show that bolus consistency can also interfere with swallowing by PD individual, as more consistent food needs better oral manipulation and because of alterations during swallowing by parkinsonians can cause an increase in both oral transition and the pharynx, thus increasing the risk of penetration and aspiration in the swallowing of less consistent foods¹⁸⁻²⁰.

The lower score obtained by individuals with PD in all SWAL-QOL domains, but Sleep, was a common datum found in both works, as opposed to other analyzed groups without dysphagia¹³ and senior citizens¹⁴. These findings positively confirm that dysphagia in PD has high incidence, close to 31%-100%, and harms the quality of life in parkinsonians²¹.

The study by Plowman-Prine EK, *et al* (2009) found significant results in only two SWAL-QOL domains (Mental Health and Social Function). This must have happened because of the sample used, as the analysis was made between 2 groups of parkinsonians that only differed by the presence or absence of dysphagia.

When the analysis was performed in two distinct groups, one with PD and the other without, as in the work by Leow LP, *et al* (2009), there were significant results in all domains, except Sleep. And when the authors checked data between parkinsonian groups, varying by disease stages (\leq stage 2 and \geq stage 2.5), significance is found in only two domains (Feeding Desire and Food Selection) and the SWAL-QOL total score. Thus, it can be deduced that analysis between disparate groups raised the probability of finding significant differences in the data.

That methodological difference in the separation of specific groups between authors has repercussions in the analysis of results obtained from parkinsonians, as Plowman-Prine EK, *et al* (2009) found significance in Mental Health and Social Function, and Leow LP, *et al* (2009) in Feeding Desire, Feeding Duration and Food Selection.

The criteria for separating analyzed groups was comprehensive enough in both studies, probably if the authors had had a bigger sample and used the original classification of the Hoehn & Yahr Scale¹⁵ to divide groups additional significant results could have been found in the SWAL-QOL domains.

Regarding both general clinical exacerbation and PD development, some authors say that these characteristics can trigger cognitive, behavioral, social and economic adjustments, as these alterations are linked with decreases in quality of life^{22,23,24,25}. Based upon that, Plowman-Prine EK, *et al* (2009) claim that their study shows a strong relation between quality of life in swallowing with a general QL in health, which presupposes that during QL assessment in parkinsonian deglutition, there could be found a lower general QL in this individual.

■ CONCLUSION

This systematic review indicates that studies assessing parkinsonian individuals' quality of life in swallowing using the SWAL-QOL questionnaire are still scarce. It remained clear, based on works included here, that its usage is more efficient when assessing general score result, and comparing the presence or absence of PD. Only a few of its domains were relevant to other conditions.

Using SWA-QOL with parkinsonians can provide the health professional with relevant information about swallowing and other manifestations going along with the decline of this function, which allows delineation of appropriate assistance.

Finally, it is necessary to have more studies using the SWAL-QOL questionnaire when assessing individuals with PD for a quality of life diagnosis

in swallowing and its variables, considered by instrument domains. Moreover, it is necessary to expand the SWAL-QOL correlation analysis with duration (time) and disease development (stages, Hoehn & Yahr), in order to be able to take this evidence into account when adjusting treatment design.

RESUMO

A doença de Parkinson pode causar distúrbios da deglutição em qualquer fase da doença devido às disfunções dos movimentos. Apesar da diversidade de sintomas, normalmente as alterações iniciais na deglutição do parkinsoniano são despercebidas e podem ocasionar prejuízo na qualidade de vida. Contudo, instrumentos que avaliam a qualidade de vida em disfagia na doença de Parkinson não têm sido sistematicamente estudados. Esta revisão sistemática objetivou identificar a utilização do questionário de Qualidade de Vida em Disfagia para avaliação na doença de Parkinson. Foram incluídos artigos com sujeitos de ambos os sexos e com doença de Parkinson idiopática, e excluídos os artigos de avaliação de tratamento e que apresentaram indivíduos com outra forma de parkinsonismo. Após a busca realizada nos portais da Bireme, Pubmed e Banco de Teses da Capes, foram analisados 30 artigos, dos quais dois foram incluídos depois da aplicação da Escala de Jadad modificada. Os dois artigos evidenciaram que o questionário de Qualidade de Vida em Disfagia é um instrumento seguro e relevante para avaliar alterações da deglutição do parkinsoniano nos domínios do instrumento, exceto no sono. Além disso, o questionário pode indicar uma compreensão da qualidade de vida geral. Sendo assim, a utilização do questionário de Qualidade de Vida em Disfagia contribuiu para avaliação da qualidade de vida em disfagia de sujeitos com doença de Parkinson.

DESCRITORES: Doença de Parkinson; Qualidade de Vida; Deglutição; Transtornos da Deglutição; Escalas

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