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ORIGINAL ARTICLE

The Impact of Dysphagia on Quality of Life in Ageing and Parkinson's Disease as Measured by the Swallowing Quality of Life (SWAL-QOL) Questionnaire

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Abstract This prospective, cross-sectional study evaluated the impact of dysphagia on quality of life in healthy ageing and in subjects with Parkinson's disease (PD) using the Swallowing Quality of Life (SWAL-QOL) questionnaire. Sixteen healthy young adults (8 males, mean age = 25.1 years) and 16 healthy elders (8 males, mean age = 72.8 years) were recruited. Thirty-two subjects with idiopathic PD (mean age = 68.5 years) were recruited from a movement disorders clinic. The severity of PD was staged using the Hoehn and Yahr scale. Results revealed that elders experienced symptoms of dysphagia more frequently than young adults but the overall SWAL-QOL scores were not significantly different. Subjects with PD who experienced dysphagia reported greatly reduced QOL, and significant differences were found in all but one subsection of the SWAL-QOL. Disease progression detrimentally impacts QOL, with subjects in later-stage PD experiencing further reduction in the desire to eat, difficulty with food selection, and prolonged eating duration. These features, which increase with disease severity, are likely to impact negatively upon nutritional status, which is already under threat from PD-related dysphagia.

Keywords Quality of life · Ageing · Parkinson's disease · Deglutition · Deglutition disorders

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Symptoms of dysphagia occur in up to 63% of healthy elders [1]. Detailed interviews with 360 elderly persons in nursing homes revealed that even though 84% felt that eating should be a pleasurable experience, only 45% found that to be true. Forty-one percent of residents admitted to feelings of panic and anxiety during mealtimes, with 35% avoiding meals in the presence of company because of dysphagia [2]. In addition to social isolation, depression may result from having to live with the consequences of dysphagia [3]. These social and psychological consequences of dysphagia are underresearched despite reports that social isolation associated with dysphagia can have a profound impact on a person's quality of life (QOL) [2–6].

Dysphagia is also a common consequence of Parkinson's disease (PD), with coughing, choking episodes, and globus sensation being reported in up to 100% of persons with PD in the later stages [7]. Prior research has also shown that elders [8] and persons with PD [9] who experience dysphagia have decreased quality of life (QOL). Social isolation and depression are also commonly reported in PD [10, 11]. Although quality of life related to dysphagia has been investigated, these studies have either combined several medical diagnoses [1], used subjective evaluations of dysphagia [12], and/or administered

questionnaires that assess overall QOL without specific regard for swallowing impairment [8, 9, 13]. As such, health-related QOL in PD using generic measures that are biased toward physical signs are unable to fully investigate the independent effect of dysphagia on QOL. Furthermore, most studies have not included matched controls to healthy persons. Although QOL may be reduced in elders with dysphagia [8], there is insufficient evidence that QOL decreases in healthy elders without dysphagia. Nonetheless, it would be important to rule out any influences of healthy ageing and look for presymptomatic signs that may alert health care professionals to future problems.

The purpose of this study was to assess the impact of dysphagia on quality of life in ageing and PD using the Swallowing Quality of Life (SWAL-QOL) questionnaire, a 44-item, validated questionnaire [14]. Disease severity has been associated with further decrease in general QOL [9] and an increase in dysphagia symptoms [15], so we anticipated that this would be reflected as a decrease in SWAL-QOL scores compared to healthy elder controls.

Methods

Subject Demographics

Following approval from the regional Health Ethics Committee, a total of 68 subjects were recruited to the study. Using an a priori α of 0.05 and power of 80%, 16 subjects in each patient group and 16 age-healthy elder controls were required to detect an effect size of 1.0 or greater. Subjects with the diagnosis of idiopathic Parkinson's disease (mean age = 68.5 years, range = 45.8-82.5 years) were recruited by advertisement from a movement disorders clinic. The subjects were staged using the Hoehn and Yahr (H-Y) scale [16], with 16 subjects being "early PD" (H-Y $\leq$ stage 2) and 16 "later PD" (H-Y stage $\geq$ 2.5). None had a history of other neurological or movement disorders. Patient medication regimen was stable without changes in the month prior to participation in the study. In addition to the PD subjects, 16 healthy young adults (8 males, mean age = 25.1 years, range = 21.3-32.4 years) and 16 healthy elders (8 males, mean age = 72.8 years, range = 61.5–84.7 years) were recruited by advertisement. Exclusion criteria for all groups included the presence of significant central neurological disorders, pulmonary diseases, and head and/or neck injury or surgery. Potential subjects on antitussive medication for coughs, colds, and hay fever allergies were excluded, as were those with a current upper/lower respiratory tract infection. Subjects with a history of smoking must have ceased smoking at least 5 years prior to participating in this study.

Procedure

Subjects were invited to the research facility where they completed the SWAL-QOL in a quiet room. Translation services into the subject's native language were offered if required. There was no time limit imposed on subjects to complete the SWAL-QOL. PD subjects were invited to come into the research facility during the "on" time of their medication cycle.

Analysis

Analysis for this present study followed the outline described by McHorney et al. [17], the authors of the SWAL-QOL. McHorney et al. [18] constructed each scale using the Likert method. Briefly, in this method of summated ratings each item is equally weighted and summed into an overall scale score. This allowed each question to be linearly transformed to a 0–100 metric, with 100 indicating the most favorable state, 0 the least favorable, and scores in between representing the percentage of the total possible score achieved. The Likert method of scaling assumes that each item correlates substantially with the scale it is hypothesised to represent.

Independent-samples *t* tests were conducted to compare the subsection total and overall total scores obtained from the SWAL-QOL between healthy young adults and elders and between subjects with early PD (H-Y stage 2) and subjects with later PD (H-Y stage $\geq$ 2.5). Paired-samples *t* tests were conducted to compare the subsection total and overall total scores obtained from the SWAL-QOL between healthy elders who were age- and gender-matched to subjects with PD. Group (Young Adults, Elders, PD) was entered as independent variable. Scores for each subsection (Food selection, Burden, Mental Health, Social Functioning, Fear, Eating Duration, Eating Desire, Communication, Sleep, Fatigue, and Symptom Frequency) and overall total SWAL-QOL score were entered as dependent variables.

Levene's test for equality of variance was calculated for all groups in the *t* tests. If Levene's test was significant, i.e., the values for both groups were variable, adjusted *p* value and degrees of freedom (df) were used to compensate for any inequality of variance in the data set.

Results

Subjects were able to complete the SWAL-QOL without difficulty. All subjects spoke English as their first language, were literate in English, and were able to complete the SWAL-QOL without any assistance beyond minor clarifications by the researcher.

T tests revealed no significant differences in scores for young adults and elders for all subsets of the SWAL-QOL with the exception of symptom frequency; elders experienced significantly greater frequency of physical symptoms associated with swallowing difficulties compared to healthy, young adults. The means and standard deviations of all subsets and mean SWAL-QOL scores across all subsets for young adults and healthy elders are presented in Table 1.

Paired-samples *t* tests were conducted to compare the subsets of SWAL-QOL scales for healthy elders with those with PD. There were significant differences in scores for elders and those with PD for all subsets of the SWAL-QOL at $p < 0.05$, with the exception of Sleep. The means and standard deviations of all subsets and mean SWAL-QOL scores across all subsets for individuals with PD and age- and gender-matched healthy elders are presented in Table 2.

Independent-samples *t* tests were conducted to compare the subsets of SWAL-QOL scales between those with early PD and those with later PD. There were significant differences in scores for these two groups for Food Selection, Eating Duration, and Eating Desire. The means and standard deviations of all subsets and mean SWAL-QOL scores across all subsets for early-stage PD subjects and later-stage PD subjects are presented in Table 3.

Discussion

The impact of swallowing disorders on quality of life has not been adequately addressed as most available assessments and prior research have administered generic questionnaires, used subjective assessment of swallowing, and/or combined several diagnostic categories. In this study, a swallowing-specific questionnaire was used to investigate the impact of dysphagia on QOL. Further comparisons of healthy elder adults with healthy young adults were undertaken to examine the influence of ageing on QOL.

For most subsections of the SWAL-QOL, as hypothesised, age did not play a significant part in influencing QOL in healthy persons. A significant difference was detected in Symptom Frequency, whereby healthy elders experienced a significantly greater frequency of symptoms such as coughing, food sticking in the throat, and excess phlegm and saliva than their younger counterparts. Elders may consider coughing, problems chewing, and/or having to clear the throat natural processes of ageing and therefore not raise any concerns.

The main finding in this study is that QOL is significantly reduced in subjects with PD (Table 2). Subjects reported difficulty in selecting the food textures that they could safely eat. Subjects also had significantly greater difficulties in finding foods that they both liked and could manage safely. The most significant difference between healthy adults and subjects with PD was for the Burden that a swallowing difficulty carried. The burden of having dysphagia may affect Mental Health, a scale item for which there was a significant difference between elders and subjects.

No healthy elders expressed fear of socialising over a meal, whereas almost a quarter of the subjects reported that having a swallowing problem was detrimental to socialising. Taking a long time to eat may be part of the overall bradykinesia experienced by subjects with PD and this was reflected by reports of significantly longer eating durations. Consequently, this may have affected subjects' desire to eat, which was also significantly lower than their healthy counterparts. Feelings of weakness, tiredness, and exhaustion

Table 1 SWAL-QOL subsections and total SWAL-QOL for young adults and healthy elders

SWAL-QOL subsections	Young adults (percentage score for each subsection)		Healthy elders (percentage score for each subsection)		*P* value
	Mean	SD	Mean	SD	
Food selection	100	–	97.7	6.8	0.188
Burden	100	–	98.4	6.3	0.333
Mental health	100	–	99.7	1.3	0.333
Social functioning	100	–	100	–	–
Fear	100	–	98.1	7.8	0.333
Eating duration	98.4	4.3	94.5	13.7	0.290
Eating desire	99	4.2	99	2.8	0.996
Communication	100	–	93	14.4	0.070
Sleep	88.3	16.8	81.3	24.6	0.352
Fatigue	88	11.4	87	14.3	0.821
Symptom frequency	97	4.2	91	10.4	0.045*
Mean SWAL-QOL score across subsections	97.3	2.5	94.5	6.5	0.119

SD standard deviation

* Significant at $P \leq 0.05$ determined by independent-samples *t* test

Table 2 SWAL-QOL subsections and total SWAL-QOL score for PD subjects and age- and gender-matched healthy adults

SWAL-QOL subsections	Healthy elders (percentage score for each subsection)		PD subjects (percentage score for each subsection)		*P* value
	Mean	SD	Mean	SD	
Food selection	97.7	6.98	76.6	20.9	0.002*
Burden	98.4	6.3	71.9	20.2	0.001*
Mental health	99.7	1.3	76.3	18.5	0.001*
Social functioning	100	–	75.9	26.1	0.002*
Fear	98.1	7.8	83.2	15.1	0.007*
Eating duration	94.5	13.7	71.1	26.9	0.005*
Eating desire	99	2.8	87.5	14.3	0.01*
Communication	93	14.4	71.1	19.2	0.004*
Sleep	81.3	24.6	76.6	20.9	0.65
Fatigue	87	14.3	63.5	17.2	0.002*
Symptom frequency	91	10.4	70.4	17.3	0.001*
Mean SWAL-QOL score across subsections	94.5	6.5	74.9	12.8	0.001*

SD standard deviation

* Significant at $P \leq 0.05$ determined by paired-samples *t* test

Table 3 SWAL-QOL subsections and total SWAL-QOL for early-stage PD subjects and later-stage PD subjects

SWAL-QOL subsections	Early-stage PD[a] (percentage score for each subsection)		Later-stage PD[b] (percentage score for each subsection)		*P* value
	Mean	SD	Mean	SD	
Food selection	92.2	14.3	78.1	16.1	0.014*
Burden	85.9	16.4	75.8	19.6	0.122
Mental health	87.8	14.6	76.9	20.1	0.087
Social Functioning	86.9	14.1	77.8	27.6	0.251
Fear	89.5	12.4	82.4	15.8	0.173
Eating duration	82	16.4	59.4	28	0.010*
Eating desire	95.8	8.1	86.5	14.9	0.037*
Communication	74.2	28.7	67.2	22.8	0.448
Sleep	75.8	22.6	65.6	21.7	0.204
Fatigue	69.3	22.3	59.4	18.2	0.181
Symptom frequency	81	13.4	70.2	19	0.072
Mean SWAL-QOL score across subsections	83.7	10.8	72.7	14	0.018*

SD standard deviation

* Significant at $P \leq 0.05$ determined by independent samples *t* test

[a] Early-stage PD = Hoehn-Yahr $\leq$ stage 2

[b] Later-stage PD = Hoehn-Yahr $\geq$ stage 2.5

with trouble falling and/or staying asleep were also significantly increased in PD subjects.

Hobson et al. [9] reported that as disease severity progresses, subjects' QOL deteriorated further. This was true for our subjects but not across all subsets. Finding suitable foods was increasingly difficult and eating desire and eating duration were further reduced. It has been noted that subjects who require diet and texture modifications may accept or reject foods based on visual appearance [19]. This would suggest that very limited and/or unappealing food textures may ultimately affect eating desire. The ramifications of dysphagia and reduced desire to eat are broad. Recent research has shown that weight loss, motor symptoms, and recumbency increased in individuals with PD who avoid solid foods compared to their healthy counterparts [20]. As dysphagia is known to detrimentally affect nutritional status and dietary intake in subjects [8, 20], reduced desire to eat would only exacerbate this problem and would require the attention of health care professionals involved in the subject's care.

Whilst this study supported the hypothesis that dysphagia detrimentally affects QOL in PD, there are several areas that could be further researched. The relationship between QOL and swallowing in PD may also be influenced by depression in these patients. There is recent evidence to suggest a significant relationship between swallow-specific QOL and depression [21]. It was an assumption of this study that PD subjects with known history of depression have their symptoms adequately controlled by pharmacological means. Although potential subjects who were being treated for depression at the time of the study were excluded, no steps were taken to detect

undiagnosed or subclinical depression which may have influenced the results.

Finally, it is pointed out that original studies by McHorney et al. [17] included subjects with a variety of etiologies that were not specific to PD. As such, the interpretability in the PD population may be limited. It is recommended that future studies take into consideration the limitations outlined above.

Conclusion

Healthy ageing does not appear to affect swallowing QOL even though elders experience more symptomatic dysphagia. PD subjects had reduced scores across all SWAL-QOL subsets (except Sleep), suggesting that the consequence of having a swallowing difficulty was severe enough to significantly affect QOL. Not all subsets of the SWAL-QOL were related to PD severity. However, our observation of a reduction in eating desire, combined with significant difficulties in food selection and longer eating duration, has important implications for those concerned with maintenance of nutritional status in subjects with PD, especially those in the more advanced stages.

References

1. Ekberg O, Feinberg MJ. Altered swallowing function in elderly patients without dysphagia: radiologic findings in 56 cases. AJR Am J Roentgenol. 1991;156:1181–4.
2. Ekberg O, Hamdy S, Woisard V, Wuttge-Hannig A, Ortega P. Social and psychological burden of dysphagia: its impact on diagnosis and treatment. Dysphagia. 2002;17:139–46.
3. Langmore SE. Issues in the management of dysphagia. Folia Phoniatr Logop. 1999;51:220–30.
4. Jacobsson C, Axelsson K, Osterlind PO, Norberg A. How people with stroke and healthy older people experience the eating process. J Clin Nurs. 2000;9:255–64.
5. Gustafsson B. The experiential meaning of eating, handicap, adaptedness, and confirmation in living with esophageal dysphagia. Dysphagia. 1995;10:68–85.
6. Lai SM, Studenski S, Duncan PW, Perera S. Persisting consequences of stroke measured by the Stroke Impact Scale. Stroke. 2002;33:1840–4.
7. Tolep K, Kelsen SG. Effect of aging on respiratory skeletal muscles. Clin Chest Med. 1993;14:363–78.
8. de Luis DA, Izaola O, de Mateo ML, Cuellar L, Terroba MC, Aller R. Quality of life, dietary intake in elderly patients with dysphagia. Nutrition. 2006;22:584.
9. Hobson JP, Edwards NI, Meara RJ. The Parkinson's Disease Activities of Daily Living Scale: a new simple and brief subjective measure of disability in Parkinson's disease. Clin Rehabil. 2001;15:241–6.
10. Miller N, Noble E, Jones D, Burn D. Life with communication changes in Parkinson's disease. Age Ageing. 2006;35:235–9.
11. Playfer JR. Depression, cognition and quality of life in parkinsonian patients. Age Ageing. 1999;28:333–4.
12. Miller N, Noble E, Jones D, Burn D. Hard to swallow: dysphagia in Parkinson's disease. Age Ageing. 2006;35:614–8.
13. Slawek J, Derejko M, Lass P. Factors affecting the quality of life of patients with idiopathic Parkinson's disease—a cross-sectional study in outpatient clinic attendees. Parkinsonism Relat Disord. 2005;11:465–8.
14. McHorney CA, Robbins J, Lomax K, Rosenbek JC, Chignell K, Kramer AE, et al. The SWAL-QOL and SWAL-CARE outcomes tool for oropharyngeal dysphagia in adults: III. Documentation of reliability and validity. Dysphagia. 2002;17:97–114.
15. Coates C, Bakheit AM. Dysphagia in Parkinson's disease. Eur Neurol. 1997;38:49–52.
16. Hoehn MM, Yahr MD. Parkinsonism: onset, progression and mortality. Neurology. 1967;17:427–42.
17. McHorney CA, Bricker DE, Robbins J, Kramer AE, Rosenbek JC, Chignell KA. The SWAL-QOL outcomes tool for oropharyngeal dysphagia in adults: II. Item reduction and preliminary scaling. Dysphagia. 2000;15:122–33.
18. Likert R. A technique for the measurement of attitudes. Arch Psychol. 1932;140:5–55.
19. Huckabee ML, Pelletier CA. Oral nutrition interventions for dysphagia, management of adult neurogenic dysphagia. San Diego, CA: Singular Publishing Group; 1999.
20. Lorefalt B, Granerus AK, Unosson M. Avoidance of solid food in weight losing older patients with Parkinson's disease. J Clin Nurs. 2006;15:1404–12.
21. Plowman-Prine EK, Sapienza CM, Okun MS, Pollock SL, Jacobson C, Wu SS, et al. The relationship between quality of life and swallowing in Parkinson's disease. Mov Disord. 2009;24:1352–8.

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