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Citation: Miller, Nick, Noble, Emma, Jones, Diana, Allcock, Liesl and Burn, David (2008) How do I sound to me? Perceived changes in communication in Parkinson's disease. *Clinical Rehabilitation*, 22 (1). pp. 14-22. ISSN 0269-2155

Published by: SAGE

URL: <http://dx.doi.org/10.1177/0269215507079096>
<<http://dx.doi.org/10.1177/0269215507079096>>

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How do I sound to me? Perceived changes in communication in Parkinson's disease

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Objective: To examine self and carer perceived changes in communication associated with Parkinson's disease and relate these to speech intelligibility, gender, age and other disease measures.

Design: Cross-sectional survey of a hospital- and community-based sample of 176 people with Parkinson's disease and their carers using a questionnaire based on semantic differential techniques.

Participants: One hundred and four people with Parkinson's disease with no history of communication difficulties prior to onset of their Parkinson's disease and 45 primary carers who returned completed questionnaires.

Main outcome measures: Differences in ratings for 'before' the onset of Parkinson's disease versus present status.

Results: There was a strong perception of negative impact on communication between 'before' and 'now', irrespective of age and gender and largely independent of disease severity and duration, intelligibility and cognitive status. Activities of daily living (assessed by Unified Parkinson's Disease Rating Scale (UPDRS) II) and depression rating scale scores had the strongest association with change (adjusted R^2 0.27). There was a significant correlation between the rank order of perceived change in features examined in people with Parkinson's disease versus their carers, though in general carers rated change as having less impact.

Conclusions: Parkinson's disease exercises a strong influence on communication even before apparent alterations to intelligibility or motor status (UPDRS).

Introduction

Parkinson's disease is a progressive neurological disorder with a prevalence of around 160/100 000 and annual incidence of 13/100 000 population.

Changes to speech and voice occur in up to 80–90% of cases.^{1–3}

These changes can impact on intelligibility and ability and desire to communicate,^{4–6} but the psychosocial impact of speech changes, including the effect on the patient's perception of themselves, self-esteem and interactive behaviour, is poorly documented.

There is no single accepted assessment tool for measuring the psychosocial impact of speech and communication difficulties in chronic neurodegenerative conditions. Quality of life measures

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typically used pay no or only cursory attention to communication issues, or questions on communication can be confounded with changes in physical or other variables.

Some studies have sought to capture elements of impact of communication changes in Parkinson's disease⁷ and neurodegenerative conditions generally⁸ through the use of questionnaires on how individuals manage in different social situations and how their feelings about communication have altered over time. One drawback of such instruments is that predetermined general questions set by the clinician may not represent the direct concerns or perspectives of the speaker, and unless a comparison is made of earlier versus later ratings the scoring assumptions may lead to misinterpretation of change.

In-depth interviews with patients with Parkinson's disease⁵ and multiple sclerosis⁹ have been used to develop a framework for establishing case history details relevant to speech and communication, but this approach is time consuming and provides qualitative rather than easily quantifiable data, making it impractical for use in larger studies or routine clinical assessment.

The semantic differential technique^{10,11} is a validated tool that has been used to examine conceptual changes in varying health settings, including neurodegenerative conditions, stroke, head injury and psychiatry.^{8,12-14} The test requires respondents to select where their position lies on a scale between bipolar adjectives or statements chosen to represent key variables in the domain of interest. The technique can be used to measure changes in self-perception and is appropriate for use in large clinical studies. To our knowledge only one previous study⁸ has included people with Parkinson's disease when using this technique to examine the impact of speech and communication problems, though others have employed it to assess health professionals' impressions of people with Parkinson's.¹⁵

The aim of this study was to investigate perceived impact of Parkinson's disease on self-perception of communication using a semantic differential based questionnaire. We also sought to compare perceptions of people with Parkinson's disease with clinical measures of Parkinson's disease and with the views of their primary carer.

Methods

Participants

A cohort of 176 subjects with Parkinson's disease acquired from a combined community- and hospital-based screening programme (acquisition methods described elsewhere¹⁶) was invited to participate in the study. Primary carers of the Parkinson's disease subjects were also invited to participate.

Parkinson's disease participants met UK Parkinson's Disease Society Brain Bank criteria for the diagnosis of Parkinson's disease¹⁷; had no history of speech, language or cognitive difficulties prior to the onset of their Parkinson's disease, nor comorbid conditions that may be associated with communication changes (e.g. stroke, head injury). They were native speakers of English. The study had full approval from the Sunderland Research Ethics Committee.

Assessments were conducted with participants in a practically defined 'off' state (anti-parkinsonian drugs withheld since midnight prior to assessment). Measures included Hoehn and Yahr rating of overall Parkinson's disease severity,¹⁸ Unified Parkinson's Disease Rating Scale (UPDRS) II and III screening of severity and functional status,¹⁹ Mini-Mental State Exam (MMSE)²⁰ and the 15-point Geriatric Depression Scale (GDS).²¹

Approximately two weeks after these assessments subjects were visited at home by the speech study investigator. A battery of speech and voice assessments was conducted (again in an 'off' state), including a speech intelligibility test and the semantic differential questionnaire used for this study. The intelligibility measure was a 60-item diagnostic intelligibility test²² based on Yorkston and Beukelman²³ but with items designed for the local British English accent of participants rather than the American original. A matched control group of 40 unaffected speakers was used to establish normal cut-off scores and severity levels.

Perceptions of change questionnaire

The questionnaire comprised 22 bipolar adjective pairs (Table 2) related to how people might feel or see themselves when they are communicating.

Talkative very quite a bit half a bit quite very Quiet
and
half

Figure 1 Sample item and rating scale from semantic differential measure.

Candidate dimensions were derived from related literature^{7,13,15,24} and from conversations with people with Parkinson's disease and other neurological speech disorders not involved in the study in response to being asked to choose important ways in which they felt communicating had changed. The 22 pairs finally chosen were agreed with the informants as reflecting their experience.

Participants rated on a 7-point scale (see Figure 1 for example) on one sheet how they saw themselves as a communicator before they knew they had Parkinson's disease and on a separate sheet how they saw themselves in general over the last few weeks, ignoring particularly good or bad days. Respondents were supplied with written instructions for how to complete the scales and sample scored items (not occurring in the questionnaire) and explanations of what that score signified. Each item had its own set of boxes to tick with the descriptors at the top of the column. It was emphasized there were no right or wrong answers.

The direction of notional positive versus negative poles was varied across the questionnaire. Participants with Parkinson's disease and carers filled in the questionnaires independently without discussing answers before or during completion. Participating caregivers completed the questionnaire in relation to their perception of communication changes for the family member with Parkinson's disease.

Data processing

Total scores for perception of self as a communicator were calculated by summing scale points across the 22 items, giving a possible minimum 'negative' score of 22 and maximum 'positive' score of 154. The 'perceived change' score was obtained for descriptive purposes by subtracting the 'now' from the 'before' total and for inferential group comparisons and regression purposes by

dividing the 'before' score by the 'now' score. For the intelligibility test, the audio-recording of each speaker was rated by three different listeners from a pool of listeners unfamiliar with Parkinson's disease who were randomly assigned to five recordings each. The final score was the mean total words correctly recognised across these listeners. Data were processed using SPSS 14.0 using descriptive and non-parametric analyses.

Results

Of the 176 subjects with Parkinson's disease invited to take part in the study, 140 agreed to assessment of their voice and speech and received questionnaires. One hundred and four completed questionnaires were obtained. Summary details of these participants appear in Table 1. Eighteen questionnaires were not returned; 18 were returned incomplete. There were no significant differences between those returning completed questionnaires and other participants in terms of age, disease severity ratings, disease duration, depression, cognition, and intelligibility. Seventy-eight carers received questionnaires. Forty-five completed the questionnaire in relation to their family member with Parkinson's disease. Ten scripts were not returned, 15 were incomplete, two wrongly filled out and six were not used because their partner with Parkinson's disease had returned incomplete sheets.

Perceived degree of change in people with Parkinson's disease

Across the cohort of all Parkinson's disease subjects completing the questionnaire ($n=104$) there was a statistically significant perception of deterioration in communication after the onset of Parkinson's disease (pre-Parkinson's disease median score 128, interquartile range (IQR) 113–139; post-Parkinson's disease median score 100.5, IQR 82–122; $z=7.69$, $P<0.001$). There were no significant differences in degree of change by age or gender, nor by whether a carer was present or not.

Table 1 Age and clinical assessment details of participants with Parkinson's disease ($n=104$)

Measures	Mean	Median	SD	Range (IQR)
Age (years)	71.6	73	8.4	46–91 (67–77)
Time since diagnosis (years)	7.1	4	7.3	0–38 (2–10)
Hoehn and Yahr stage (1–5 severe)	2.4	2	0.9	1–5 (2–3)
UPDRS II (max 52 severe)	14.5	15	6.34	1–30 (10–19)
UPDRS III (max 108 severe)	33.5	32	14.7	8–73 (22–42)
Intelligibility (max 60; normal cut-off 51)	50.1	51	6.0	33–59 (45–54)
GDS ≤ 4 normal	4.5	4	3.2	0–14 (2–6)
MMSE ≥ 23 normal	25.0	27	4.3	8–30 (23–28)

IQR, interquartile range; GDS, Geriatric Depression Scale; MMSE, Mini-Mental State Exam.

Thirty-four (33%) people with Parkinson's disease and 17 (37%) carers rated 'after' status within 10 points of the 'before' score. Twenty-one (20%) people with Parkinson's disease and seven (15%) carers perceived a change between 11 and 20 points. Forty-nine (47%) people with Parkinson's disease and 22 (48%) carers gauged a difference >20 points. In the >20 points change group there were proportionately more people with Parkinson's disease with dementia ($n=15$, 62% of those with dementia, i.e. MMSE <23) compared with those without dementia ($n=34$, 43%), but the difference was not significant (chi-squared 3.98, $P=0.14$).

The median change ratio (before/after) was 1.16 (IQR 1.03–1.52). One person with Parkinson's disease perceived a significant change for the better of 70 points; and one carer a significant positive change of 37 points. These individuals are discussed below. Removing them from calculations did not alter any group comparisons from significant to non-significant or vice versa.

All individual tested domains were significantly changed for the worse in the Parkinson's disease group. Some domains were perceived as changed more than others. These data are presented in rank order in Table 2, with rank 1 indicating the most altered rating.

Perceived change: patients versus carers

In the subgroup for whom there were matched patient and carer completed questionnaires ($n=45$) for comparison, carers typically demonstrated a more optimistic median rating for before, after and ratio of change (Table 3).

Table 2 Questionnaire items rank ordered according to differences between before-now ratings for patients ($n=104$)

Feelings when communicating before Parkinson's disease (PD) diagnosed versus now	All PD Rank ($n=104$)	z all PD
In control–not in control	1	6.82***
Feel confident–not confident	2	6.50***
Get message over easily–difficult	3	6.49***
Speaking enjoyable–frustrating	4	6.37***
Feel adequate–inadequate	5	6.14***
Feel independent–dependent	6	6.05***
Clear–unclear	7	5.51***
Competent–incompetent	8	5.49***
Assertive–unassertive	9	5.18***
Leader at front–follower at the back	10	5.04***
Sociable–withdrawn	11	4.79***
Talkative–quiet	12	4.76***
Feel equal–unequal	13	4.60***
Relaxed–tense	14	4.43***
Not self conscious–self conscious	15	4.38***
Carefree–worried	16	3.95***
Intelligent–stupid	17	3.62***
Patient–impatient	18	3.59***
Speaking big role in life–not big role	19	3.31***
Caring–unfeeling	20	2.99**
Valued–worthless	21	2.99**
Friendly–unfriendly	22	2.96**

** $P\leq 0.01$; *** $P\leq 0.001$.

However, no differences were statistically significant.

There was a significant correlation between rankings of items for degree of perceived change between people with Parkinson's disease who have a carer and their carers ($r=0.59$, $P=0.004$). Nevertheless, there was some variation in the ranking of individual items across groups. Carers ranked changes in dependence at rank 14 whilst

Table 3 Ratings 'before' onset of Parkinson's disease versus 'present' for people with Parkinson's disease and their carers

	'Before' median (IQR)	'After' median (IQR)
Subjects with Parkinson's disease ($n=45$)	128 (116–139)	101 (85–121)
Their carers ($n=45$)	132 (121–144)	112 (86–123)

IQR, interquartile range.

it was at 5 and 6 for people with Parkinson's disease without and with carers. Carers ranked being more self-conscious (rank 4) and impatient (rank 8) as more pronounced than their partners (18 and 20, respectively). However, none of the perceptions of degree of change was statistically significantly different, except a borderline outcome for carers feeling their partners had not become less talkative ($z=1.86$, $P=0.06$) and carers not perceiving communicating as so frustrating ($z=1.93$, $P=0.05$).

Relationship of perceived change to other Parkinson's disease variables

Perceived change in communication scores (ratio of before to after totals) was examined in relation to other measures of Parkinson's disease status. Analysis of variables individually indicated a weak association of communication change with disease severity as measured by the UPDRS II and III (Spearman's $r=0.35$, $P<0.001$ and $r=0.30$, $P=0.002$), but not with Hoehn and Yahr status ($r=0.17$, $P<0.08$). Neither longer disease duration ($r=0.15$, ns) nor cognitive status ($r=0.12$, ns) were associated with greater perceived change in communication. The same held true for cognition when the subgroups with ($r=-0.015$, ns) and without dementia ($r=-0.009$, ns) were examined separately. Greater perceived change was weak–moderately associated with lower intelligibility scores ($r=-0.23$, $P=0.03$) and greater depression ($r=0.39$, $P<0.001$).

To examine the possible relative strength of association of these variables to perceived change they were entered into a linear regression model for prediction of change ratio. Entering all factors produced $r=0.54$ ($R^2=0.29$; adjusted $R^2=0.25$). A model retaining GDS and UPDRS II gave $r=0.53$ ($R^2=0.28$; adjusted $R^2=0.27$).

Partial correlations for MMSE score with change scores, controlling for the other entered variables, were non-significant for the subgroup without ($r=-0.04$, ns) and with dementia ($r=-0.16$, ns).

To further examine the association of depression ratings to perceived change a partial correlation was conducted entering all above features as control variables. This resulted in $r=0.43$ ($R^2=0.18$, $P<0.001$) of GDS with change ratio. All people with Parkinson's disease were divided into groups with no depression (GDS score 0–4, $n=59$), mild depression (GDS 5–7, $n=27$) and moderate–severe depression (GDS ≥ 8 , $n=18$). Analysis of covariance, with 'before' total scores, MMSE, intelligibility, UPDRS II and disease duration as covariates showed a significant difference between groups in terms of perceived change ratios ($F=13.59$, $P<0.001$).

The profile of change across items was compared for the subgroup with versus without dementia. Overall change scores were borderline more severe for those with dementia ($P=0.055$). Nevertheless people with dementia perceived themselves as significantly more dependent ($P=0.003$), more frustrated ($P=0.008$), more withdrawn ($P=0.03$), less confident ($P=0.04$), less able to get their message over ($P=0.04$) and less carefree ($P=0.03$). They were also older ($P=0.04$), more depressed ($P=0.02$), less intelligible ($P=0.001$) and had a worse UPDRS III rating ($P=0.02$), but not Hoehn and Yahr stage ($P=0.21$).

Discussion

The main finding of this study is that, almost without exception, Parkinson's disease exercises a negative influence on communication, irrespective of age and gender. The results underline that the extent of perceived impact bears only a weak

relationship to other speech, demographic and disease severity measures. Only level of depression appeared to have an association with perceived 'after' scores, though even here the correlation was modest. It is perhaps noteworthy that one of the stronger correlates of change was the UPDRS II score, which derives from patients' own views as opposed to clinician ratings.

In general, individuals sense they have lost control in communicating, are less confident, find it difficult to get their message across, with consequent frustration, feelings of inadequacy and sense of loss of independence. Precisely these feelings may lead to withdrawal from communicating, passing over the burden of communication to carers, independent of any objectively measured decline in underlying speech skills.⁵ By contrast, people still felt as if they conveyed a sense of friendliness, caring and being valued.

The fact that speaker and carer independently agreed on communicative status before Parkinson's disease suggests that people with Parkinson's disease were not viewing their former self with retrospectively distorted 'rose-tinted' glasses. That people with Parkinson's disease generally viewed changes as more extensive suggests that carers may not necessarily appreciate the full consequences for their partner of how far communication changes have impacted on them. Further, it contradicts views of those²⁵ who feel that a feature of many with Parkinson's disease is that the person is unaware of the extent of their communication impairment. However, ratings were dependent on the memories of both people with Parkinson's and carers. It is conceivable that they shared an over-optimistic view of the past. Future work should track perceptions longitudinally with respondents recording perceptions at the current time-points to remove the element of possibly distorted retrospection.

The rank order of dimensions attained broad agreement between people with Parkinson's disease and carers. There were divergences. Carers did not perceive difficulty conveying messages, loss of independence, being less talkative and feelings of inadequacy as so acutely felt. They rated being more self-conscious and showing impatience as higher. It is conceivable that these are the manifestation to carers of the feelings of inadequacy and frustration.

There were hints at differences between people with Parkinson's disease with and without carers that suggest lines of further enquiry. In terms of group rank orders Parkinson's disease speakers without a carer recorded more difficulty getting their message across, being more unclear, more self-conscious when communicating and less valued and quieter. Speculatively, these differences in ranking could relate to the absence of a sympathetic, informed listener and someone who can help or take over some burden of communication. Such a perspective accords with the view that communicating is very much a partnership and success stems equally from the role played by the listener. It would also emphasize the centrality of involvement of partners in work directed at communication.

Regarding depression, the present design does not permit us to state firmly the direction of cause and effect. Depression is a notable feature of Parkinson's disease²⁶ and clearly influences communication, both from the speaker's and the listener's perspective. Depression is also a common reaction to impaired communication.²⁷ Balancing this, amongst present participants there were individuals scoring within the normal range on the GDS who demonstrated a strong impact score, and conversely people with marked depression outcomes who evidenced minimal perceived communication change. Further, the dimensions perceived as being least affected by the full group of people with Parkinson's disease concerned more core personality traits such as being caring, friendly, feeling valued. Thus, whilst outcomes suggest there may indeed be some interaction between depression and altered communication, the link is not inevitable and interaction likely to be bidirectional. Further work is required to tease out the nature of the interaction of these factors.

Selected dimensions of change were significantly more affected in people with dementia, even though MMSE totals did not appear to exercise an independent effect. Participants with dementia were also older, more depressed, had lower intelligence scores and the subgroup distribution was skewed towards the mild end (MMSE IQR 18–22, with 11 in the range 20–22). Hence, again, this study is unable to definitively characterize the

interaction between presence of dementia and perceived impact.

We found no significant correlation of perceived change with overall severity measured by Hoehn and Yahr stage (though a weak association existed for the more sensitive UPDRS measure). This may be reflective of the common finding across chronic disabling conditions that physical change and cognitive, affective and social interactive impact do not mirror each other. A secondary factor may be the distribution of participants across Hoehn and Yahr stages. The cohort clustered around stages 2–3 ($n = 79$, 76%) with only $n = 13$ (12.5%) in 1–1.5 and $n = 12$ (11.5%) in 4–5. Whilst there were no significant differences between people recruited to the overall study who did or did not return questionnaires, our cohort was on average around six years younger (71 versus 77 years) and less likely to be living in residential accommodation than the whole population with Parkinson's.¹⁶

One carer and one person with Parkinson's disease perceived strongly positive consequences for communication after Parkinson's disease onset. The carer's explanation was that before her partner knew he had Parkinson's disease he realized something was wrong, even though he had been told all was well. From her perspective, this had had a pervasive negative effect, including on speaking. Once he had received a firm diagnosis he had felt reassured and become his former bright self. The person with Parkinson's disease felt coming to terms with having Parkinson's disease had given her 'the incentive to be positive in everything I say and do', to see what she was still capable of despite her Parkinson's disease. For her it was a matter of 'maintaining mind over matter'. These individuals add to findings from diverse conditions that disability associated with a chronic condition can also bring about change for the better.^{28–30}

Psychosocial barriers to communication associated with acquired neurological disorders can form a greater impediment to adjustment, acceptability and (re)integration than frank impairment changes, a phenomenon not unique to Parkinson's disease.^{31–34} Individual profiles indicate that these changes are perceived even early on in the course of Parkinson's disease, and in the presence of no apparent decline in intelligibility. As such they

may be hidden factors. Such a view also tallies with findings from other chronic conditions of a low correlation between physical, impairment changes and quality of life.^{35–37}

In terms of clinical implications, findings stress that any speech–language therapy work be geared as much to maintaining and re-establishing control and independence, seeking ways alone or in partnership with the listener of conveying messages clearly without frustrating hurdles, as focusing on impairment-directed therapy. Where the latter is instigated findings emphasize that this must be to the service of wider psychosocial ends. There also exists an argument for early referral for evaluation of communication changes extending to psychosocial impact, and not focusing narrowly on voice and speech alteration. If one waits until these become obvious, the person may well have developed such feelings of loss of control and confidence that these become significant added barriers to improvement in speech.

Finally, we have concentrated on overall findings. Summing scores across 22 items enabled us to present group trends on this particular set of domains, but inevitably masked variability in individual profiles of impact and leaves open the issue of the generalizability of the item set. The potential strength of the semantic differential technique lies in an individual focus and what it can offer as a measure of rehabilitation planning and outcomes. Inspection of individual profiles should permit greater insights into that individual's perceptions, as an end in itself, or in comparison to past status, carer perceptions, a wished-for state after rehabilitation. The technique also permits construction of dimensions chosen by the individual against which to rate perceived differences.¹⁰

To strengthen the validity of the instrument as a general assessment tool requires validation against matched participants with no neurological involvement; searches for factors possibly unique to people with Parkinson's disease would necessitate comparisons with populations with other neurological conditions.

Despite these unanswered questions, we argue that the present study delivers important insights into the nature of perceived communication changes in people with Parkinson's disease

Clinical messages

- Perceived impact of communication changes bears only a weak relationship to other speech and Parkinson's disease measures.
- Speakers and carers agreed communication status before Parkinson's disease; however carers tended to view changes as less extensive.
- Early perceived changes with no apparent decline in intelligibility points to early referral for evaluation of communication.

and illustration of a methodology that is readily transferable to other populations.

Competing interests

None declared for any authors.

Contributors

NM participated in the original initiation and design of the study; devised and piloted the questionnaire items used; took part in recruitment; conducted data collection, processing and analysis. He was the principal investigator and the lead author in preparing drafts.

EN participated in speech data collection and processing, and critically commenting on drafts and final version.

DJ participated in the original initiation and design; in overall conduct/monitoring of the study; and critically commenting on draft versions of the work.

LA participated in recruitment, data collection and reviewing and critically commenting on drafts and final version.

DB participated in the original initiation and design, in data collection and reviewing and critically commenting on drafts and the final version.

Acknowledgements

The authors gratefully acknowledge funding from the Parkinson's Disease Society, UK. LA was supported by an NHS Research

and Development Training Fellowship RRCC/01F/019.

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