

# Life with communication changes in Parkinson's disease

NICK MILLER<sup>1</sup>, EMMA NOBLE<sup>1</sup>, DIANA JONES<sup>2</sup>, DAVID BURN<sup>3</sup>

<sup>1</sup>Speech Language Sciences, George VI Building, University of Newcastle, Newcastle-upon-Tyne GB-NE1 7RU, UK

<sup>2</sup>Allied Health Professions Research, School of Health, Community and Education Studies, Northumbria University, Coach Lane Campus, Newcastle-upon-Tyne GB-NE7 7XA, UK

<sup>3</sup>Regional Neurosciences Centre, Newcastle General Hospital, Westgate Road, Newcastle-upon-Tyne GB-NE4 6BE, UK

Address correspondence to: N. Miller. Email: nicholas.miller@ncl.ac.uk

## Abstract

**Background:** acoustic and perceptual changes to speech in Parkinson's disease (PD) have been widely studied. 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 communication impact on the lives of people with PD.

**Design:** in-depth interviews with qualitative analysis of content.

**Setting:** community.

**Subjects:** twenty-three men and 14 women with PD.

**Methods:** participants were purposively sampled to give a mix of men, women, family circumstances, stage and duration of PD and severity of speech symptoms. Individuals were interviewed at home. Interviews were transcribed. Emergent themes were identified and fed back to participants for confirmation and clarification.

**Results:** participants identified changes to voice and articulation. Language changes featured prominently. Four impact themes: (i) interaction with others, (ii) problems with conversations, (iii) feelings about intelligibility and (iv) voice; and four corresponding coping themes (a) helping others understand, (b) managing conversations, (c) monitoring and adjusting and (d) physical strategies emerged. Of main concern was not the nature of speech-voice-language changes, but how these affected self-concept, participation inside and outside the family and family dynamics. Individuals employed a range of fluid coping strategies moving from background withdrawal to foreground striving strategies.

**Conclusions:** speech and language changes in PD impact upon individual and family life long before frank impairment of intelligibility is apparent. The role of early referral to speech and language therapy is therefore worthy of detailed investigation.

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

## Background

Communication changes are almost inevitable for people with Parkinson's disease (PD). Around 80–90% experience voice changes; 45–50% show alterations in articulation [1, 2]. The perceptual, acoustic and kinematic changes associated with speech and voice deterioration have been described in detail [2–9]. Language changes have received less attention [10].

Perceptually, speech is typified as monopitched, monoloud, imprecise and dysfluent. Associated acoustic changes point to altered voice fundamental frequency (Fo), reduced variability of Fo, decreased sound intensity, lower harmonics-to-noise ratio and spectral distortions for many consonant types. Physiological and kinematic studies link acoustic findings to reductions in movement strength, endurance, peak velocity and amplitude.

Notably absent from this standard characterisation is the perspective of the individual who experiences these changes. Small-scale studies have endeavoured to capture a patient-centred view through questionnaires. Speakers with PD have been included in more general studies of the impact of dysarthria [11–13]. Apart from the comparatively small scale of most of this work and that PD was not always the specific centre of attention, an added drawback of several studies is that changes in communication as a result of speech–language factors have been poorly separated from the broader consequences for communication of physical and lifestyle change.

What therefore remains unclear is whether elements of oral change prominent in speech science studies coincide with those perceived by and of concern to individuals with PD; even if they do, can or should their impact on peoples' lives be understood purely in terms of alteration of voice

and speech parameters? We aimed to gain insights into these questions through in-depth interviews with people with PD, focusing on the nature of any communication changes, what impact these had on their life, and what coping strategies they adopted.

## Methods

The present qualitative study formed part of a wider investigation which used 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 wider investigation recruited 141 participants from a community-based study of all people with PD in Sunderland, UK [14]. We employed qualitative methods in a subset of participants to enable a detailed exploration of feelings and attitudes towards living with dysarthria.

A purposive sample of thirty-seven individuals (F: 14; M: 23) was identified, to achieve a group covering men and women; differing ages, family circumstances, stages and duration of PD; and varying severity of speech symptoms. Overall characteristics of the group are given in Table 1, including Hoehn and Yahr stage [15], Unified Parkinson's Disease Rating Scale (UPDRS) [16] totals and speech sub-scores, Mini-Mental State Exam (MMSE) [17] and Geriatric (GDS) [18] and Montgomery-Åsberg Depression Rating Scales (MADRS) [19] and the general score from the GRBAS voice rating scale [20]. Thirty-four were receiving dopaminergic medication (mean daily levodopa equivalent [21] dosage 459 mg, median 451, SD 300.22, range 0–1,350). The participants in the survey not interviewed (n 104) received mean daily 381 mg (median 300, SD 294.22, range 0–1,221). The difference between groups was not statistically significant ( $t$  0.65,  $P$  0.168 two-tailed). Twelve people interviewed had had contact with speech-language therapy

(SLT) services at some point: three a one-off appointment; three for three spaced out advice sessions; six had received a block of six treatment sessions, with only one of these having a further six sessions 2 years later. All participants joined after informed consent in accordance with Local Research Ethics Committee approved procedures.

A semi-structured interview schedule was developed to explore the onset of speech changes, their impact and strategies used to manage the changes. Interviews with one of the research team (EN, NM) 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 [22] for analysis. Transcripts were read on screen and data was 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 cross tabulation of quantitative scores 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

In response to the question of how speech changes were perceived, four themes emerged, centred around 'my interaction with others was affected'; 'I had problems with conversations'; 'feelings about making myself understood'; 'my voice'.

Early voice changes included feeling the voice was husky, getting deeper, quieter, requiring constant throat clearing. "... my voice doesn't come out correctly . . . it quietens down as I'm speaking, and I've got to start again" (Male (M) 77 years, disease duration (DD) 21 years, Hoehn and Yahr (HY) 3, intelligibility measure of (IM) 56 (maximum possible 60). "I never know when I start to talk . . . what tone or pitch is going to come out." (F (female) 56, DD 17 years, HY 2, IM 58).

Deterioration in intelligibility featured as a problem, perceived in terms of mumbling, tight mouth, slowness of speech, loss of clarity, effort required to maintain intelligible speech. Effects of freezing and day-to-day variability could be bothersome and demoralising – starting a sentence and not knowing whether one would reach the end; feeling one is succeeding one day but lamenting a relapse the next. "It's hard work trying to talk, trying to get the words out" (M 68, DD 7 years, HY 2, IM 44); "... you sort of stutter and sometimes you're just talking and it disappears" (F 74, DD 5 years, HY 2, IM 35). "I want to say something but something different comes out and I get awful confused" (F 67, DD 10 years, HY 3, IM 50).

Central concerns were not that voice was monopitch, particular sound contrasts difficult, or similar. Except in the most severely affected speakers these restrictions could in extremis be modified, at least for brief stretches. Rather individuals focused on the impact changes exerted on ability to communicate, their view of themselves, and the detrimental

**Table 1.** Summary statistics for demographic, disease and speech measures for interview participants

Measures (cut-off from normal where relevant)	Mean	Median	SD	Range
Age (years)	70.9	73	9.6	50–88
Disease duration (years)	9.45	6	7	3–38
Hoehn and Yahr stage (1, mild; 5, severe)	2.67	2.5	0.9	1–5
MMSE (>23; max 30)	23.9	25	4.5	15–30
GDS (>5 depressed; 0–15)	5.1	5	3.1	0–12
MADRS (>6 depressed; 0–60)	4.4	4	3.0	0–11
UPDRS II speech (0 normal–4)	1.73	2	0.8	0–3
UPDRS II total (0 normal–52)	16.67	16	6.5	1–33
UPDRS III speech (0 normal–4)	1.32	1	0.8	0–3
UPDRS III total (0 normal–108)	38	36	17	8–73
Intelligibility (max = 60; normal cut-off 51)	47.26	50	9.0	14–58
GRBAS general voice (0 = normal; max 3)	1.12	1	0.6	0–3

effects of the effort required to overcome physical and mental limitations for anything beyond short periods.

Further difficulties with conversations linked to changes such as distractibility, diminished attention span, problems initiating speech movements, difficulty finding words and formulating ideas. These rendered it difficult to get into conversations and hold one's place there, led to feelings of frustration at not being able to make one's needs known and depression or annoyance at being neglected by others. A frequent consequence was withdrawal.

"Three times I lost the thread about what I was talking about . . . . where am I going with this? I had no idea. I struggle to string words and sentences together" (F 56, DD 17 years, HY 2, IM 58) . . . "It's difficult to keep my attention going, I drift away . . ." (M 77, DD 21 years, HY 3, IM 56). "It comes out back to front and sometimes it makes you not want to talk to anybody. I don't talk at all then" (F 55, DD 19 years, HY 4, IM 45).

Views falling within the interaction with others category focused additionally on how speakers felt they were being treated by conversation partners and the impact this had on desire to communicate and feelings of self worth. The perception amongst the people with PD that listeners lacked an appreciation of difficulties they were facing in talking, talked over them, talked for them, did not wait for an answer, ignored them, assumed they were stupid all featured strongly. On the positive side people felt supported by others accepting differences, giving choice, negotiating how to make conversations easier, helping them to laugh about things.

"By the time you've finished, the subject has changed and they haven't waited for your answer to come out" (M 74, DD 8 years, HY 3, IM 54). "Some people don't understand, they don't know I've got a problem anyway and they just think I'm daft, saying the wrong things" (M 82, DD 2 years, HY 2, IM 55). "I don't feel as if I am talking quiet, I feel as if I am shouting but you can see it on peoples' faces, they haven't heard what you're saying but they're too embarrassed to say" (F 55, DD 19 years, HY 4, IM 45). "People accept that I'm slow in getting over what I want to say, they appreciate it" (M 75, DD 8 years, HY 4, IM 50).

Communication changes directly impacted socialisation, from apprehension at interaction to social withdrawal. Representative reactions included ' . . . sometimes I just can't do the conversation, I just say, oh, I hope they don't talk to us, you know, they'll just say, hello, how are you, and walk away' (F 67, DD 10 years, HY 3, IM 50). 'Embarrassed, people just keep staring at you when you cannot get your words out. . . so I just avoid the people' (M 82, DD 4 years, HY 3, IM 47). 'Speaking to people was making him self-conscious. When there was a crowd there he felt embarrassed. He's not been to the club for about 2 and a half years, not since then' (M 76, DD 5 years, HY 3, IM 43).

In talking of coping with changes, again four themes emerged: physical strategies; monitoring and adjustment strategies; managing conversations; helping others to understand.

Individuals devised ways of adapting to the reduced physical capability – by telling themselves to maximise

effort; acknowledging that even though they sensed they were already shouting, the listener probably still heard only a quiet voice; keeping sentences short and manageable. Intelligence could be enhanced by slowing down, concentrating hard, persevering. "You've just got to concentrate a lot more on what you want to say, be determined to get it out" (F 74, DD 5 years, HY 2, IM 35) "If you try hard enough, it's constant in your mind and you do it" (M 75, DD 8 years, HY 4, IM 50).

Individuals monitored their physical and mental resources, weighing up whether they could succeed in a given situation, or how to succeed. Generally they were sensitive to whether listeners could hear them and understand and adjusted accordingly. For some families though arguments arose over whether it was the speaker mumbling or the listener not attending. "My husband he's very patient, but now and again, he'll say I cannot hear you, he gets agitated and then I just don't talk" (F 55, DD 19 years, HY 4, IM 45). Such incidents were a source of tension, depression, resignation and withdrawal.

Strategies to manage conversations disclosed a largely passive approach on the one hand – not speaking unless directly addressed, adopting the role of listener. "At one time I could keep a conversation going for ages but I can't now, I just sit back and listen" (F 67, DD 10 years, HY 3, IM 50). On the other hand alternative channels of communication might help – email, gesture, note writing. "Best thing invented was the email, if I make a mistake I can just cross it out, I can take half an hour over a sentence and that's a long time" (M 75, DD 8 years, HY 4, IM 50).

Coping with negative attitudes and treatment could be dealt with via informing people about PD, resolving not to be cowed, intimidated, or frightened to try. "I think it's better if everyone knows that I have Parkinson's, then the next time I see them and they think something is wrong with us, they know what it is" (F 64, DD 3 years, HY 2, IM 58). "I let them know how I cope, I think you haven't got to be afraid and that's what a lot of people are frightened of" (M 75, DD 8 years, HY 4, IM 50).

Perceived change and coping categories were not static. Individuals generally did not feel locked into one category. Which impact factor and which coping strategy was salient varied in relation to a range of interweaving factors. Determinants revolved around whom the person was speaking with, the place, time and purpose of the conversation; the number of people in the conversation and their perception of listeners' attitudes to them; how the speaker was feeling at that time in terms of energy, motivation to speak, urgency to convey a particular message. At times of lowest ebb complete withdrawal may be the only tactic available. Other times withdrawal was employed to conserve strength for more important contributions. In such cases making sure someone else put one's view was a tactic to the fore. "I don't speak unless I have to as I'm frightened I don't get my words out, and if I go to the hospital my wife comes and does all the talking" (M 68, DD 7 years, HY 2, IM 44). Where success was desirable or imperative, individuals maximised effort in voice, speech and concentration to succeed by themselves.

## Discussion

This study aimed to move beyond acoustic, perceptual and physiological changes to speech, divorced from the speaker, the listener and the communicative situation. Understanding the impact of changes on the life of the individual and their family ran beyond an interpretation strictly in terms of fundamental frequency variation, sound pressure level changes or rate of speech. Changes were generally experienced in terms of their effects on communication overall, roles and relationships. Other sources of difficulty for people with PD – e.g. fatigue, attention, freezing – exercised knock-on effects on communication.

Coping encompassed a wide range of strategies from giving up completely to those who ‘toughed it out’ (M 84, DD 8 years, HY 2.5, IM 48). A recurrent finding was that individuals seldom stuck to one strategy. Their affective and physical state had a decisive influence on whether and which strategies were adopted, and crucially the influence of the social situation and real and perceived listener reactions also shaped behaviour. Effects of, and responses to, communication changes might therefore place an individual literally and metaphorically in the background, or they might strive to place themselves in the foreground. Several implications for case management arise from these views.

Absence of perceived voice and speech changes or change insufficient to impair intelligibility does not equal an absence of communication problems. Most individuals interviewed would not be classed as having speech-voice changes to a degree that warranted referral to SLT for speech articulation/intelligibility intervention. Neither was speech necessarily their priority concern. Despite this almost all felt acutely aware of an all-pervasive negative impact from speech and germane changes on their ability to communicate, echoing earlier indications that embarrassment at other peoples’ reactions creates a barrier to communication and socialisation [23].

This suggests that routine referral of people newly identified with PD should be the norm rather than delay until frank speech and voice changes develop. Similar sentiments are expressed in the National Service Framework for Long-term Conditions [24], where a ‘quality requirements’ recommendation concerns early and specialist rehabilitation, with community rehabilitation and support, highlighting the need for timely input with a focus on participation in the full range of life roles. The draft National Institute for Clinical Excellence guidelines for PD [25] likewise point out amongst their ‘areas likely to have the most significant impact on patient care and outcomes’ the importance of ‘regular access to rehabilitation interventions including . . . SLT’; and, ‘at diagnosis and regular review meetings consideration should be given to referring people with PD for . . . SLT interventions’.

Referral for behavioural intervention would also be supported in view of studies that find no corresponding improvement in speech intelligibility associated with gains in other motor functions from dopaminergic or surgical intervention [26, 27].

A risk of delayed referral is that by then maladaptive coping strategies and feelings of frustration may well have cornered a speaker into withdrawal, isolation and family

tensions, militating against full socialisation and participation. As one interviewee (F 55, DD 19 years, HY 4, IM 45) expressed, who had been turned down from SLT: even if the initial referral had been to make an audio-recording for subsequent comparison, the therapist would later have at least understood how differently she was speaking to previously and how much that meant to her. Against this, a minority of respondents felt they did not want to discuss possible later difficulties before they were no longer able to cope by themselves, they preferred to hide or deny their PD symptoms as long as possible.

This perspective sets preventative health education work as a central thread in therapy. In clinical review it also emphasises that the pertinent question regarding communication centres not on whether the person is intelligible or not, but what changes in self perception and daily living have arisen from speech and voice changes.

Findings show that language assessment should not be neglected. Word retrieval, sentence formulation and comprehension difficulties were frequently reported, and not confined to participants who fell below cut-off levels for dementia on the MMSE [17].

The views of people interviewed accorded with the view that in assessment the role, abilities, concerns of the listener in negotiated communicative success are as important as the status of the speaker [28, 29]. This highlights equally the central involvement of communicative partners in intervention.

Participants’ responses presented insights with potential for constructive management of communication breakdown. Positive strategies addressed how to balance energy for communication against energy for other needs, how to compensate for physical aspects of voice-speech deterioration, how to engage listeners in building successful exchanges. Their message was that communication that works in the face of inevitable physical decline grows out of the person with PD being in tune with their own strengths, limitations and wishes, coupled with knowledge on the part of the listener of what hurdles speakers face and how best to support them in crossing these.

Being shut out from conversations is a major factor in loss of dignity [30]. The humiliation, poor communication, exclusion that this brings undermines autonomy and the independence that brings dignity. Coming to grips with all dimensions of communication change and its impacts assumes centre stage importance in helping the individual with PD and their family maintain this dignity against the odds stacked against them.

## Key points

- Communication changes exercised a salient influence on daily living for the individuals with PD and their families interviewed in this study.
- Changes to communication were felt even though individuals might sound intelligible to listeners.
- Main impact arose from changes to voice, making oneself understood, managing conversations, reactions of others. A minority of individuals preferred to deny change had happened.

- Coping centred on physical strategies; monitoring and adjustment strategies; managing conversations; helping others to understand.
- Which impact and strategy was to the fore varied according to when, where, with whom and about what the person was conversing.

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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.

## References

- Logeman J, Fisher H, Boshes B, Blonsky E. Frequency and co-occurrence of vocal tract dysfunction in the speech of a large sample of Parkinson patients. *J Speech Hear Dis* 1978; 43: 47–57.
- Sapir S, Pawlas AA, Ramig LO *et al.* Voice and speech abnormalities in Parkinson disease: Relation to severity of motor impairment, duration of disease, medication, depression, gender, and age. *J Med Speech-Lang Pathol* 2001; 9: 213–26.
- Forrest K, Weismer G, Turner GS. Kinematic, acoustic, and perceptual analyses of connected speech produced by Parkinsonian and normal geriatric adults. *J Acoust Soc Am* 1989; 85: 2608–22.
- Ackermann H, Ziegler W. Articulatory deficits in parkinsonian dysarthria: an acoustic analysis. *J Neurol Neurosurg Psychiatr* 1991; 54: 1093–8.
- Stelzig Y, Hochhaus W, Gall V, Henneberg A. Laryngeal findings of patients with Parkinson's disease. *Laryngo Rhino -Otol* 1999; 78: 544–51.
- Solomon NP, Robin DA, Lushei ES. Strength, endurance, and stability of the tongue and hand in Parkinson disease. *J Speech Lang Hear Res* 2000; 43: 256–67.
- Holmes RJ, Oates JM, Phyland DJ, Hughes AJ. Voice Characteristics in the progression of Parkinson's disease. *Int J Lang Commun Disord* 2000; 35: 407–18.
- Penner H, Miller N., Hertrich I, Ackermann H., Schumm F. Dysprosody in Parkinson's disease: an investigation of intonation patterns. *Clin Ling Phonet* 2001; 15: 551–66.
- Goberman AM. Correlation between acoustic speech characteristics and non-speech motor performance in Parkinson Disease. *Med Sci Monit* 2005; 11: CR109–CR116.
- Grossman M, Lee C, Zurif E *et al.* Information processing speed and sentence comprehension in Parkinson's disease. *Neuropsychology* 2002; 16: 174–81.
- Hartelius L, Svensson P. Speech and swallowing symptoms associated with Parkinsons-disease and multiple-sclerosis - a survey. *Folia Phoniatr Logop* 1994; 46: 9–17.
- Antonius K, Beukelman D, Reid R. Communication disability in Parkinson's disease: perceptions of dysarthric speakers and their primary communication partners. In: Robin D, Yorkston K, Beukelman D, eds. *Disorders of Motor Speech*. Baltimore: Paul Brookes, 1996: 275–86.
- Walshe M. Impact of acquired neurological dysarthria on the speaker's self concept. *J Clin Speech Lang Stud* 2003;12/ 13:9–33.
- Allcock LM, Ulyart K, Kenny RA, Burn DJ. Frequency of orthostatic hypotension in a community based cohort of patients with Parkinson's disease. *J Neurol Neurosurg Psychiatr* 2004; 75: 1470–1.
- Hoehn MM, Yahr MD. Parkinsonism: onset, progression and mortality. *Neurology* 1967; 17: 427–42.
- Goetz CG, Poewe W, Rascol O *et al.* The Unified Parkinson's Disease Rating Scale (UPDRS): status and recommendations. *Mov Disord* 2003; 18: 738–50.
- Folstein M, Folstein S, McHugh P. 'Mini-mental state'. A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975;12:189–98.
- Sheikh J, Yesavage J. Geriatric Depression Scale (GDS): recent evidence and development of a shorter version. *Clin Gerontol* 1986;5:165–73.
- Montgomery SA, Asberg M. New depression scale designed to be sensitive to change. *Br J Psychiatr* 1979; 134: 382–9.
- Webb AL, Carding PN, Deary IJ, MacKenzie K, Steen N, Wilson JA. The reliability of three perceptual evaluation scales for dysphonia. *Eur Arch Oto Rhino Laryn* 2004; 261: 429–34.
- The Deep Brain Stimulation for Parkinson's disease Study Group. Deep brain stimulation of the subthalamic nucleus or the pars interna of the globus pallidus in Parkinson's disease. *N Engl J Med* 2001;345:956–63.
- QSR. QSR NUD\*IST N6. QSR International Pty Ltd, Doncaster, Victoria: 2002.
- Yelland S. Survey of members of the Parkinson's Disease Society: Parkinson's Disease Society of the United Kingdom; 1999.
- NSF. National service framework for long-term conditions: Department of Health, United Kingdom, 2005.
- NICE. Parkinson's disease: diagnosis and management in primary and secondary care: National Collaborating Centre for Chronic Conditions: Draft for First Consultation. London, UK: Royal College of Physicians, 2005.
- Pinto S, Ozsancak C, Tripoliti E, Thobois S, Limousin-Dowsey P, Auzou P. Treatments for dysarthria in Parkinson's disease. *Lancet Neurol* 2004; 3: 547–56.
- Rousseaux M, Krystkowiak P, Kozlowski O, Ozsancak C, Blond S, Destee A. Effects of subthalamic nucleus stimulation on parkinsonian dysarthria and speech intelligibility. *J Neurol* 2004; 251: 327–34.
- Cruice M, Worrall L, Hickson L, Murison R. Finding a focus for quality of life with aphasia: social and emotional health, and psychological well-being. *Aphasiology* 2003; 17: 333–53.
- Lyon JG, Cariski D, Keisler L *et al.* Communication Partners: enhancing participation in life and communication for adults with aphasia in natural settings. *Aphasiology* 1997; 11: 693–708.
- Woolhead G, Calnan M, Dieppe P, Tadd W. Dignity in older age: what do older people in the United Kingdom think? *Age Ageing* 2004; 33: 165–70.

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