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Perceived changes to swallowing in people with Parkinson's: a comparison with clinical measures, people without Parkinson's and perceptions of carers

Abstract

Purpose: We describe the relationship between perceived swallowing difficulties in people with Parkinson's and disease specific measures, carers' perceptions of swallowing problems and responses of control participants.

Method: 119 people with Parkinson's, their carers and matched controls answered a specifically prepared functional swallowing changes questionnaire. People with Parkinson's completed a water swallow test (WST). Motor status, cognition and mood were assessed.

Results: People with Parkinson's scored poorer than controls ($p < 0.001$) on the questionnaire. Those reporting swallowing problems scored poorer than those who did not ($p < 0.01$). However 74 people with Parkinson's who perceived no swallowing problem fell below cut-off scores on the WST; 41 fell below cut-off scores on the questionnaire. There was a weak correlation WST:questionnaire ($r = 0.276$). Carers' evaluations correlated with their partners' ($r = 0.796$). Carers perceived changes as less severe ($p < 0.03$).

Conclusions: Despite reduced swallowing efficiency some people with Parkinson's can successfully compensate. A sizeable proportion, however, remain unaware of swallowing problems when asked simply 'Do you have a problem?', but indicate difficulties with more specific questions. The present questionnaire provides a guide for gaining such insights for diagnosis, education and outcomes.

Keywords: Parkinson's; swallowing; dysphagia; self-reported; questionnaire

Background

Objective measures reveal changes in deglutition from the earliest stages of Parkinson's disease (Coriolano et al. 2012, Troche et al. 2011, Miller et al. 2009, Sung et al. 2010, Rodrigues et al. 2011, Kalf et al. 2012). The strong association of chest infection, hospital admission, mortality and chronic undernourishment (Nobrega et al. 2008, Monteiro et al. 2014) suggest dysphagia is a risk factor for poorer health and quality of life outcomes in Parkinson's. Dysphagia has been linked to sialorrhea and poorer oral health (Nobrega et al. 2008, Bakke et al. 2011). Swallowing changes, even when not life-threatening, can place a considerable social and psychological burden on the individual and their family (Plowman-Prine et al. 2009, Leow et al. 2010, Miller et al. 2006). Medical interventions in Parkinson's may have limited influence on swallowing (Melo and Monteiro 2013). Sutton (2013), though, pointed to flaws in Melo and Monteiro and argued that there is a case for positive effects of levodopa on some aspects of the swallowing process, although the question of longer term and functional outcomes remains open. In the case of surgery, effects may be none or even adverse (Troche et al. 2013). Nevertheless, straightforward advice and behavioural therapies directed at diet and modification of eating and drinking may bring significant improvements in health and quality of life (Miller and Patterson 2014). For these reasons it is important to ascertain the presence and degree of dysphagia in people with Parkinson's.

Even though instrumental assessments may detect changes from earliest stages in up to 100% of people with Parkinson's, typically, in slowly progressive conditions, the daily living impact of underlying changes may not be immediately apparent to those involved.

Conscious or unconscious compensation by individuals may further blur the picture. It is often only when the underlying deterioration reaches a critical stage or the onset or severity of a parallel symptom undermines compensation that a clear swallowing disorder becomes obvious to the patient and/or clinicians (Suntrup et al. 2013, Sung et al. 2010).

Consequently dysphagia may not initially be apparent at clinic or on 'bedside' assessments,

and individuals themselves may be unaware of a swallowing problem (Sung et al. 2010, Miller et al. 2009, Bayés-Rusiñol et al. 2011, Ding and Logemann 2008), or they attribute alterations to eating to other causes (Cheon et al. 2008). Hence asking the standard question, “Have you any swallowing problems?” may well elicit a negative answer. However asking questions relating to the everyday experience of mealtimes and eating might illuminate subtle changes in function in a long term, degenerative condition.

There has been an increasing interest in the use of patient reported outcome measurement (PROM) alongside objective clinical measures (Duncan et al. 2014, Plowman-Prine et al. 2009, Nisenzon et al. 2011, Silbergleit et al. 2012). PROM can enhance communication, especially about living with a long term condition, and support shared decision making about treatments and their effectiveness (Yorkston, Baylor, Amtmann (2014). Studies indicate that when PROM results are correlated with physiological bolus flow or other objective measures associations are modest or low, indicating their distinct contributions to information gathering (Leow et al. 2010, Miller et al 2006, Sung et al. 2010, Miller et al. 2009, Bayés-Rusiñol et al. 2011, Ding and Logemann 2008). This highlights the importance of combining objective measurement of dysphagia (e.g. water swallow tests, videofluoroscopy or endoscopic examination of swallowing) which assess, amongst other things, aspects of timing and presence or not of aspiration and penetration, with patient report of how they feel they manage with swallowing in an everyday functional context. This would help gain a more holistic picture of swallowing issues and insights in to the ways in which eating, drinking and social behaviours around meals might have altered.

This combination of assessment has received comparatively little attention in relation to swallowing and Parkinson's. The utility of combined clinical screening and rating of functional changes has been established (Clarke et al. 1998, Manor et al. 2007, Lam et al. 2007). Only Clarke et al. (1998) employed healthy comparators for their screening questions,

a notable omission from other studies given that swallowing efficiency declines naturally with age and neurologically unaffected older people may evidence swallowing difficulties (Serra-Prat et al. 2012, Miller and Patterson 2014, Roy et al. 2007, Nogueira and Reis 2013).

Comparison to carer ratings has been neglected. The latter may be of relevance in gauging carer perception and appreciation of possible problems with swallowing and relating this to issues in carer burden. It also would offer insights into how accurate it might be to rely on proxy ratings of swallowing changes by carers.

We aimed to examine changes to swallowing in people with Parkinson's as rated by themselves and their carers on a specifically developed questionnaire and investigate how these ratings related to a water swallow test and disease specific measures. We hypothesized that:

- people with Parkinson's would perform significantly differently to age matched control participants in their eating and drinking habits;
- that decline in eating habits would correlate significantly with measures of overall disease severity;
- but that self-awareness of a swallowing problem would correlate poorly with swallowing change scores and performance on a water swallow test given the poor awareness of swallow change.

Methods

Participants: Subjects from a community and hospital acquired cohort of patients with Parkinson's were invited to take part in the study in accordance with Great Britain National Health Service Research Ethics Committee approved procedures. These included stipulations that testing occur only after receipt of informed written consent from participants, there was opportunity for participants to reflect and seek independent advice before consent, and emphasized their right to withdraw consent at any stage without let or reason.

Individuals were included if they satisfied UK Parkinson's Disease Brain Bank criteria for Parkinson's (Hughes et al. 1992) and consented to participate in the study. People were excluded if they had an akinetic-rigid syndrome not due to Parkinson's; a history of acquired speech-language disorder or dysphagia prior to Parkinson's symptom onset; co-morbidity that could be associated with speech or swallowing changes, including denture/dental problems; or did not wish to join the study.

Assessment: For the physical assessments testing took place first thing in the morning, at home, with patients in a practically-defined off state – i.e. anti-parkinsonian therapy withheld and fasting since midnight – in order to obtain a direct comparison across subjects and clearer insight into the influence of underlying motor severity. Swallowing was assessed by a single research speech and language pathologist using a 150ml water swallow test (WST) (Nathadwarawala et al. 1992), from which a measure of swallowing speed (millilitres/second) is derived. For participants who did not complete the full 150ml, swallowing speed was prorated on the basis of time taken for the amount drunk. Motor status was judged using the Unified Parkinson's Disease Rating Scale (UPDRS) Activities of Daily Living and Motor Examination (Parts II and III) (Goetz et al. 2003) and Hoehn and Yahr Parkinson's stage rating (Hoehn and Yahr 1967). Depression and cognitive status were screened using the Geriatric Depression Scale (GDS) (Sheikh and Yesavage 1986) and cognitive Mini Mental State Examination (MMSE) (Folstein et al. 1975) respectively.

Participants with Parkinson's and their primary carers received a copy of a swallowing changes questionnaire (appendix 1) to complete in their own time for return in prepaid envelopes. Couples were requested to respond using their personal perception of the swallowing status of the person with Parkinson's without discussion between partners. It was emphasized both verbally and in written instructions that responses should relate exclusively to effects related to swallowing status and not any other changes associated with Parkinson's.

Development of questionnaire items

The questionnaire items were derived from interviews with people with Parkinson's, enquiring about changes they had perceived in eating and drinking because of their Parkinson's (Miller et al 2006). Questions were formulated based on this, as well as taking items from other questionnaires (Nathadwarawala et al. 1992, Clarke et al. 1998, Wallace et al. 2000) that had shown strong associations with swallowing difficulties and matched descriptions by people with Parkinson's regarding changes which they experienced. . The final set of items was reviewed by a subset of interview participants. They were asked to judge whether the questions addressed changes they themselves had experience or knew to have happened to other people with Parkinson's whom they knew. They were asked to indicate if there were issues they or others had experienced that were not covered by the items, and conversely if there were items enquiring about changes no one had experienced. Individuals who reviewed the questions were also asked to paraphrase what they believed the questions were asking, to check that this accorded with the intended meaning. All items were agreed to capture personal experiences; no items were removed or added. Wording was understood as intended. No rewording took place, but some examples were added to help remove possible doubt about definitions – e.g. soft vs hard foods (see appendix 1). The questionnaire represented a novel combination of items, even though some were highly similar to ones found in other batteries. Further, some other questionnaires regarding swallowing changes in Parkinson's have not included control participants, a serious omission given that swallowing behaviours may alter with age. Also, some previous questionnaires have been developed with general stroke or degenerative neurological groups rather than specifically with people with Parkinson's. For these reasons we also obtained normative data from people without Parkinson's in order to establish cut-off scores between changes associated with normal ageing versus due to Parkinson's for individual items and for total scores.

The volunteer control participants who completed the questionnaire were friends or family members of the people with Parkinson's, with no history of neurological illness or other conditions likely to impact on eating and drinking, including dental problems. They were recruited via participants with Parkinson's following the same Ethics Committee stipulations of informed voluntary consent with option to withdraw.

Data processing: Total scores for the questionnaire were derived from the sum of scores from items 'swallowing thin liquids' to 'less happy eating in public' inclusive (appendix 1), giving a maximum score of 28 (severe) and minimum 0 (no perceived problem). All items were scored as 0 (no problem/ never occurs) to 2 (always occurs/ severe problem) except the items on 'going down the wrong way (0 never to 4 every time I eat/drink) and attitude to eating in public (no problem to 4 very much less happy now). We set a cut-off for having a problem or not based on the total questionnaire score of control participants. A score of 4 or greater was taken, representing the 15th percentile or less for control totals. Based on results from the people with Parkinson's the questionnaire showed high internal consistency and reliability (Cronbach's alpha 0.862).

To gain insight into the relationship between perceived changes and swallowing efficiency measures we compared the WST scores of those who answered 'yes' they do have a problem swallowing with WST measures of those who felt they had 'no problem'. To examine the strength of association between questionnaire totals and WST outcomes we used correlational measures comparing ml/sec measures with questionnaire totals.

Data was tested for normality of distribution and equalness of variance. Generalized linear models were applied to parametric data whilst categorical analysis and nonparametric methods were applied to frequency and ordinal data. Significance level was set at $p \leq 0.05$.

Results

Sample

One hundred and seventy-six people with PD were invited to join the study. Of the 140 agreeing to participate, 137 carried out the 150ml water swallow test and received a copy of the swallowing questionnaire. All were feeding orally. One hundred and nineteen complete questionnaires were returned. Summary details of participants with Parkinson's appear in table 1.

Table 1 about here

Mann Whitney comparisons indicated no significant differences in disease duration (time since reported initial symptoms), age, Hoehn and Yahr stage nor UPDRS II and III scores between those who did or did not consent to participate. There were no significant differences in these variables, nor in MMSE, between those who completed the swallow test but did or did not return a questionnaire. Those who did not return copies were less depressed ($p=0.03$).

The 110 control subjects (female $n=67$) who completed the questionnaire had a mean age of 71.0 years, SD 7.5, range 60-90 years. There was no significant difference in age between those with and without Parkinson's.

Do people with Parkinson's differ from matched controls when reporting their swallowing behaviour?

People with Parkinson's had significantly higher (i.e. poorer) total scores (Mann Whitney $p<0.001$) than the control group (table 2) on the questionnaire. They gave significantly higher ratings for all items compared to control respondents - all $p<0.001$, except 'needing to specially prepare' ($p<0.01$) and 'food goes down the wrong way' ($p=0.03$). The latter was the only item rated by control participants with median 1 (IQR 0-1) rather than 0. There were no significant gender differences in either group on any items or total scores.

Table 2 about here

On the initial item on the questionnaire 45 (38%) people with Parkinson's stated they had a problem with swallowing, compared to 7 (6%) control participants. Forty-seven (39%) people with Parkinson's were bothered by their swallowing (penultimate question on form). It featured amongst the top three problems associated with their Parkinson's for 13 (11%). Six (5%) control individuals stated they were bothered by their swallowing. Twelve (10%) people with Parkinson's noted no changes in eating habits on any questionnaire items, compared to 26 (24%) control subjects.

Relationship between self-report of a swallowing problem and questionnaire reported swallowing behaviour

People with Parkinson's who stated they had a problem swallowing produced significantly poorer ratings on all items compared to those declaring no problem (Mann-Whitney, $p < 0.01$). Table 3 illustrates the proportions and percentage of people with Parkinson's who fell above or below this operational cut-off in relation to their response to the question 'Do you feel you have a problem with swallowing food and/or drink?' (question 1 on the questionnaire).

Table 3 about here

Eighty-two (69%) people with Parkinson's had indications of swallowing changes compared to 24 (22%) amongst the control group. Three people with Parkinson's indicated they did have a problem but their total score fell just above the cut-off. In the control group everyone who declared a problem scored below the cut-off. However, so did 18 further individuals (15% total group) who felt they had no problem, giving 25 (23%) control participants in all below the cut-off.

Relationship between glass of water swallowing test results and self-report of a swallowing problem and self-reported swallowing behaviour

Using the WST cut-offs for normal-non-normal in (Nathadwarawala et al. 1992) (i.e. <32.07 ml/sec males; <20.9 ml/sec females) all people with Parkinson's fell below in swallowing efficiency. People with Parkinson's achieved a median 6.42 ml/sec speed of drinking (IQR 3.45-11.96 ml/sec; full range 0.2-30.9 ml/sec). There was a significant difference in ml/sec between those reporting a swallowing problem or not (Mann-Whitney $p=0.01$). There was a significant but weak correlation between ml/sec drunk and questionnaire totals (Spearman's $r .276$, $p<0.01$).

Of the 74 people with Parkinson's who declared no problem, 32 (43%) fell below the median of the whole group with Parkinson's for ml/sec on the WST (representing 52% of all those who fell below the median). Fourteen (19%) who admitted no problem failed to complete the full 150ml, compared to 12 (27%) who did declare a problem. Twenty-one (28%) of those who felt they had no problem nevertheless fell >-2 SD below the mean values for control subjects or failed to complete 150ml, constituting 52.5% of all people with Parkinson's who fell >-2 SD below the control means.

Concerning which questionnaire items might differentiate slower from quicker swallowers, those who fell below the median ml/sec value for people with Parkinson's on the WST rated significantly poorer than those above on all items except for needing to 'specially prepare food', 'managing thick liquids' and 'taking longer to eat'. They were borderline different on 'keeping food in the mouth' ($p=0.058$) and being 'less happy in public' ($p=0.056$). Comparing those who fell >-2 SD or <-2 SD below control means, only 'food left in mouth' ($p=0.047$) and 'longer eating' ($p=0.051$) fell at or close to significance. Those who did not complete 150ml rated significantly poorer than those who did only on questionnaire items 'longer eating and drinking' ($p=0.03$) and 'less happy in public' ($p=0.04$).

Correspondence between ratings by people with Parkinson's and their carers

Sixty-four carers completed questionnaires. There was a strong correlation between carers' and partners' total scores ($r = .796$, $p < 0.001$). Carers, however, perceived changes (total raw scores median 4, IQR 1-12) as less severe ($p = 0.03$) than people with Parkinson's (median 8, IQR 3-16). In particular, individuals with Parkinson's felt more unhappy about eating in public ($p < 0.01$).

Relationship between questionnaire totals and Parkinson's status and other measures

There were statistically significant low to moderate associations of total questionnaire score with Hoehn and Yahr stage ($r = .225$, $p = 0.05$), swallowing speed ($r = .276$, $p < 0.05$), disease duration ($r = .320$, $p < 0.01$), UPDRS III total ($r = .348$, $p < 0.01$), depression rating ($r = .378$, $p < 0.01$) and UPDRS II total ($r = .577$, $p < 0.01$). The relationship between the questionnaire total and the UPDRS II swallowing item was $r = .360$, $p < 0.01$; for UPDRS III swallowing, salivation and facial expression sections the correlations were $r = .415$ ($p < 0.01$), $r = .220$ ($p = 0.02$) and $r = .093$ (NS) respectively. There were no significant correlations between questionnaire total scores and age or MMSE, although participants falling below the MMSE cut-off (< 23 ; $n = 33$; median 21, IQR 18-22) for cognitive decline rated more poorly than patients above the cut-off ($p = 0.01$). This cannot be taken here to unequivocally conclude that there is an association between perceived swallowing changes and cognitive status since the participants with lower MMSE scores were also significantly older and had worse UPDRS II and III and Hoehn and Yahr ratings. There was a significant ($r = .378$, $p < 0.001$) association between depression score (GDS) and total questionnaire score.

Discussion

We confirmed in a large community and hospital based sample that people with Parkinson's report significant changes to their eating habits compared to age matched control subjects and that performance declines with time and overall motor status. In line with surveys of swallowing in healthy community dwelling older individuals (Serra-Prat et al. 2012, Roy et al.

2007, Nogueira and Reis 2013) we found that the latter are not free from both recognised and unrecognised alterations to eating and drinking, emphasising that evaluation of swallowing in Parkinson's, predominantly a condition of later life, must take place in this context. Whilst questionnaire scores did correlate significantly with disease status measures, associations were not strong. Furthermore, significant differences on the more objective water swallow test did not necessarily carry through to questionnaire scores. Several (interrelated) possibilities may account for this.

As in previous studies, self-report of a swallowing problem in people with Parkinson's did not strongly predict questionnaire ratings, nor the relationship between questionnaire ratings and speed of drinking. Specifically, a sizeable proportion of individuals with Parkinson's reported no swallowing problem, yet performed poorly on the water swallow test. Whilst questionnaire total scores did differ between those with and without declared swallowing problems, importantly individuals who perceived no problem still fell amongst those with greatest changes to eating and drinking. This contradicts the claims of Clarke et al. (1998) who concluded that asking 'Do you have any difficulty in swallowing food?' was sufficient to screen for significant changes to swallowing.

Results confirm findings from investigations which found poor awareness of swallowing difficulties amongst people with Parkinson's (Bayés-Rusiñol et al. 2011, Miller et al. 2009). Lack of awareness of dysphagia (and other symptoms) is not restricted to Parkinson's (Miller and Patterson 2014), though it appears to be particularly prevalent amongst this group. This is possibly linked to a sensory component, also shared with voice production (Rodrigues et al. 2011, Hammer et al. 2013), which affects scaling and estimation of sense of effort and more generally distorts feedback around sensory-motor tasks. Others may perceive alterations to swallowing but not associate them with Parkinson's (Cheon et al. 2008), attributing them instead to general effects of ageing or fatigue. In assessment, self-reports of absence of swallowing difficulties are therefore no guarantee of no dysphagia and no

risks. Indeed, Parker et al. (2004) noted that people who are aware of swallowing dysfunction may be less at risk of secondary problems associated with dysphagia since they are more liable to compensate for or avoid problematic situations.

There are implications for clinical practice. People with Parkinson's may not report a swallowing problem if asked simply whether they have difficulty swallowing or not. Results here support the notion that enquiring about behavioural changes around eating and drinking may succeed in uncovering problems of activity and impact. These changes may be subtle and pass by unnoticed on a day to day basis, but questioning that sets the behaviour within the life context of an individual or family may yield richer understanding. Employing a brief tool as we have introduced here offers a framework for exploring this with those affected, not just in terms of monitoring degree of change, but as a method of facilitating communication and promoting patient centred management around eating and drinking. Such a process does not seek to replace assessments for aspiration and penetration or identification of other red flags around swallowing assessment, but insights from such discussion can alert to when (conscious or subconscious) self-management has reached its limits (Sung et al. 2010, Suntrup et al. 2013) and when an issue has reached the stage of requiring more active clinician support.

There was a strong association between carer and person with Parkinson's perceived changes, though generally carers underestimated changes compared to their partners. Carers' recognition of changes here may relate to the social nature of eating and drinking. Alterations to swallowing will be apparent from their partner changing their food preferences, with implications for shopping and food preparation in the family; taking longer over meals than the rest of the family; experiencing choking or fear of choking episodes (Miller et al. 2006, Plowman-Prine et al. 2009) and similar. Nevertheless carers still significantly underestimated the impact of these changes on their partners, suggesting that carer ratings do not represent entirely insightful proxy estimation.

In agreement with other studies (Miller et al. 2006, Han et al. 2011, Plowman-Prine et al. 2009, Manor et al. 2009) we found a weak-moderate association of reported swallowing problems with depression. The association requires further investigation. It is not apparent from current data whether there is a cause-effect relationship, and, if so, which variable might be the predictor, which the outcome. Alternatively they may both be associated with a shared aetiopathogenesis.

Testing people with Parkinson's in a practically defined off-medication state may have influenced outcomes regarding relationships of questionnaire scores to WST. Questionnaire responses were to perceived status 'over the last weeks ignoring particularly good or bad days', whilst performance on the water swallow test related to in effect a worst state scenario. Future comparisons between questionnaire ratings and on- versus off-state WST outcomes may throw more light on this, though whether dopaminergic medication exercises a positive effect on swallowing status remains debated (Melo and Monteiro 2013, Sutton 2013).

The disease (Parkinson's) and dimension (swallowing) specific patient report questionnaire developed here was derived from interviews with people with Parkinson's and prior research. It was devised as a method to give insights into individuals' feelings around swallowing status in relation to different foodstuffs and situations rather than as a tool for definitive diagnosis of presence or not of dysphagia. Nevertheless, in as far the questionnaire demonstrated feasibility, utility and communicability future development may examine scores derived in relation to wider measures of swallowing status, both objective and observational.

Conclusions

People with Parkinson's experience swallowing changes beyond those associated with normal ageing, even in the relatively early stages of Parkinson's represented by the current cohort. We showed that phrasing questions (do you have a problem swallowing) or conducting assessments (e.g. WST) around swallowing changes at a level of impairment

though may yield less information than enquiry at the level of activity around eating and drinking (i.e. the possible changes to eating/ swallowing behaviour probed in the questionnaire). Self-reported changes to a variety of swallowing behaviours offer potentially deeper insights into the on-going work of self-management involved in long term degenerative conditions. In as far as cultural factors around eating and drinking are strong determinants of what and whether changes represent an issue the questions also form a starting point for development of tools adapted to other cultural practices. In the meantime this stresses the relevance of using questionnaire responses as a basis for discussions with individuals. Such discussions also provide the bridge between indepth individual interviews around disease impact and questionnaire data that gives a cross-sectional overview of changes that might be typical for people with a particular medical diagnosis. Only objective assessment such as videofluoroscopy or endoscopic examination of swallowing will reveal the structural nature of any swallowing disturbance. Future work may gainfully employ these and other objective methods to compare underlying impairment changes to swallowing and when and how particular thresholds of impairment change, once passed, may manifest themselves in altered eating/ drinking behaviours. In this manner it would be also possible to gather more information on which items are more or less sensitive to specific underlying changes and/or whether alternative rating scales may better reflect degrees of change. This may also afford greater insights into when and how the limits of compensatory neurological reorganisation (Suntrup et al 2013) might be reached. In the meantime the WST and a self-report behavioural questionnaire may alert clinicians to consider closer monitoring of and more specific advice on managing eating and drinking at a biopsychosocial level.

Implications for rehabilitation

1. People with Parkinson's report changes to swallowing beyond those associated with normal ageing.

2. Self-report of absence of swallowing difficulties is no guarantee of absence of dysphagia.
3. Clinical swallowing tests and functional change questionnaires tap different aspects/
levels of swallowing behaviour and insight.
4. Using a combination of a clinical swallow test and patient report functional questionnaire
can provide a feasible method of identifying individuals in need of advice, objective
assessment and monitoring.

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Competing interests

There are no competing interests.

Dedication

This work is dedicated with love and gratitude to our esteemed colleague Emma Noble who sadly died before it could come to fruition.

Appendix 1

Swallowing changes questionnaire

Do you feel you have a problem with swallowing food and/or drink?

yes no

Do you feel you take longer over eating and drinking than you did a year ago?

no yes a little yes a lot

Do you feel you have to be careful when swallowing thin liquids (tea, coffee, juice, beer and so on)?

no yes a little yes a lot

Do you feel you have to be careful when swallowing thick liquids (yoghurt, custard, thickened gravy and so on)?

no yes a little yes a lot

Do you feel you have to be careful when eating soft foods (mashed potato, scrambled egg and so on)?

no yes a little yes a lot

Do you feel you have to be careful when eating hard foods (tough meat, raw fruit and raw vegetables)?

no yes a little yes a lot

Do you feel you have to be careful when eating dry foods (biscuits, toast etc.)?

no yes a little yes a lot

Do you have to specially prepare food before you can eat it – for example liquidize it or mash it up?

yes always yes sometimes no never

Do you have to avoid some foods because you find them difficult to eat/drink?

yes always yes sometimes no never

If yes, which ones: _____

Swallowing in Parkinson's disease

Does food ever 'go down the wrong way', make you cough, when you are eating/ drinking?

never rarely / once a month or so about once a week

about once a day every time I eat/drink

Do you find food left in your mouth after you have finished eating?

yes always yes sometimes no never

Do you ever have problems keeping food/ drink in your mouth?

yes always yes sometimes no never

Is chewing of food a problem for you?

yes always yes sometimes no never

Are you less happy now about eating in public?

no a little bit less happy quite a bit less happy

a lot less happy very much less happy

How much are you bothered in general by your swallowing?

not at all a little bit quite a bit

a lot very much

If you are bothered, what is the reason? _____

Of all the things that bother you about your Parkinson's disease, where does swallowing come (tick the line that is closest to what you think)?

-It's the main problem, the thing that bothers me most

-The second worst problem, there's only one other problem worse than the swallowing

-The third worst problem

-It bothers me, but it's not amongst the main problems

-It doesn't bother me at all.

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Table 1. Descriptive details of people with Parkinson's who returned questionnaires. IQR interquartile range. SD standard deviation

	Median/ mean	IQR/ SD	Full range
Age (years)	73/ 71.36	67-77/ 7.96	45-91
Hoehn Yahr stage (5 severe)	2.5	2-3	1-5
UPDRS II (68 severe)	15/ 14.69	10-19/ 6.56	1-30
UPDRS III (108 severe)	34/ 34.35	23.5-42.5/ 14.57	8-73
GDS (15 severe; ≥5 depressed)	4/ 4.81	2-6/ 3.36	0-14
MMSE (30 max; ≥23 normal range)	27/ 24.92	23-28/ 4.19	8-30
Disease duration (years)	5/6.32	3-11/5.72	1-33

Table 2 Swallowing changes questionnaire ratings with comparison Parkinson's-control scores (SD = standard deviation)

Questionnaire item	Parkinson's			Controls			
	Median	Interquartile range	Total range	Median	Interquartile range	Total range	p
Do you feel you have to be careful when swallowing thin liquids? (tea, coffee, juice, beer and so on)	0	0 - 1	0 - 2	0	0 - 0	0 - 1	<0.001
Do you feel you have to be careful when swallowing thick liquids? (yoghurt, custard, thickened gravy and so on)	0	0 - 0	0 - 2	0	0 - 0	0 - 1	<0.001
Do you feel you have to be careful when eating soft foods? (mash potato, scrambled egg and so on)	0	0 - 0	0 - 2	0	0 - 0	0 - 1	<0.001
Do you feel you have to be careful when eating hard foods? (tough meat, raw fruit and raw vegetables)	1	0 - 1	0 - 2	0	0 - 1	0 - 2	<0.001
Do you feel you have to be careful when eating dry foods? (biscuits, toast etc.)	1	0 - 1	0 - 2	0	0 - 0	0 - 1	<0.001
Do you have to specially prepare food before you can eat it? (for example liquidize it or mash it up)	0	0 - 0	0 - 2	0	0 - 0	0 - 1	<0.01
Do you have to avoid some foods because you find them difficult to eat/drink?	0	0 - 1	0 - 2	0	0 - 0	0 - 1	<0.001
Does food ever 'go down the wrong way', make	1	0 - 2	0 - 4	1	0 - 1	0 - 2	<0.03

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you cough, when you are eating/ drinking?							
Do you find food left in your mouth after you have finished eating?	0	0 - 1	0 - 2	0	0 - 0	0 – 2	<0.001
Do you ever have problems keeping food/drink in your mouth?	0	0 – 0.5	0 - 2	0	0 - 0	0 – 1	<0.001
Is chewing of food a problem for you?	0	0 - 1	0 - 2	0	0 - 0	0 – 2	<0.001
Are you less happy now about eating in public?	1	0 - 2	0 - 4	0	0 - 0	0 – 1	<0.001
Total score (0 no perceived problem; 28 maximum score)	6.0 Mean 6.71	3-10 SD 5.25	0-23	1 Mean 2.07	0.75-3.0 SD 2.45	0-15	<0.001

Table 3: Numbers of people with Parkinson's who stated they did/did not have problems with swallowing in relation to their total questionnaire scores

Response to question 1	Stated had problem or not	Scored above operational cut-off	Scored below cut-off
Yes I do	45 (100%)	3 (7%)	42 (93%)
No I don't	74 (100%)	34 (46%)	40 (54%)
Total participants	119 (100%)	37 (31%)	82 (69%)