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Hard to swallow: dysphagia in Parkinson's disease

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Abstract

Background: swallowing changes occur from the earliest stages of Parkinson's disease (PD), even in cases asymptomatic for dysphagia. Little empirical evidence exists concerning the individual's own perception of changes, the impact these have on their life and coping strategies to deal with them.
Objective: to establish if and how changes in swallowing impact on the lives of people with PD.
Design: in-depth interviews with qualitative analysis of content.
Setting: community.
Subjects: a total of 23 men and 14 women and their carers.
Methods: participants were purposively sampled to give a mix of men, women, family circumstances, stage and duration of PD and severity of swallowing symptoms. Individuals were interviewed at home. Interviews were transcribed. Emergent themes were identified and fed back to participants for confirmation and clarification.
Results: two broad themes emerged: (i) effects on swallowing of underlying physical changes, with subthemes of oral-pharyngeal-laryngeal changes, manual changes, effects of fatigue and (ii) psychosocial impact, with subthemes of alterations to eating habits, feelings of stigma, need for social adjustment and carers' issues. Coping strategies could aid swallowing problems but often to the detriment of others in the family through altered demands on preparation and organisation. Presence of significant impact was not necessarily associated with abnormal range scores on objective swallowing assessments.
Conclusions: the psychosocial consequences of the physical changes concerned people most. The importance of the early detection of changes for health and quality of life is underlined.

Keywords: *dysphagia, Parkinson's disease, impact, quality of life, elderly*

Introduction

Swallowing dysfunction occurs from the earliest stages of Parkinson's disease (PD), even in asymptomatic cases [1, 2]. Changes range from drooling (despite indications of decreased salivary production in PD) [3]; food residues in the oral sulci long after meals; poor bolus formation; slowed oral transit; repeated tongue pumping for retropulsion of the bolus; delayed triggering of the pharyngeal swallow reflex; reduced diameter but prolonged opening of the upper oesophageal sphincter; to vallecular stasis, residue in the piriform sinuses with risk of aspiration and true aspiration [4–6]. For some individuals, eating and drinking are additionally hampered by changes to limb control that affect their ability to handle cutlery and cups. Studies consistently indicate that objective changes, including silent aspiration, precede subjective complaints of dysphagia.

Although Clarke, Gullaksen, Macdonald and Lowe [7] found a significant relationship between dysphagia severity and disease duration, other studies [1, 3–5, 8] have not. In addition, the relationship to overall PD severity remains unclear. L-dopa therapy improves function in only a subgroup of patients [8, 9], suggesting that dysphagia in PD is not mediated solely by dopaminergic deficiency.

Dysphagia in PD is associated with increased morbidity and mortality [10, 11] and may place a considerable social and psychological burden upon the individual and their family [7, 12, 13]. This dimension has received little attention in PD. To gain more insight into subjective aspects of eating, we held in-depth interviews with 37 people with PD. We asked these subjects whether PD had affected their eating; what strategies they used to cope with any effects; whether, and if so how and how much, perceived changes impacted on their daily living and feelings about themselves.

Methods

This qualitative study formed part of a wider investigation, which employed a comprehensive battery of quantitative measures to examine the prevalence, nature, severity and impact on the individual and family of speech and swallowing problems in PD. The original study recruited 141 participants from a community-based investigation of all people with PD in Sunderland, UK [14]. We employed qualitative methods in a subset of these participants [15] to enable a detailed exploration of feelings and attitudes towards living with (possible) changes in swallowing.

A purposive sample of 37 individuals [Female (F), 14; Male (M), 23] was identified, to achieve a group covering men and women; differing ages, family circumstances, stages and duration of PD (DD) and varying severity of swallowing symptoms. Overall characteristics of the group appear in Table 1, including Hoehn and Yahr stage (HY) [16], Unified Parkinson's Disease Rating Scale (UPDRS) [17] totals and swallowing (sw) subscores, millilitres/second (ml/s) achieved in the glass of water test [18] and score on a questionnaire (QS) about changes to eating behaviours (see Appendix 1 in the supplementary data on the journal website, http://www.ageing.oxfordjournals.org/). Thirty-four subjects were receiving dopaminergic medication [mean daily levodopa-equivalent dosage 459 mg, median 451, standard deviation (SD) 300.22, range 0–1350]. The participants in the survey not interviewed (n = 104) received a mean daily levodopa-equivalent dose of 381 mg (median 300, SD 294.22, range 0–1221). The difference between groups was not significant (t = 0.65; P = 0.168 two-tailed). Twelve people interviewed had had contact with speech-language therapy services at some point: three participants with a one-off appointment; three participants for three-spaced-out advice sessions and six participants for treatment sessions. Only one participant recalled receiving advice on swallowing. All participants joined after informed consent in accordance with Local Research Ethics Committee approved procedures.

Table 1. Summary statistics for age, disease and swallowing measures of the interview participants

	Mean	Range	SD
Age (years)	70.89	50–88	9.63
Disease duration (years)	8.91	2–38	7.27
Hoehn and Yahr stage	2.67	1–5	0.97
UPDRS II total (normal 0)	16.67	1–33	6.56
UPDRS III total (normal 0)	38.00	8–73	17.00
UPDRS II salivation score (normal 0)	1.24	0–4	1.18
UPDRS II swallowing score (normal 0)	0.59	0–2	0.64
UPDRS II cutting food (normal 0)	1.02	0–3	1.09
UPDRS II tremor (normal 0)	1.24	0–3	0.86
UPDRS III action tremor right (normal 0)	1.21	0–4	1.37
UPDRS III action tremor left (normal 0)	0.83	0–4	1.19
UPDRS III hand movements right (normal 0)	1.40	0–3	0.89
UPDRS III hand movements left (normal 0)	1.52	0–3	0.84
Questionnaire on impact of swallowing (normal cut-off ~3)	31.02	5–103	24.06
Glass of water test, ml/s, normal cut-off >10.7 ml/s	6.06	0.21–30.99	5.52

SD, standard deviation; UPDRS, Unified Parkinson's Disease Rating Scale.

A semi-structured interview schedule was developed to explore the onset of possible swallowing changes, their impact and strategies used to manage the changes. Interviews with one of the research team (E.N. and N.M.) took place in participants' homes, lasted ~45 min to 1 h and were audio-recorded. Carers could be present, but it was emphasised that initially we were interested in the views of the person with PD. Verbatim transcripts were made and imported into NUD*IST N6 [19] for analysis. Transcripts were read on screen, and data were coded to a developing node tree of categories agreed within the research team. Key themes were derived from the categories. Results of quantitative measures were also imported to allow matching of individual patient details (enclosed in brackets below after quotations) with qualitative text. Sampling and analysis continued until categories were saturated, and no new information emerged. Results were fed back to participants for confirmation and clarification.

Findings

Two broad themes emerged from the interview analysis—effects on swallowing of underlying physical changes and psychosocial impact. Within the physical changes theme,

subthemes emerged in relation to oral-pharyngeal-laryngeal changes, manual changes and effects of fatigue. Within the psychosocial impact theme, subthemes centred on alterations to eating habits, feelings of stigma, need for social adjustment and carers' issues.

Frequencies for ratings on selected UPDRS subitems reflecting physical impairment appear in Table 2. These can be viewed in the light of the words of participants below compared with their individual profiles, which illustrate a lack of any consistent relationship between physical measures and perceived impact of changes. Strength in the arms and hands affected ability to cut food; tremor and dyskinesias impaired the ease or possibility of bringing food or drink to the mouth. 'I notice when I'm picking a cup up now; I'm spilling more than I'm drinking' (F 76, DD 3 years, HY 2, UPDRS tremor 2, UPDRS sw 1, ml/s 4.5, QS 20). 'Well if there's anything to cut with a knife ... I just have to leave it' (M 68, DD 7 years, HY 2, UPDRS sw 0, ml/s 8.31, QS 17). Reduced strength and endurance rendered lengthy or hard chewing problematic. 'I love Yorkshire puddings [note: a relatively soft food] but I've got to chew and chew, and in the finish I often just have to take it out' (F 67, DD 10 years, HY 3, UPDRS sw 2, ml/s 2.08, QS 26). Managing saliva was a factor faced by some. This and the perceived stigma of having to continually wipe the mouth and have a handkerchief ready was an element influencing psychosocial impact. 'He doesn't want to face people when he's eating, he slavers you see' (M 84, DD 8 years, HY 2.5, UPDRS sw 0, ml/s 1.66, QS 17).

Eating was almost invariably slowed—from reduced rate and strength of chewing, problems manipulating the bolus and difficulty clearing food from the throat. 'I can chew but I've got to chew for a long, long time. I used to be a quick eater but now it takes me ages. In fact by the time you get to the end of it you're sick' (F 67, DD 10 years, HY 3, UPDRS sw 2, ml/s 2.08, QS 26). These problems extended to swallowing medication. 'Sometimes I just can't swallow my pills' (F 55, DD 19 years, HY 4, UPDRS sw 1, ml/s 3.85, QS 27); 'I have bother getting a tablet down, sometimes they sort of stick there and you cough them back up' (F 74, DD 5 years, HY 2, UPDRS sw 1, ml/s 11.19, QS 4).

Choking, even just the fear of it, featured prominently as disruptions to meal times. 'It's awful, you have to order something you know you're not going to choke on' (F 55, DD 19 years, HY 4, UPDRS sw 1, ml/s 3.85, QS 27); 'I feel like my throat is tight, it feels like I have something there and I cannot move it' (F 76, DD 3 years, HY 2, UPDRS sw 1, ml/s 4.5, QS 20). 'We don't go out for meals now as I'm always frightened I choke' (F 55, DD 19 years, HY 4, UPDRS sw 1, ml/s 3.85, QS 27). Others felt altered sensations in their mouth and consequent changes to food appreciation affected eating.

Participants were asked how they coped with changes. Strategies revealed a wide range of self-taught compensations or ones adopted on advice from others. Modified cutlery, cups and plates helped. Taking smaller sips or bites; having someone tenderise, mash or liquidise food beforehand; taking ones time; avoiding certain foodstuffs were other solutions.

Although compensatory tactics may aid eating, they did not necessarily lessen the psychosocial impact for the person with PD and their family. Loss of mealtime enjoyment from slowness, changed diet and dependence on a carer to cut food added to a feeling of misery for some. One participant spoke for many when expressing the feeling of guilt and selfishness at causing all the disruption to family mealtimes and placing added burden on the carer. Restricting diet to particular foods or preparing dishes in a more manageable fashion may aid swallowing, but this could mean extra shopping, preparing two sets of meals and added preparation time on top of an already full day of caring.

All or any of these variables could combine to alter social habits around eating—cessation of eating out, trips to the club, inviting friends for a meal. Only exceptionally had participants become withdrawn from close family mealtimes. Nevertheless, the fact that they remained at the table long after others had finished and that food had gone cold in the meantime could contribute to the perceived burden of swallowing difficulties and detriment of the personal and social enjoyment of eating. 'Sometimes I start off with the steak on the plate, and he's finished his and washed up and I still ... haven't gotten half way through mine and I give up. I just leave it' (F 55, DD 19 years, HY 4, UPDRS sw 1, ml/s 3.85, QS 27).

A recurrent theme concerned how carers became affected. 'Didn't affect me, it affected me wife. She had to do most of the things for me' (M 75, DD 8 years, HY.4, UPDRS sw 2, ml/s 1.29, QS 22). 'If I'm shaking a lot trying to get something on the fork or spoon, it just ends up on the floor, so I shout for my wife and she just feeds us' (M 67, DD 18 years, HY 4, UPDRS sw 0, ml/s 4.63, QS 9). Carers spoke of loss of quality in their lives from the added drain on time and energy and disruption to family life from extra or separate preparation of food, not being able to eat together, extra time to eat, to clear up, not going out, not having visitors around to dine. 'When he's finished I have to clean up, it's on the floor or down his clothes' (M 74, DD 8 years, HY 3, UPDRS sw 0, ml/s 2.3, QS 6).

Conflicting with this sentiment, carers may experience guilt seeing their partner struggling to eat, not enjoying meals, drinking and eating less or not so exciting food, whereas they themselves eat whatever they wish. Fear of choking and what to do if their partner should choke was a worry for some. Partners may additionally worry that their husband/wife was not eating or drinking enough to sustain them.

Table 2. Frequencies for ratings of the interview participants on selected UPDRS II and III subitems

Rating (0 normal)	0	1	2	3	4
UPDRS II salivation	12	12	7	4	2
UPDRS II swallowing	18	16	3	0	0
UPDRS II cutting food	17	6	10	4	0
UPDRS II tremor	8	14	13	2	0
UPDRS III action tremor right	16	9	3	6	3
UPDRS III action tremor left	19	12	2	1	3
UPDRS III hand movements right	6	14	13	4	0
UPDRS III hand movements left	6	10	18	3	0

UPDRS, Unified Parkinson's Disease Rating Scale.

On the positive side, not everyone experienced all or any of these problems. Others faced changes but had succeeded in making adjustments to how, what and when they ate and drank, meaning they could maintain mealtime enjoyment long after difficulties arose. Initiatives covered those aired above (slowing; smaller portions/sips; finer cutting or tenderising, avoidance) as well as adopting a particular posture for swallowing, eating little and often; so, they could be satisfied at main family mealtimes with a smaller portion, managed in the time others took for their main meal.

It was not our aim to establish why strategies worked for some and not others. However, remarks pertinent to the topic were made. These were in the direction of a determination to keep going and succeed at all costs; the influence of real and perceived family support and appreciation of problems faced. 'I just try hard to get through it' (M 70, DD 4 years, HY 4, UPDRS sw 0, ml/s 9.37, QS 15); 'Oh I'd still go out but I'd just make sure that I had something that wouldn't choke us you know' (F 67, DD 10 years, HY 3, UPDRS sw 2, ml/s 2.08, QS 26); 'I just accept it, it doesn't alter my enjoyment of mealtimes' (M 67, DD 18 years, HY 4, UPDRS sw 0, ml/s 4.63, QS 9).

Discussion

The views expressed in this study move beyond earlier reports in emphasising that underlying swallowing impairment need not be severe to occasion significant impact. There was clear incongruence between statements concerning individual impact and the apparently mild picture of changes gained from other disease stage and severity measures. Impact exerted significant influence on peoples' lives, and the swallowing problems had consequences as likely to encroach on the carer as on the person with PD. Furthermore, effects impinged not narrowly on chewing and swallowing but on broader practical and social activities surrounding mealtimes (e.g. shopping, preparation, clearing up and socialisation). Positive coping strategies were found, but what might help the person with PD could be an added burden for the carer; what might be a solution for one family proved negative for another.

In general, such views accord with outlooks found for other neurological conditions, in how swallowing changes can negatively impact quality of life. They also concur with the widespread acknowledgement that major illness impacts on the life of carers as much as on the person with the primary condition [20, 21].

Several other implications can be drawn from this study. In as far as the precise issue for individuals and families could differ markedly, as could what constituted an ideal or workable solution, a very much individual approach to management is advocated. Off-the-shelf dysphagia management programmes or techniques unmodified to individuals' circumstances, and perceptions are unlikely to succeed if this is not acknowledged.

In reviewing PD status or considering referral for support for swallowing difficulties, questioning must cover swallowing from more than a perspective that asks whether choking is present or not on screening tests or imaging assessments. Rather it should also probe possible wider repercussions that swallowing changes can exert on self-esteem, enjoyment, family dynamics, fatigue and social life. Few of the families interviewed ranked swallowing amongst the highest negative consequences of their PD. Nevertheless, for all but a few, it was a significant factor in adding to their perceived burden and worries.

In terms of supporting families, most felt that they were dealing with swallowing changes alone and that nothing could be done against inevitable decline. This degree of pessimism is not warranted. Despite a lack of randomised controlled studies [22], there are indications that improvement can be brought about by relatively straightforward interventions [23–26]. What needs to be ensured is that services are organised to cover training for families and subsequent monitoring. It is important at all stages of PD to evaluate swallowing status [18, 27, 28]; to harness the resources of the multidisciplinary team in supporting and maximising function [29, 30] and through this prevent or delay onset of several avoidable problems in feeding and swallowing in PD.

Key points

- Swallowing impairment need not be severe to cause significant impact on the lives of people with PD and their carers.
- Eating is a social activity, and physical changes affecting chewing, swallowing and manual skills can have profound psychosocial consequences for individuals.
- Adjustments to how, what and when people ate and drank could extend mealtime enjoyment in the face of increasing difficulty.
- However, the same adjustments could be perceived by other families as an increase in pressure in relation to mealtime preparation and organisation.
- Screening to enable early detection of physical swallowing changes and psychosocial distress has the potential to prevent or delay avoidable secondary problems.

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Conflicts of interest

The authors have no conflicts of interest.

Ethical approval

The Sunderland Local Research Ethics Committee reviewed and approved the design and methods of conduct for this study.

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