

Voice treatment in Parkinson's disease: patient perspectives

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Abstract: Speech and voice changes are a central feature of the symptom complex of people with Parkinson's disease (pwPD). Speaking is a social activity involving the pwPD, family, and the wider communicative context. Sensory-motor, cognitive-linguistic, and affective changes in Parkinson's disease (PD) combine to alter communication, impacting on psychosocial quality-of-life, leading to risks of social withdrawal and increased depression and anxiety. The underlying pathophysiology of speech, voice, and communication difficulties in pwPD is multi-factorial and complex. Sensory-motor changes in the respiratory, phonatory, and articulatory subsystems, underscaling of effort, and central processing problems are further affected by broader cognitive-linguistic difficulties, and non-speech motor deficits. Many studies show that, when pwPD are asked to rate their own voice and how it functions in everyday situations, they show increased voice-related disability and negative impact relative to healthy controls. Voice treatment is integral to improving communication in pwPD. Studies show positive benefits from the perspective of pwPD and carers. Treatment approaches vary from one-to-one to group interventions, a singular focus on increasing loudness to more general voice exercises, and choral singing. The nature and underlying pathophysiology of speech, voice, and communication changes in pwPD are reviewed before exploring the effects of voice treatment programs and pwPD and carer perceptions of their effect. Larger scale, better powered, controlled trials of intervention for voice and speech that measure clinically and socially relevant outcomes are finally underway. Future research should also focus on issues of treatment compliance, practicality (for service delivery and use), and long-term follow-up outcomes. The role of carers in longer-term maintenance represents a further important area of exploration.

Keywords: voice, speech, treatment, quality-of-life, patient perspectives

Introduction

Motor and non-motor changes relating to spoken communication are commonly experienced by people with Parkinson's disease (pwPD).¹⁻³ Indeed, changes to voice quality and loudness frequently represent the first signs for pwPD and their family that something is amiss.⁴ Communication ability can be altered by (a) direct effects from motor changes to respiratory, laryngeal, and articulatory movements, and (b) cognitive (eg, language processing) and affective consequences (eg, depression or anxiety). Several other common disruptions to oro-motor functioning, including dysphagia and sialorrhea, may also exercise secondary effects on speech and voice.⁵ (Miller N, Walshe M, Walker R. Sialorrhea in Parkinson's Disease: Prevalence, impact and management strategies, personal communication, March 2019). Several recent articles have reviewed the nature of speech and language changes encountered by pwPD.⁶⁻⁸ However, one area of relative neglect concerns

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issues around the effects of communication changes on daily living as perceived by the pwPD themselves and their carers. Coupled with this is the issue of how best to capture these perceptions in clinical treatment planning and in the evaluation of outcomes, especially important given the renewed emphasis across recent years to focus content of intervention and measurement of outcomes on patient reported and preferred variables. This represents the focus of this invited review. It aims to provide an update for speech and language therapists/pathologists, and other professions involved in supporting pwPD and their carers on the issue of how communication changes are viewed by those directly impacted and the clinical practice consequences of these changes.

The state-of-the-art review first briefly outlines the scope of communication changes in pwPD and their relationship to more general underlying pathology before focusing centrally on the remit of patient and carer perspectives of these changes and treatment programs designed to address them. Although the title states “voice” treatment, we interpret that here to encompass all aspects of spoken communication—respiration, phonation, prosody, and articulation. For this paper we interpret patient perspectives regarding voice treatment as meaning one or all of the following: the use of patient chosen or patient reported outcome measures (PROMs); documentation of pwPD reports of the impact of communication difficulties on everyday living; pwPD views of the process of voice treatment and of speech and language therapy (SLT) intervention in general; and patients’ contributions to the design of voice treatment. Although the perspectives of pwPD are a key focus of this paper, we also considered the perspectives of a spouse/carer of a pwPD as integral.

Identification of studies for review entailed a literature search of Ovid Medline and CINAHL to identify relevant papers published between 2008 and 2018. Subject headings (MeSH) and text words relating to Parkinson’s disease (PD), Speech & Language Therapy, voice treatment, treatment outcomes, patient reported outcomes, and quality-of-life were used, with the search limited to the English language. We included studies published between 2008 and 2018 which had voice/speech treatment as a main focus, which included PROMs and/or sought to obtain the perspective of pwPD on voice/SLT treatment. The initial search yielded 75 articles of potential interest. We excluded papers if: they were not written in English; did not have voice treatment as the main focus; or did not include a PROM and/or information pertaining to pwPD

perspectives on voice/SLT treatment. Sixty papers were excluded on this basis, leaving 16 papers for analysis. Any additional papers meeting inclusion criteria identified from reading the selected articles were also included in the review.

Speech and voice changes in PD

Up to 90% of pwPD report changes to their speech and voice^{3,9–11} with around 50% experiencing deterioration which renders it difficult to make themselves understood to strangers.⁹

The underlying pathophysiological bases of voice, speech, and language changes in PD are complex. Voice quality changes, reduced loudness, loss of intonation variation, and imprecise articulation relate in part to rigidity and stiffness in the oral, laryngeal, and respiratory muscles.^{12–15} However, stiffness and rigidity are insufficient to totally account for changes.

A crucial common denominator that appears to link impairment of articulatory movements, voice production, hand gestures accompanying speech, as well as many other non-communication related motor responses, concerns a failure to adequately scale the dynamics of movement to achieve the required range, force, and velocity, even though basic tone, power, and coordination are sufficient to do so.^{13,14} Further, pwPD exhibit reduced awareness of the extent and consequences of the under scaling. This appears associated with a deficit in central sensory processing.^{16,17} Thus, the pwPD is able to achieve adequate loudness, articulatory precision and emphasis when specifically asked to do so—even though increases in loudness may not match those that unaffected speakers make when asked to speak loudly.^{18,19} However, the pwPD may find it difficult to maintain these features during general conversation.

It is also important to emphasize that changes in language processing affect the speed at which pwPD can formulate and follow utterances, and can result in some distinct cognitive-linguistic impairments.^{11,20–22} Importantly, changes may not involve just expressive spoken communication but may also include the understanding and following of the speech of others. These receptive difficulties apply to prosody too. PwPD are poorer than people without PD at comprehending the tone or implications of an utterance that are signaled in the prosodic content.^{13,17,23,24} Issues with understanding the prosodic content of others’ utterances as well as producing adequate prosodic cues on the part of the pwPD have been particularly linked to the expression and understanding of

emotional content.^{14,25,26} Together, the cognitive-linguistic and prosodic disturbances commonly result in carer reports that their partner with PD no longer seems to appreciate humor in the way they used to or regularly misunderstands conversations where the message relies on decoding prosodic, lexical, or syntactic subtleties.

PwPD perspectives on change in speech and voice

In terms of pwPD perspectives, impaired communication results in significant restrictions on daily living activities and social participation, and is strongly associated with reduced quality-of-life.²⁷⁻³³ Perceived impact can be significant for the pwPD, even when listeners detect no apparent major issues with voice and speech.^{28,30,34-36} PwPD describe their voice as too quiet, or volume fades fast over an utterance or in conversation; they describe voice quality as hoarse, breathy, tremulous, and that they have difficulty initiating or sustaining utterances.^{37,38} Freezing of voice can be as troublesome as freezing of gait.²⁷ Disturbance to speech prosody (stress, intonation, rhythm of speech) is also described as a strong feature.³⁹⁻⁴¹ PwPD report the frustrations of listeners seeming to misunderstand or miss the emotion they are aiming to convey, or the constant feeling that people believe them to be depressed, disinterested, and unmotivated when they are not.⁴²⁻⁴⁴ Such impressions are reinforced by hypomimia.^{45,46} To listeners, articulation may sound distorted or sounds omitted and/or syllables and words slurred together, which may give the impression that the pwPD is speaking too fast. Listeners also describe sudden rushes of accelerated speech, maybe in an attempt to complete a sentence on insufficient breath.

Such insights illustrate how challenges in communicating go well beyond (just) a quiet voice. Furthermore, difficulty initiating voice often means the pwPD is unable to signal they want a turn in conversation, with the situation not aided by a masked expression which removes the usual facial expression cues one gives to others that one wishes to say something. Hesitancy and pauses once a pwPD commences speaking may be mistaken by listeners that a turn was not wanted after all or the pwPD has finished their contribution. Conversations require sustained attention with complex switches in topic and between speakers; they require fast processing of what is said and, if a reply is to be made, rapid formulation of a reply. Typically several strands of conversation have to be attended to simultaneously, and speaking is often

performed alongside other motor activity (eg, walking and gesturing). Therefore, communication takes place in a dual or competing task situation and all of these demands represent areas affected in pwPD.^{26,47}

However, voice and speech convey much more than merely linguistic messages. They are integral to one's view of oneself and how people perceive you. Voice and speech convey ones personality (eg, warm, distant, friendly) and how one is feeling (eg, happy, sad, anxious, tired, excited). Voice and speech also signal ones gender, age, class, geographical provenance, as well as ones hopes, allegiances, and aspirations.⁴⁸ Changes to how all these are signaled when one has dysphonia, dysarthria, dysprosody, and altered language processing can seriously alter ones confidence in the view of oneself, and the view that others might hold of a pwPD. More broadly, people with acquired motor speech disorders similar to pwPD have reported these changes as a kind of personality theft.^{49,50} They feel unable to convey the deeper message they intend, and feel that listeners continually misinterpret the sentiments, emotions, beliefs, and affective intentions they wish to convey. Loss of the ability to communicate in the way they used to, the way they wish to, may lead to a sense of bereavement as much as losing a limb, eyesight, or a friend.⁵¹

These factors translate into common threads in reports from pwPD about how communication changes impact on them and their families. In a questionnaire survey,^{10,30} pwPD rated themselves (compared with before they had PD) as less in control in conversations, that communication was more frustrating, that it was harder to get the message across, and that they felt less confident, less adequate, and less independent. Interviews with pwPD^{27,33} disclose concerns over the effort (and consequent added fatigue) involved in communicating, challenges from the vigilant attention required, and from the physical challenge of sustaining intelligible speech. Speakers felt they had to make decisions between not always joining in conversations in order to conserve energy but at the same time not wishing to withdraw from social discourse altogether. Frustrations arose too from people talking across them, not permitting enough time for responses, having to repeat over and again, and from being perceived as muddled or stupid. In addition to coping with the impairment arising from communication changes, pwPD also have to cope with issues of loss of confidence, social withdrawal, and change in personality.^{27,30,33,50}

Such reports are consistent with the growing emphasis on patient-centered care and the shift from a narrow focus purely on speech-voice mechanics.⁵² People experience dysarthria differently, and personal context (including co-existing physical disability) is important in deciding the nature (and delivery) of treatment.^{28,50,53,54} Yorkston et al⁵⁵ identify five important themes to consider in treatment for pwPD: (1) the difficulty of thinking about how to speak as well as what to say (thinking about speaking); (2) fatigue related to trying to “make the unconscious conscious” (weighing value vs effort); (3) expressions of frustration, embarrassment, and loss (feelings about speaking); (4) the distracting effect of PD on the other person (people and places); (5) waiting until medication takes effect to talk (PD and speaking). Spurgeon et al⁵⁶ describe four further considerations: (1) emotional reactions (eg, frustration, embarrassment, lack of confidence, anxiety); (2) physical impact (eg, fatigue, breathing, and swallowing); (3) practical aspects (eg, cost of treatment, waiting times), and (4) expectations about treatment (met vs unmet expectations).

These points offer a number of important implications for assessment and intervention, as discussed in the next section.

Assessment considerations

Traditional assessment of PD speech characteristics concentrate on assessing speech/voice loudness (habitual loudness and variability of loudness), voice quality, articulatory precision, prosody, and intelligibility.^{54,57,58} However, the patient and carer experience require detailed assessment too, in particular for how communication changes impact on daily living and psychosocial well-being. Increasingly attention to this aspect of outcomes is attended to through use of patient reported outcome measures (PROMs).

Studies summarized in Table 1 show that PROMs are utilized to some extent in treatment studies using the LSVT[®] programme^{56,59–62} variants of LSVT,^{63–65} and programs based on singing and group voice treatment.^{65–68} The measures are widely used in voice clinics, and include the Voice Handicap Index (VHI),⁶⁹ the Voice Activity & Participation Profile (VAPP),⁷⁰ and the Voice Related Quality of Life Measure (V-RQoL).⁷¹ PROMs, in addition to measuring disability, allow the clinician to measure the effect of intervention on a person’s quality-of-life regarding activity and participation in social situations. Several such tools specifically devised for pwPD/dysarthria have been developed and psychometrically validated, including the use of semantic differential scales,³⁰ the Dysarthria Impact

Profile (DIP),⁵³ the Communicative Effectiveness Survey (CES),⁷² and the Communicative Participation Item Bank (CPIB).⁷³ Some studies have used questionnaires and/or interviews to find out from pwPD and spouse/carer what are the issues related to communication for them in daily living.^{2,33,56,65} Together the PROMs designed to measure disability related to voice/speech difficulties and first hand reports from pwPD and spouse/carer point to issues that should be addressed in treatment. These issues will be elaborated on in a later section, titled “PwPD perspectives regarding speaking and voice treatment”.

Treatment outcomes relating to PROMs and patient perspectives

Intervention that focuses on improving loudness, articulatory precision, and unambiguous prosodic signals is a first step in rehabilitation. However, communication is social and, hence, rehabilitation must also address how to employ improvements to gain entry to and maintain an individual’s part in conversations. Further, as problems maintaining intelligibility increase in dual- or competing task contexts, intervention should employ methods that tackle maintenance and generalization of communicative competence outside the clinic room in naturalistic environments that are inherently of a dual and competitive task nature. The treatment studies summarized in Table 1 highlight that different approaches (eg, LOUD[®], LSVT variations, standard SLT treatment, voice/singing) and different treatment contexts (one-to one, group, online) have been used.

Considering the salience and functional impact of loudness deficits in pwPD, it is not surprising that a major treatment focus has been on increasing loudness levels (also measured sometimes as sound pressure level, SPL) in an effort to improve overall intelligibility. The Lee Silverman Voice Treatment (LSVT[®]) approach developed pre-existing attention to effort techniques to specifically address this.⁶² The main outcome measures are SPL when producing a prolonged /a/, and intelligibility rating of a reading passage and conversational speech. In addition, the LSVT[®] program evaluates the perception of the spouse/carer regarding a range of parameters, including loudness, intelligibility of speech, initiating conversation, using a 100 m visual analog scale (VAS).

The effect of treatment on voice disability, communicative function, and social interaction and the duration of any treatment benefit is highly relevant. Table 1 summarizes the findings of treatment studies (2008–2018)

Table 1 Summary of treatment studies incorporating patient perspectives and/or self-report measures

Study	n	Study design	Voice treatment	Outcome measures	Self-report/patient perspective findings	Level of evidence
Whitehead ³³	4 pwPD, 4 spouses	Semi-structured Interview pwPD: Effect (physical) of communication changes & perception of effect Spouses: perspective of communication changes	N/A	N/A	pwPD expressed changes to “identity”; “communication”; “psychological”; “social changes”; & “how I used to be”	N/A
Miller et al ²	168 pwPD, 47 carers	Survey Questionnaire Views re communication & swallowing Changes & support they envisage needing Feasibility study	N/A	N/A	Generally positive experience re SLT Not everyone who wanted SLT received it Suggestions from pwPD re service issues	N/A
Searl et al ⁶⁵	15 pwPD	Feasibility study	8-week voice group “mimicking” LSVT [®] Weekly 90 minute session, 8 consecutive weeks	1. Questionnaire pwPD 2. VHI 3. Vocal intensity (dB) 4. F0 5. MPT	1. Answered 7 questions (voice/speech change, strategies to increase intelligibility, change in amount of talking, focus & what not like about group) 2. Total meanscores pre–post treatment 50.40 ±22.49–35.80±20.79, P=0.004 1. Total mean scores pre–post treatment (22.4–24.34, P=0.96)	Level 3
Elefant et al ⁶⁶	10 pwPD	Feasibility, repeated study Group music therapy x1 group	Voice & singing therapy 60 minutes weekly x20 consecutive weeks	1. VHI 2. Speaking 3. Singing 4. Depression	1. Total meanscores Immediate group: 45.6 ±20.9–36.6±18.3–31.0±13.3 (n/s) Delayed group: 43.1±14.9–34.0±13.1 –42.8±20.3 (n/s)	Level 3
Halpern et al ⁵⁹	16 pwPD, 8 carers	RCT Immediate treatment (n=8) Delayed treatment (n=8)	LSVT [®] face-to-face with assistive technology (LSVT companion)	1. VHI 2. LSVT VAS (carer) 3. CETI-M (carer) 4. SPL 5. Perceptual rating of sentence pairs		Level 3

(Continued)

Table 1 (Continued).

Study	n	Study design	Voice treatment	Outcome measures	Self-report/patient perspective findings	Level of evidence
Shih et al ⁶⁷	15 pwPD	Pilot open label	Group choral singing 12x90 minutes/ weekly sessions	1. VHI 2. VRQoL 3. SPL (connected speech) 4. Max cued volume & phonation time /a/ 5. Average speaking F0 6. Pitch range 7. S/Z ratio	1. Total mean±scores 43.7±22.2–47.0±15.4–47.9 ±21.0 (P=0.84) 2. Total score 69.2±18.0–70.6±19.4–68.1±24.0 (P=0.90)	Level 3
Simberg et al ⁶⁴	6 pwPD, 4 carers	Prospective 15 day in-patient rehabilitation course (10 & 5 days, separated by 3 month break) Individual (10x30 minutes) & Group (9x60 minutes) Spouses of 4 pwPD attended last 2 days of part 1 of course	Proprioceptive awareness, Vocal loudness intonation (LSVT approach)	1. VAPP pwPD 2. Auditory perceptual Voice Quality (GRBASl) 3. Acoustic (F0 in speech) SPL (reading & speech)	1. Total mean ± scores 83±35–63±57–65±62 (p=0.294)	Level 3
Spurgeon et al ⁵⁶	9 pwPD	Retrospective Semi-structured Interviews (telephone)	NHS 6–8 sessions x60 minutes (not described) LSVT® 16 sessions x60 minutes LSVT®	Qualitative thematic analysis findings	Four key themes emerged • Emotional impact of therapy • Physical effects • Practical concerns • Expectations	N/A
Wight and Miller ⁶⁰	33 pwPD, 23 carers	Retrospective Clinical audit		1. VHI 2. Carer VAS ratings 3. SPL (prolonged vowels, reading, monolog)	1. Total median (IQR) scores pre–post: 54 (69–33) – 29 (43–12) P<0.001 12 months: 30 (42–25) P=0.01 24 months: 34 (45–22) P=0.173	Level 4
Dias et al ⁶³	20 pwPD	Prospective	Telerehabilitation LSVT-X	1. Structured questionnaire (4 questions: satisfaction with online approach & quality of audio/video recording 2. Voice quality rating	1. Online approach relative to face-to-face: 100% satisfied Satisfaction with online treatment: 80% very satisfied; 20% satisfied	Level 3

(Continued)

Table 1 (Continued).

Study	n	Study design	Voice treatment	Outcome measures	Self-report/patient perspective findings	Level of evidence
Stegemöller et al ⁶⁸	27 pwPD	Prospective pilot	Group Therapeutic Singing High dosage (twice weekly) Low dosage (once weekly) X8 weeks N/A	1. V-RQoL 2. Voice (intensity, duration, range) Respiratory (MIP & MEP) 3. Health QoL	1. Total meanscores pre-post High dosage: 22.2±2.9-17.2±2.3 Low dosage: 18.4±2.3-18.1±2.2 Pre-post testing: P=0.008 Interaction effect: P=0.017	Level 3
Yorkston et al ⁵⁵	24 pwPD (community dwelling)	Interview (face-to-face semi-structured) Qualitative Impact of communication disorder Some had/had not treatment	N/A	N/A	Two major themes: Speaking (physical & cognitive effort in a social context) Treatment Positive experiences Dissatisfaction (speech drills, exercises, lack of focus on social aspects of communication) PwPD enjoyed singing in a group format, regarded group as fun, social, and engaging, appreciated fellowship with other pwPD, felt more like a social or support group Reported improvements in breathing, and loud speaking	N/A
Stegemöller et al ⁷⁸	20 pwPD	Interview Qualitative content analysis	Group therapeutic singing x8 weeks (1-2 sessions weekly) Vocal exercises followed by group singing LSVT [®]	N/A	N/A	N/A
Moya-Galé et al ⁶¹	15 pwPD	Prospective	LSVT [®]	1. VHI 2. Conversational intelligibility score	1. VHI total meanscores pre-post-1 month 37.54±27.67-29.54±24.37-29.98±22.27 (not significant)	Level 3
Ramig et al ⁶²	81 pwPD 25 HC	Prospective un-blinded RCT LSVT LOUD LSVT ARTIC (articulation) UNTXPD (untreated PD)	LSVT [®]	1. CETI-M 2. SPL (reading, spontaneous speech)	1. Median (IQR) scores Change baseline-1 month: 13 (0.21) P=0005 Change baseline-7 months: 8 (2.15) P=0.0011	Level 2

(Continued)

Table 1 (Continued).

Study	n	Study design	Voice treatment	Outcome measures	Self-report/patient perspective findings	Level of evidence
Sackley et al ⁷⁴	89 pwPD	Pilot 3-arm RCT Feasibility study	LSVT® SLT (NHS) Control (No intervention)	1. VHI 2. V-RQoL 3. Additional voice, speech, QoL measures	1. VHI total mean±scores pre–3 months Mean difference (95% CI) LSVT: 42.2±20.2–33±22.4 NHS: 42±25.5–36±21.2 Control: 42±21.0–46±25.1 LSVT vs Control: –12.5 (–26.2 to 1.2) NHS vs Control: –9.8 (–23.2 to 3.7) 2. V-RQoL total mean±scores pre–3 months Mean difference (95% CI) LSVT: 20±8.9–18±7.8 NHS: 20±8.3–19±5.6 Control: 21±7.1–22±8.0 LSVT vs Control: –3.5 (–8.1 to 1.1) NHS vs Control: –3.2 (–7.1 to 0.7)	Level 2

Abbreviations: Fo, fundamental frequency; PD, Parkinson's disease; pwPD, people with PD; RCT, randomized controlled trial; VHI, Voice Handicap Index; V-RQoL, Voice Related Quality-of-Life Measure; QoL, quality-of-life; NHS, National Health Service; N/A, not applicable; HC, healthy controls; CETI-M, CETI-M Modified Communication Effectiveness Index; MPT, maximum phonation time; MIP, maximum inspiratory pressure; MEP, maximum expiratory pressure; SPL, sound pressure level; S/Z, S/Z ratio; VAPP, voice activity and participation profile; VAS, visual analog scale; SLT, speech and language therapy.

which incorporated a patient reported outcome measure (PROM) and/or sought to determine the perspective of pwPD of speech/voice and/or treatment. A range of PROMs including the VHI,^{59–61,65–67,74} the V-RQOL,⁷⁴ VAPP,⁶⁴ LSVT VAS,^{59,60} and CETI- M^{59,62} for spouse/carers were used to determine the effects of treatment.

The studies reviewed show a mixed picture regarding voice treatment effect on disability both in the immediate post-treatment and longer term period. Using the VHI in an 8-week voice group “mimicking” LSVT, Searl et al⁶⁵ reported a statistically significant reduction in VHI scores in the immediate post-treatment period whereas Elefant et al,⁶⁶ in a 20-week music therapy group, reported a slight increase (increasing disability) without significance post-treatment. Studies have also looked at the longer-term effects of intervention using the VHI.^{59–61,67} Moya-Galé et al,⁶¹ using LSVT[®], reported a reduction in scores without significance 1 month post-treatment. Shih et al⁶⁷ reported a slight non-significant increase in scores (increased disability) 3 months post-treatment using group choral singing. Halpern et al,⁵⁹ using LSVT[®] with assisted technology, reported a reduction in VHI scores without statistical significance 6 months post-treatment. Finally, in a retrospective clinical audit of pwPD receiving LSVT[®], Wight and Miller⁶⁰ reported a significant reduction (improvement) in VHI scores at 12 months, which was not maintained at 24 months.

Using different PROMs measures to the VHI, other studies also show mixed findings regarding the effect of treatment on voice disability and communication. Shih et al⁶⁷ found no significant change in VRQoL scores in the immediate or 3-months post-treatment period when pwPD engaged in a group singing therapy. Simberg et al⁶⁴ reported a reduction in VAPP scores (improvement) following an intensive 15 day rehabilitation course in speech and voice treatment 6 months and 12 months post-treatment without significance. Finally, using the CETI-M, which is a broader communicative measure than any of the aforementioned voice disability measures, Ramig et al,⁶² using LSVT[®] in an RCT, reported a significant change in median CETI-M scores at 1 and 7 months post-treatment.

To take a broader look at the level of evidence for voice treatment studies covered by this review, we also applied the Oxford Centre of Evidence-Based Medicine 2011 Levels of Evidence table,⁷⁵ which ranges from level 1 (systematic review of randomized trials) to level 5 (mechanism-based reasoning studies). Table 1 shows that

the majority of intervention studies (n=8) were prospective non-randomized controlled cohort studies (Level 3), but with two RCT studies (Level 2). Clearly a larger range of high quality (Level 2) intervention studies would strengthen the evidence base.

Improved social participation is an important indicator of treatment outcomes, since it shows that intervention has made a meaningful impact on the ability of a pwPD to do the things he/she wants and needs to do.^{53,72,73} The World Health Organization, International Classification of Functioning, Disability and Health (ICF)⁷⁶ defines participation as “involvement in life situations”. The Communicative Participation Item Bank (CPIB)⁷⁷ was designed as a self-report measure, intended for community dwelling adults across a range of communication disorders and life situations specifically to measure communicative participation. Used in a large cohort of 378 pwPD in the US and New Zealand, the CPIB results (alongside other PD specific, a Global Health Instrument, and self-report measures) showed that communicative participation in pwPD is influenced by demographic and disease-based variables.⁷³ The findings call for a broader view of the communicative experiences of pwPD. Increased use of the CPIB, DIP, and similar tools in future PD treatment studies would enhance the knowledge of pwPD communicative participation in everyday life and how it changes in response to SLT and/or voice intervention.

PwPD perspectives regarding speaking and voice treatment

Consistent with the growing emphasis on patient-centred care,⁵² we need to understand the issues for a pwPD communicating on a day-to-day basis and to hear their experience of living with a communication disability, their experience of voice treatment, and what they would like to see happen in the future. Important contributions emerge when patients and spouses are asked directly to give their opinions through interviews and surveys.^{55,56} When the views of 24 community dwelling pwPD were sought regarding their communication experiences, five subthemes emerged including: difficult to think about how to speak as well as what to say (thinking about speaking); fatigue related to trying to make the unconscious conscious (weighing value vs effort); expressions of frustration, embarrassment, and loss (feelings about speaking); the distracting effect of PD on the other person (people and places); waiting

until the PD pills take effect to talk (PD and speaking).⁵⁵

Regarding voice treatment and/or SLT, pwPD have reported positive comments in studies.^{54,56,64} However, since the focus of the above studies was to identify areas of potential improvement (rather than what SLT intervention is working well for pwPD), there is little elaboration in the studies regarding what pwPD and/or carers found helpful. PwPD commonly report the importance of peer support (meeting others with PD) during treatment.^{54,64,67,78} For example, the participants in Simberg et al's⁶⁴ 15-day treatment study emphasized the positive effect of peer support during the course which had combined one-to-one and group therapy. This is highly relevant feedback since the LSVT LOUD treatment approach delivered in a one-to-one context (face-to-face or remotely) is used more frequently than any other voice treatment approach for pwPD in many countries. Stegemoller et al⁷⁸ reported findings from an 8-week group program delivered by a music therapist to 20 pwPD, with a focus on voice exercises and singing. PwPD found the group fun, enjoyed the social aspect of meeting others with PD, and valued an outlet independent of family members and close friends.

Studies that have focussed specifically on pwPD perspectives provide valuable insight into the issues for pwPD embarking on a rehabilitation journey, and how SLT intervention could address these concerns.^{2,33,54-56} Using a survey approach, Miller et al² reported on 168 pwPD and 47 carers' views regarding SLT service provision relating to communication and swallowing. Their goal was to ascertain the issues that were a priority for attention for pwPD (those who had received an SLT referral, and those who had not), the methods of delivery and organization, and the level of support that might be favored. Pointers for improvement centered on the timing, intensity, duration, and access to SLT, as well as issues around transfer and maintenance of gains outside the clinic and (lack of) attention to psychosocial dimensions. Availability of ongoing support as the situation evolved and access to SLT when it was needed were two prominent features in pwPD feedback.

Other studies report negative issues which could impact adversely on rehabilitation outcomes. Spurgeon et al,⁵⁶ in a qualitative telephone interview pilot study of nine pwPD who had received voice treatment (NHS standard treatment or LSVT), found that emotional factors associated with having speech/voice problems and

treatment were the biggest issue for the interviewees.⁵⁶ The pwPD talked about the persistence of speech problems after treatment (the embarrassment, lack of confidence, disappointment, and anxiety related to their communication difficulties), and fatigue related to getting to and from sessions. On a practical level, issues related to the cost of treatment, waiting list times, and the actual clinical experience were also raised by pwPD during the interviews. A final issue emerged relating to met vs unmet expectations around therapy outcomes and maintenance of therapy over time. PwPD with high expectations from therapy were typically disappointed with the clinical outcomes and maintenance over time, in contrast to those with lower expectations, who gave more positive feedback on the process and the results.⁵⁶

These aforementioned studies provide important insight into the perspectives of pwPD regarding their lived experiences with a communication disability and their views on voice treatment. Another and often forgotten aspect is finding out from the pwPD spouse and/or caregiver their views on the impact of the communication disability on their relationship and social.

The spouse/carer perspective

Communication changes occur in a social context. Consequently, it is important to explore the views of the spouse/carer of a pwPD views concerning the communication difficulty, the impact on everyday living, social interaction, and emotional well-being, and the value of the treatment approaches. In Miller et al's² study, carers reported a number of issues in relation to their specific pwPD including "reduced loudness" (25%), a reluctance to engage in conversations (21%), social isolation (23%), and a reduction in confidence. Whitehead³³ interviewed three spouses of pwPD in a qualitative interview based study. The spouses considered that, for their respective pwPD, communication was limited because of a number of factors including speech & language changes, loss of confidence, and social withdrawal. These carer observations are clearly similar to the pwPD self-reports.

A number of carer's questionnaires,^{59,60,64} interviews,⁶⁴ and surveys^{30,54} have been used to as a voice treatment outcome measure. Wight and Miller⁶⁰ in their LSVT treatment study showed that spouse/carers rated all areas on the LSVT VAS as having improved significantly post-therapy. However, at 12 months, only perceived loudness, strain, mumbling, and intelligibility remained statistically

significantly above baseline with no significant gains persisting to 24 months. Halpern et al⁵⁹ used the CETI-M and the LSVT VAS with carers. The CETI-M asks significant others to indicate how effective they believe that the participant is at communicating in each of 10 different situations. Simberg et al,⁶⁴ in their interviewing of six spouses of pwPD post in-patient intensive treatment, focused on loud voicing and intonation, reported that all spouses had noticed a change in the voices of the respective pwPD, with voice being more vivid and expressive, easier to understand, and with no need for repeating utterance as before. These changes remained relatively constant 3 months after the first part of the course, when all the spouses were interviewed by telephone.

In conclusion it would seem that the carer's perspective of the impact of voice and speech therapy treatment provides valuable information, but is currently limited and worthy of significantly more investigation.

Conclusion

This review has highlighted that the motor changes of PD may influence voice and speech, but there are additional issues related to the disease process itself, including fatigue, cognitive decline, and medication effects that together impact on social functioning, and emotional well-being for the pwPD and his/her spouse.

This review shows that voice treatment studies (2008–2018) are primarily impairment focused, with PROMs used to measure disability pre- and post-treatment. Alongside this, some studies extend voice treatment into singing and group voice work, as an adjunct to traditional one-to-therapy, or as a sole treatment approach. A number of voice and speech therapy treatment programs show promise at improving speech and voice parameters as well as quality-of-life. In general terms, pwPD appear positive about SLT and/or voice treatment.^{54–56,62,64,65,78} However, it seems as though emotional factors and long-term maintenance issues are rarely addressed in current treatment programs.^{54,56}

Similarly, practical issues such as fatigue related to traveling to sessions, treatment cost, and waiting list times are rarely considered.^{54,56}

Moving forward, greater cognisance should be given to the lived experiences of pwPD (and their spouses) with a communication disability, and how SLT/voice treatment can best support the patient. Issues for consideration are optimum location for treatment (transport issues), timing

(medication-related), frequency and duration of treatment (fatigue), one-to-one and/or group treatment, etc.

Future research should also focus on treatment compliance, practicality, and long-term follow-up. It is acknowledged the carer of the pwPD is a key partner, especially for wider implementation and maintenance of gains and judging intervention efficacy.

Abbreviation list

CES, Communicative Effectiveness Survey; CETI-M, Modified Communication Effectiveness Index; CPIB, Communicative Participation Item Bank; GSI, Group Singing Intervention; HC, healthy controls; LSVT-X, LSVT extended; MPT, maximum phonation time; MEP, maximum expiratory pressure; MIP, maximum inspiratory pressure; NHS, National Health Service; N/A, not applicable; UNTXPD, Untreated PD; SPL, sound pressure level; VAPP, voice activity and participation profile; VAS, Visual Analog Scale; VHI, Voice Handicap Index; V-RQoL, voice related quality-of-life measure.

Disclosure

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