CLINICAL SIGNIFICANCE OF THE LEE SILVERMAN VOICE TREATMENT (LSVT) FOR PERSONS WITH PARKINSON DISEASE: A PILOT STUDY

by

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at

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For Dr. Karen Nicholson, whose too short life and career was largely dedicated to contributing important work to the literature and helping students reach their full potential

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Abstract

The present study investigated the clinical significance of the Lee Silverman Voice Treatment (LSVT). Participants with idiopathic Parkinson disease (IPD) received LSVT in a quasi-experimental repeated measures pre-post design. Individuals with IPD and their family members (FMs) completed communication-related quality of life (QoL) scales and open-ended interviews during three phases: pre-treatment, post-treatment, and 6 months post-LSVT. Social validation data were collected by having unfamiliar judges rate and make written observations of videotaped conversations across each phase.

Quantitative and qualitative analyses of communication-related QoL scales from participants with IPD and FMs revealed perceived improvements in voice and communication quality, on two of the three measures used, immediately after LSVT; but not in the maintenance phase. Unfamiliar judges did not perceive quantitative or robust qualitative improvements in the quality of the communication between the participant with IPD and their FM after LSVT. The clinical implications and recommendations of these results are discussed.

List of Abbreviations Used

DVD	Digital video disk
EBP	Evidence based practice
FM	Family member
IPD	Idiopathic Parkinson disease
LSVT	Lee Silverman Voice Treatment (Ramig et al., 1988; 1995; 1996; 2001)
MEC	Members of the extended community
PD	Parkinson disease
PRF	Perceptual Rating Form (Ramig & Fox, 2005)
QCL	Quality of Communication Life Scale (Paul et al., 2004)
RA	Research assistant
RCT	Randomized controlled trial
SLP	Speech-Language Pathology/Pathologist
SPL	Sound pressure level
VHI	Voice Handicap Index (Jacobson et al., 1997).

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Chapter 1: Introduction

Statement of Topic and Research Questions

Estimates suggest that over 100,000 Canadians are coping with Parkinson disease (PD) (Parkinson's Society Canada, 2005); of those, 89% suffer from related speech and voice impairments (Liotti et al., 2003). Parkinson disease causes rigidity and tremors of the vocal mechanism; resulting speech and voice impairments are known as hypokinetic dysarthria (Pinto, Thobois, & Costes, 2004). Dysarthria is a neurological motor speech impairment characterized by changes in the speed, strength, coordination, and/or range of movements of the speech musculature (Duffy, 2005). Thus, dysarthria results in reduced speech intelligibility and ability to function in communication situations, which can lead to social isolation and depression (Kuopio, Marttila, Helnius, Toiconen, & Rinne, 2000; Tickle-Degnen & Lyons, 2004). Treatment by speech-language pathologists (SLPs) may improve speech intelligibility (i.e., understandability of speech) and/or communication comprehensibility (i.e., understandability of communication through speech plus nonverbal cues).

Over the past four decades, SLPs have developed a variety of treatment approaches to improve communicative effectiveness for persons with PD. Traditional treatments included using rate control strategies to improve intelligibility (Dagenais, Southwood, & Lee, 1998; Hammen, & Yorkston, 1996), and the use of alternative or augmentative communication strategies¹ (Armstrong, Jans, & MacDonald, 2000; Beukelman, & Garrett, 1988; Yorkston, & Garrett, 1997). A review of the literature on

¹ Alternative and/or augmentative communication usually consists of a communication aid, such as picture/word boards or high technological device (e.g., a computer with speech output capabilities).

the efficacy of these treatment strategies revealed variable results across participants, usually with limited generalization and maintenance of trained skills (Yorkston, 1994).

The Lee Silverman Voice Treatment (LSVT) represents a paradigm shift in speech treatment for persons with PD. Using a standardized intensive treatment protocol, the goal of LSVT is to have the client use a good quality, louder voice 'automatically' in daily life (Dromey, Ramig, & Johnson, 1995; Fox, Morrison, Ramig, & Sapir, 2002; Ramig et al., 2001a; Ramig, Countryman, Thompson, & Horii, 1995; Ramig, Countryman, O'Brien, Hoehn, & Thompson, 1996). Ramig and colleagues have provided substantial efficacy data (i.e., statistically significant data in randomized controlled trials (RCT) under ideal conditions in the laboratory setting). Information regarding the clinical significance of LSVT, however, has not been published. Clinical significance can be thought of as the practical or applied value of intervention effects or whether the treatment makes a difference in everyday life. This is a broad concept that encompasses issues such as generalization and maintenance of treatment outcomes outside of the clinic environment, quality of life (QoL) effects, and social validity ratings.

The current study investigated the clinical significance of LSVT effects outside of the laboratory, using quantitative and qualitative methods to examine communicationrelated QoL and social validity outcomes. Communication-related QoL can be defined as the extent to which a person's communication acts, influenced by personal, environmental, and self-perceptual factors, allow for meaningful participation in daily life situations (Paul et al., 2004). Communication-related QoL scales and interviews were completed by participants with idiopathic Parkinson disease (IPD) and their family members (FMs). Data collection occurred at three different times: immediately prior to treatment, immediately after LSVT, and 6 months post-treatment. Additionally, social validation procedures were utilized to determine whether LSVT produced noticeable, and socially desirable, outcomes (Kazdin, 1977; Wolf, 1978).

The present study examined communication-related QoL and communication quality in the home of participants with IPD and their typical communication partners (i.e., FMs). Social validity ratings completed by unfamiliar judges were also examined. The following research questions were addressed:

- Does LSVT impact the participants with IPDs' perceptions of voice and QoL immediately post-treatment, as well as 6 months post-LSVT, based on communication-related QoL scales and open-ended interviews?
- Does LSVT impact FMs' perceptions of their spouse's voice and QoL immediately post-treatment, and 6 months post-LSVT, based on a communication-related QoL scale and open-ended interviews?
- 3. Will social validity ratings reflect changes in voice and communication quality immediately post-LSVT, and 6 months post-treatment, based on observations of two groups of unfamiliar judges: (a) members of the extended community who have minimal knowledge and experience with IPD, and (b) peers with IPD with no experience with LSVT or knowledge of the study?

Evidence Based Practice

In recent decades, medical treatments for diseases and disorders have been influenced by an increasing emphasis on the paradigm of evidence-based practice (EBP), which requires health care workers to employ treatments supported by scientific research (Evidence-Based Working Group, 1992). The former paradigm relied on unsystematic observations of clinical experience, common sense, and opinion of experts to diagnose and to treat illnesses. Limitations resided in the fact that anecdotal inference and intuition may be misleading and incorrect.

In contrast, EBP requires the health care worker to employ treatments that are supported by scientific research. Thus, health care providers are responsible for remaining current regarding the literature of their specialties. The EBP paradigm still uses the development of clinical experience, but via the clinicians' systematic recording of observations in a reproducible and unbiased fashion, as well as scientific data. Such procedures give rise to knowledge regarding diagnosis, prognosis, and treatment efficacy (Evidence-Based Working Group, 1992). Thus, it is assumed that use of EBP results in superior care (Chwalisz, 2003; Evidence-Based Working Group; Robey & Schltz, 1988).

The distinction between treatment efficacy and treatment effectiveness is generally related to the level of control under which the treatment is conducted, or the extent to which the measurement conditions are ideal versus 'real world'. Treatment efficacy refers to the probability that a treatment will be beneficial under ideal experimental conditions with respect to the following variables: selection of treatment recipients, selection and training of clinicians, treatment delivery, and outcome measurements (Carding, 2000; Robey & Schltz, 1988). The 'gold standard' of treatment efficacy research is evidence from RCTs, which determine whether treatment outcomes are treatment-specific and not the result of extraneous variables.

In contrast, treatment effectiveness refers to the probability or extent to which a treatment is shown to be beneficial under average or ordinary conditions (Carding, 2000). Treatment effectiveness research examines clinical outcomes obtained by more typical clinicians, under the circumstances of average clinical practice. Treatment effectiveness research also aims to evaluate the quality of the treatment, the benefits of the treatment in

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real life circumstances, and the generalizability of the treatment outside of controlled experimental conditions (e.g., generalization to QoL outcomes). For a treatment to be highly regarded, its effects should generalize and maintain outside of ideal clinical settings, and these effects should have an important impact on the client receiving the treatment and/or others in the environment. Furthermore, evaluating effectiveness is important for clinical, financial, and family-centered reasons (Carding).

Robey and Schultz (1998) suggested that a logical, ethical, and sequential process should be followed when testing the value of a treatment. To ensure high quality and valued results for clinical outcome research, a five-phase hierarchical model was developed for use in treatment research (see Appendix A) (Cullen, 1986; Gehan, 1961; Greenwald & Cullen, 1984; 1985; World Health Organization, 1975). The hierarchy is to be followed sequentially; first to develop the treatment and outcome measures in smallscale studies, followed by RCTs, and then additional studies of personal and financial impact of treatments (i.e., efficacy then effectiveness).

Relevant Research on Parkinson Disease

Overview of Parkinson Disease

Parkinson disease is a relatively common disease, usually affecting the elderly, with prevalence between 0.1% and 1.0% worldwide (Kolb & Whishaw, 2003). Simply put, PD is a degenerative clinical syndrome caused by disordered ganglia in the brain whereby dopamine neurons deteriorate, producing abnormalities in movements and behavior (Kolb & Whishaw). This disease is often divided into four classifications based on clinical origin, namely: (1) primary, or IPD, (2) secondary parkinsonism (3) Parkinson-plus syndrome, and (4) heredodegenerative diseases (Waters, 1998). A complete description of each classification of PD is beyond the scope of this document (for a review, see Waters). The present research focused on individuals with IPD. The four major symptoms of IPD include: resting tremors, rigidity, bradykinesia, and postural reflex impairment (Chou & Hurtig, 2005; Elmer, 2005; Kolb & Whishaw; Waters).

Idiopathic Parkinson disease usually begins insidiously between 40 and 70 years of age, and often progresses with a distinct clinical pattern of symptoms. Typically, this pattern begins with a unilateral resting tremor in one hand and slight stiffness in the extremities. The disease then progresses bilaterally resulting in poverty of movement and masking of facial expression with reduced eye blinking and emotional expression. Posture may become stooped and gait impaired. Speech becomes slow, quiet, monotonous, and difficult to understand. Dysphagia is present in up to 95% of people with IPD (El Sharkawi et al., 2002). People with IPD experience functional limitations (e.g., difficulties eating, bathing, dressing, walking, and voice production) that are commensurate with disease progression (Koplas et al., 1999). Additionally, they may experience a curious symptom, known as the 'on-off' phenomenon, due to the effects of certain medications. This phenomenon is characterized by fluctuations in hyperkinetic or hypokinetic states that can occur several times a day (Palmer, Schmier, Snyder, & Scott, 2000). The off-times are usually associated with the 'wearing-off' of the medication after prolonged use (Kumar, Huang, & Calne, 2005). This issue highlights the importance of consideration of the 'on-off' phenomenon and medication cycles in the experimental design of research involving persons with IPD (G. Turnbull, personal communication, September 22, 2005). Death is not a direct result of IPD, although it may occur from secondary causes (e.g., falling; respiratory complications) (Korell & Tanner, 2005).

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Dysarthria and Idiopathic Parkinson Disease

Many individuals with IPD suffer from persistent communication deficits (e.g., hypokinetic dysarthria), which is one of the most noticeable and devastating consequences of IPD for FMs (El Sharkawi et al., 2002; Kolb & Whishaw, 2003). As noted previously, dysarthria is a neurological speech disorder characterized by abnormalities in speed, strength, range, steadiness, tone, and movements required for control of the subsystems of speech production: respiration, phonation (i.e., voice), articulation, resonance, and prosody (i.e., stress and intonation patterns) (Duffy, 2005; Swigert, 1997). Hypokinetic dysarthria is manifested by a decreased range of movement of speech structures and impairments are primarily noticeable in voice, articulation, and prosody. Persons with hypokinetic dysarthria can present with inconsistent rate and short rushes of speech, reduction in loudness and pitch, poorly articulated consonants, and a breathy or hoarse voice (Duffy; Schultz & Grant, 2000). These dysarthric symptoms often result in reduced intelligibility because it is generally dependent on the quality of articulation, prosody, voice quality and loudness, and resonance (Yunusova, Weismer, & Kent, 2005).

Traditional Speech Treatment for Person's with Parkinson Disease

Historically, there was little research-based support or public confidence in speech therapy for individuals with IPD (Schultz, & Grant, 2000). Researchers found that the participants' speech seemed to improve during therapy, but revert back to pretreatment pathological patterns immediately after the session (Sarno, 1968). Thus, the effectiveness of speech therapy was thought to be limited. The reason for this immediate improvement, but lack of carryover, was likely a result of the client performing for the therapist, but unable to incorporate the therapeutic techniques into daily life. In other

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words, the individual was able to use the clinician's feedback (i.e., external cues) to execute the desired exercise while in the clinical setting. Due to an inability to accurately self-monitor performance, and without the immediate feedback from the therapist, this level of performance disintegrated outside of the clinic.

Research in the last several decades, however, has suggested that speech therapy for individuals with IPD is somewhat beneficial (e.g., Erb, 1973; Johnson & Pring, 1990; Le Dorze, Dionne, Ryalls, Julien, & Ouellet, 1992; Scott & Caird, 1983). Generally accepted practices of the 1980s and 1990s included treatment procedures that focused on posture, respiration, articulation, and prosodic aspects of speech. Alternative practices emphasized external device usage to modify articulation/rate or to improve the acoustic signal produced by the speaker (for a description of these devices see Schultz & Grant, 2000). Other techniques, such as picture/communication boards, were shown to be minimally efficacious (Yorkston, 1994). More recently, the emphasis for individuals living with IPD in speech treatment is on improved vocal function and quality. To date, the most efficacious therapy targeting vocal function is LSVT (Ramig et al., 1996; Ramig et al., 2001b).

Lee Silverman Voice Treatment

Core Components

The LSVT, developed by Ramig and colleagues (1995), was originally designed to modify laryngeal pathophysiology via intensive phonatory exercises for persons with PD. Ultimately, the purpose of the treatment was to allow individuals with PD use their voice more effectively (i.e., loudly) and automatically in daily communication situations (Ramig & Fox, 2005). Ramig and Fox suggested that PD results in disruption of internal cues for movement due to under-activation of the supplementary motor area of the brain. As such persons with IPD may have an over-active auditory cortex and hear their soft voice as adequate for communication. The LSVT seeks to recalibrate the auditory system, through mass practice, such that a loud voice becomes automatic for the client.

The primary principle of LSVT focuses on a single unifying system (i.e., phonation) and simplifying procedures for clients. Thus, clients are taught to focus on vocal loudness through repetitive modeling and instruction to "think loud" in a systematic hierarchy of simple tasks (Ramig et al., 2001b). Research has found that this emphasis on increased loudness results in increased phonatory and respiratory effort, as well as improved articulation (Ramig et al., 1995, 1996, 2001b).

Treatment Procedures

The LSVT protocol is delivered in an intensive format: 1 hour per day, 4 days per week, for 4 weeks. Within the first half of each LSVT session, the client participates in high effort repetitive tasks (i.e., sustaining maximum effort during phonation of 'ah' and to alternate the pitch of 'ah'); during the second half of the session, the client participates in carryover of the high effort phonatory behavior to increasingly complex and spontaneous functional speech tasks (Ramig et al., 1995). The client is consistently given feedback regarding loudness and voice quality and is instructed to gradually increase self-monitoring of voice/speech production. This treatment is thought to teach persons with PD to re-calibrate the amount of speech motor effort needed to produce a functional voice (Fox & Ramig, 2005; Ramig et al.).

Evidence for the Lee Silverman Voice Treatment

With respect to efficacy studies, LSVT is the most supported and well-researched voice treatment. Efficacy research has consistently indicated that LSVT is a successful method of treating voice disorders due to PD, when examining both short-term and long-term outcomes in ideal contexts (El Sharkawi et al., 2002; Fox et al., 2002; Huber, Stathopoulos, Ramig, & Lancaster, 2003; Ozsancak & Auzou, 2005; Ramig et al., 1995, 1996, 2001a, 2001b; Ramig, Pawlas, & Countryman, 1988; Sapir, et al., 2002; Spielman, Borod, & Ramig, 2003), as will be reviewed below.

Ramig and colleagues (1995, 1996) compared two forms of intensive speech treatment for individuals with IPD: a treatment developed to increase respiratory support for speech, and LSVT. Pre- and post-treatment outcome measures included the duration and loudness of sustained phonation of 'ah', loudness levels during oral reading of the 'Rainbow Passage²', and a monologue. Pitch was also measured by analyzing the average fundamental frequency and maximum high and low pitches produced. Results revealed that, although both experimental groups showed improvements, those who received LSVT demonstrated significantly greater, and more consistent, improvement in voice intensity and pitch variation immediately post-treatment. Moreover, results revealed that only the participants in the LSVT group maintained these voice improvements, in the laboratory setting, 12 months post-treatment. Further evidence for long-term maintenance of treatment effects was provided by an investigation that evaluated IPDs' phonation 24 months after completing LSVT (Ramig et al., 2001a). Results revealed that effects of

² The Rainbow Passage is a short reading which contains all the phonemes in the English language.

LSVT were significantly better than for the respiratory treatment at two years posttreatment when tested in an ideal experimental setting.

Ramig and colleagues (2001b) extended investigations regarding the efficacy of LSVT by comparing three groups: one experimental group of individuals with IPD who received LSVT, and two control groups: persons with IPD who underwent a high effort respiratory treatment, and healthy individuals who completed LSVT. Vocal intensity and pitch were measured in various tasks across treatment phases: immediately pre- and post-treatment, and 6 months post-treatment. Results revealed that participants with IPD treated with LSVT demonstrated significantly increased vocal intensity, while both control groups remained relatively constant across pre- and post-treatment phases. Thus, Ramig et al. suggested that treatment effects were not due to extraneous factors.

To investigate perceptual outcome variables of LSVT, Ramig and associates (1995) used a visual analog scale to determine FMs acoustic perception of persons with IPD's voice while reading a passage and during a conversational monologue pre- and post-treatment. Family members rated statistically significant perceptual improvements from pre- to post-treatment in loudness and intelligibility.

Overall, the literature suggests that LSVT is an efficacious voice treatment for persons with IPD (for a review, see Fox et al. 2002). Lacking from the literature surrounding this treatment, however, is evidence for its effectiveness. Thus, phase IV and V of EBP research (see Appendix A) is needed to establish the clinical significance of LSVT in typical contexts.

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Quality of Life and Idiopathic Parkinson Disease

Living with a chronic disease, such as IPD, can have a significant impact on many aspects of a person's QoL. Quality of life can be defined loosely as "perceptions of one's own position in life in the context of the culture and value systems where one lives and in relation to one's goals, expectations, standards and concerns" (The WHOQOL Group, 1996, p. 354). Quality of life can also be described as an individual's sense of self worth, purpose in life, autonomy, ability to assume worthwhile roles, as well as significant and intimate relationships (Koplas, et al., 1999). Given the many voice and articulation disturbances caused by IPD, it is not surprising that individuals with IPD report that speech issues negatively impact their QoL (Behari, Srivastava, & Pandey, 2005).

Decreased speech production poses communication problems for individuals with IPD. For example, they are often less able to enjoy speech-based activities (e.g., conversation); creating limitations for social and functional participation. An individual with speech related problems due to IPD may be forced to resign from his or her job prematurely, for instance. Due to the effects of bradykinesia, a person with IPD may require additional time to speak, resulting in impatience of the conversational partner. Thus, an individual with IPD may become self-conscious of his or her speech limitations and avoid various communication situations (e.g., dinner with friends) or feel that he or she can no longer fulfill previous community or family roles (e.g., read at church; discuss finances with the accountant). Social participation and one's concept of social roles are essential factors contributing to communication-related QoL (Levasseur, Desrosiers, & Noreau, 2004). Koplas and colleagues (1999) investigated specific QoL domains in persons with IPD, including specific symptoms, stage of the disease, and the extent to which participants felt they could control their symptoms. Results indicated that participants' perception of personal control over the parkinsonian symptoms was proportionally correlated to their global QoL. Given that LSVT purports to train individuals with IPD to use their voice more effectively and automatically, thus gaining further control over voice symptoms, LSVT outcomes may contribute to improved perceived QoL.

Quality of Life Measurement

The diversity of symptoms and management associated with IPD can affect the individual's physical, social, and mental well-being. The goal of most therapeutic interventions is to manage symptoms thus mitigating their negative effect on health related well-being and consequently improving QoL (Damiano, Snyder, Strausser, & Willian, 1999). As such, it is important to document these changes by incorporating standardized measures of health-related outcomes, such as QoL, in clinical studies (Sano, Stern, Marder, & Mayeux, 1990). A variety of measures have been used for communication-related QoL outcomes due to intervention. Those pertinent to this study include the Quality of Communication Life (QCL) scale (Paul et al., 2004), the Voice Handicap Index (VHI; Jacobson et al., 1997), and the Perceptual Rating Form (PRF; Ramig & Fox, 2005).

The QCL scale (Paul et al., 2004) (see Appendix B) was designed for use with adults with acquired communication impairments. This measure includes items to assess the functional impact of a communication disorder on an adult's QoL, particularly with respect to communicative contexts (i.e., leisure, work, psychosocial consequences). The QCL scale is completed by self-report using visual analogue scales. This tool was reported to be valid and reliable for persons with dysarthria due to progressive neurological disorders, regardless of age, gender, education level, severity of the disease, or race/ethnicity (Paul et al).

The VHI (Jacobson et al., 1997) (see Appendix C) is a statistically robust questionnaire that measures individual's self-perception of the psychological consequences of a voice disorder. This self-report inventory includes 30 questions, describing the individual's judgment of impact of the voice disorder on functional, emotional, and physical status, answered on a 5-item Likert scale. Authors of the test, as well as Ramig and colleagues, suggested that the VHI can be used to measure the effectiveness of specific treatment techniques and its functional outcomes (Hogikyan & Rosen, 2002; Jacobson et al.; Ramig, & Fox, 2005; Rosen, Murray, Zinn, Zullo, & Sonbolian, 2000).

The PRF (Ramig & Fox, 2005) (see Appendix D) is a visual analogue scale that was specifically designed to measure LSVT outcomes. As per Ramig and colleagues (e.g., 1995), the PRF was used to obtain the FM's ratings, of loudness, monotonicity, hoarseness, overall intelligibility, and the extent to which the participant with IPD initiated conversation.

Social Validation

Social validation measures are currently recognized as a valid and rigorous means of assessing clinically significant changes in treatment outcomes (Carr, Austin, Britton, Kellum, & Bailey, 1999; Hickey & Rondeau, 2005; Kazdin, 1977; Kenedy, 1992; Lapointe, Katz, & Braden, 1999; Wolf, 1978). Additionally, social validation represents a movement to go beyond clinical judgment or statistical significance of experimental tasks to encompass social desirability and importance of changes in behavior. Social validity has been used to measure consumer satisfaction, treatment acceptability, ecological validity, and the clinical importance of treatment outcomes (Kenedy, 1992). The ultimate purpose of social validation techniques is to answer the question: has the behavior changed, and if so, is the behavior and/or the process used to change it, socially valuable/desirable? Social validity measurement is thought to be a valid way of overcoming problems (e.g., artificialness; generalization to other environments) potentially associated with standardized tests (Carr; Kazdin; Wolf; Foster & Mash, 1999). In some clinical scenarios (e.g., discharge from hospital), social validation measures are reportedly more reliable than standardized testing (Lapointe et al).

A critical component of social validation is to determine the importance of outcomes for the client as well as others who may be affected by the treatment (Kazdin, 1977). One way to measure this is to have unfamiliar observers, or judges, rate the clients' behaviors pre- and post-treatment. Unfamiliar judges may include: (1) indirect consumers, or those who pay for, or are affected by, the intervention, but are not directly involved in the treatment (e.g., indirect consumers may be peers with IPD), and (2) individuals who were not involved in the treatment in any way but have an investment in the treatment nonetheless, such as a financial stake via paying into healthcare. These individuals may include members of the extended community, or the general public (Schwartz & Baer, 1991).

When collecting social validity data pre- and post-treatment, Kazdin (1977) suggested using rating scales, providing clear, concise, and relevant rater instructions,

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using judges who are competent in identification of the target behaviour (i.e., conversational voice in this case), and using judges who are peers of the study participants. In terms of social validation for communication purposes, others (e.g., Hickey & Rondeau, 2005; Lapointe et al., 1999) have suggested that individuals from the general public should serve as unfamiliar judges, as they represent those with whom participants may interact with on a daily basis. Researchers (e.g., Carr et al., 1999; Hickey & Rondeau; Kazdin; Kenedy, 1992; Lapointe et al.; Wolf, 1978) suggested that failure to use social validation measures may jeopardize the understanding of the treatment's clinical significance, potentially compromising knowledge regarding its true utility or importance.

Justification of the Current Study

Based on substantial efficacy data, LSVT represents a paradigm shift in speech treatment for IPD. Whereas previous efforts focused on adapting communication strategies for slowly progressive dysarthria, LSVT focuses on improving the speech/voice mechanism and has been shown to have long-term benefits in ideal experimental settings. The clinical significance of LSVT (e.g., effects on communicationrelated QoL and social validation) has not been examined. Given the significant resources being expended on LSVT (e.g., time, finances, effort by clinicians and clients), researchers and clinicians must determine whether LSVT produces lasting results on communicative function in the home environment, and whether the procedures and outcomes are important and acceptable to clients and their FMs. Thus, this study sought to expand the literature surrounding LSVT by investigating its clinical significance in persons with IPD. This research examined various aspects of communication-related QoL, and features of social validity, as judged by members of the extended community and peers with IPD.

Hypotheses

Previous studies of LSVT have repeatedly demonstrated positive outcomes in experimental settings. Participants with IPD and their FMs, therefore, were hypothesized to perceive improvements in voice quality, ultimately leading to perceived improvements in communication-related QoL outcomes. Additionally, unfamiliar judges were hypothesized to notice significant improvements in voice and communication in naturalistic settings. More specific hypotheses are described below:

- Participants with IPD were expected to have a higher perceived communicationrelated QoL immediately post-LSVT, likely due to their improved ability to communicate. This improvement was anticipated to decrease 6 months posttreatment, but not to pre-treatment levels.
- 2. Family members were expected to perceive a louder voice and overall improved communicative effectiveness of the participants with IPD immediately post-treatment. This improvement was presumed to decrease 6 months post-treatment, but not to pre-treatment levels.
- 3. When compared to pre-LSVT, unfamiliar judges would rate post-LSVT conversations as having improved voice quality, loudness, and overall communication. Treatment effects were expected to be noticed by the judges at 6 months post-LSVT, but to a lesser extent.

Gains made immediately post-treatment were expected to decrease 6 months after treatment for two reasons: (1) IPD is a progressive disease, and (2) participants would not

adhere strictly to the post-treatment homework protocol³ prescribed by Ramig and

colleagues.

³ The post-treatment homework requires practicing many tasks that were present during treatment (e.g., 'ahs', highs and lows). Homework should take approximately 15 minutes each day.

Chapter 2: Method

Overview

A quasi-experimental design, examining both qualitative and quantitative measures, was used to address the clinical significance of LSVT by examining communication-related QoL and social validity outcomes. Five participant dyads (i.e., person with IPD and their FM) took part in the first section of this study, which occurred over a 7 to 8 month period. Communication-related QoL measures were conducted, and conversations videotaped, during each of the three phases of this study: (1) immediate pre-LSVT, (2) immediate post-LSVT, and (3) 6 months following LSVT (i.e., maintenance phase). After these data were collected, social validity measures were obtained by having unfamiliar judges rate randomly selected videotaped conversations of each dyad from each phase.

Participants .

A total of 23 individuals participated in this study. Ten individuals participated in the LSVT and communication-related QoL portion of the study and the remaining 13 participants took part in the social validity aspect of the study.

Participants with Idiopathic Parkinson Disease

A power analysis⁴ revealed that five individuals with IPD were needed to participate in LSVT. These participants were recruited through purposeful sampling by

 $d = X_1 - X_2 / s = 69.36 - 64.7 / 2.97 = 1.157$

At a power set at 0.91 and alpha2 = 0.05

 $n=(\delta/d)^2 = (3.30/1.57)^2 = 4.4$

Thus, approximately 4 to 5 individuals would be required to detect an effect size.

⁴ As no effectiveness studies have been conducted, relavent data were taken from Ramig et al. (2001a) efficacy study to determine an estimate for the effect size and power.

posting announcements in the Maritime Parkinson Society Newsletter and the Dalhousie University Notice Digest (see Appendix E); additionally, an administrator from the Maritime Parkinson Society mailed recruitment brochures to members in the Halifax Regional Municipality (see Appendix F). Interested persons were asked to contact the investigator by phone or email to learn more about the study. If an individual was interested in participation, an appointment was scheduled to obtain informed consent (see Appendix G) and to screen for inclusion/exclusion criteria. Each participant met the following inclusion criteria: (1) was at least 2 years post-diagnosis of IPD, (2) had hypokinetic dysarthria with voice disorder as the primary symptom, as determined by the Evaluation of Structure and Function of the Speech Production Mechanism (Strand, Yorkston, & Miller, 1995) (see Appendix H), (3) was between the ages of 50- to 75-years old, (4) had cognitive abilities within normal limits to mildly impaired⁵, based on the Montreal Cognitive Assessment (Nasreddine et al., 2005) (see Appendix I), (5) had no known or mild⁶ neuropsychiatric deficits based on self-report (6) spoke English as primary language, (7) lived with a FM (e.g., spouse/child) who was willing to participate in the completion of outcome measures, and (8) was medically stable to participate in intensive vocal exercises as per self-report. Participants also met the following exclusion criteria: (1) had a diagnosis of Parkinson-plus syndrome, (2) had moderate-to-severe cognitive deficits, (3) had known neuropsychiatric deficits (e.g., schizophrenia), and (4) lived alone or did not live with a FM who was willing to participate in this study. There

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⁵ Many individuals with IPD suffer from cognitive impairments. Those with mild cognitive deficits are able to complete the tasks involved in the study. It is important to include this population so that results may have a broader application.

were no restrictions regarding race or gender. See Table 1 for demographic and medical

characteristics of participants with IPD.

Table 1

Demographic and Medical Information for Participants with Idiopathic Parkinson Disease

	Participants				
	IPD1	IPD2	IPD3	IPD4	IPD5
Age	54	51	71	62	74
Sex	Female	Male	Male	Male	Male
Ethnicity	Caucasian	Caucasian	Caucasian	East-Indian	Caucasian
Years post-diagnosis	3	19	5	2	2
Other medical diagnosis reported	None	None	None	None	 Colitis Soberrheaic dermatitis Hyperten- sion
Medications	- Fosamax - Spirolactin - Mirapex	- Sinemet - Mirapex - Comtan	 Amantadine Novo- Selegiline Apo- Levocarb Comtan Flomax 	- Vitamins	- Salazopyrin - Minocen - Lipitor - Vitamins
Score on cognitive assessment*	29/30	28/30	27/30	29/30	21/30

⁶ Many individuals with PD suffer from depression. This can include those with mild depression or depression that is treated or stable. It is important to include this population so that results may have a broad application.

			Participants		-
	IPD1	IPD2	IPD3	IPD4	IPD5
Primary voice/ communication deficit	 Mild hypokinetic dysarthria Decreased volume; Hoarseness Pitch breaks 	 Moderate- severe hypokinetic dysarthria Decreased volume Reduced breath support Poor markers for word boundaries 	 Mild hypokinetic dysarthria Decreased volume Occasional poor markers for word boundaries 	 Mild hypokinetic dysarthria Decreased volume Breathy vocal quality 	 Mild- moderate hypokinetic dysarthria Decreased volume Occasional poor markers for word boundaries
Miscellaneous	- Daily exercise - Works part-time	 Daily exercise Had a deep brain stimulator inserted in 2005 Works part-time 	 Daily exercise Retired Active in community 	 Daily exercise Works part-time Active in community 	 Daily exercise Retired Active in community

* Scores based on the Montreal Cognitive Assessment (Nasreddine, et al., 2005)

Family Members

One FM of each participant with IPD participated. Family members met the following inclusion criteria: (1) spoke English as primary language, (2) had normal communication abilities, based on an informal assessment conducted by a SLP, (3) had no known neuropsychiatric deficits based on self-report, (4) was willing to participate in the completion of outcome measures with the person with IPD, (5) was at least 18 years of age, and (6) was medically stable to participate in outcome measures. There were no restrictions regarding race or gender for the FMs. All FMs provided informed consent (see Appendix G). Refer to Table 2 for demographic information on FMs.

Table 2

Participants FM1 FM2 FM3 FM4 FM5 Sex Male Female Female Female Female Ethnicity Caucasian Caucasian Caucasian East Indian Caucasian Spouse Spouse Spouse Spouse **Relation to** Spouse person with IPD

Demographic Characteristics of Family Members

Attrition

One dyad (IPD4 and FM4) did not take part in the maintenance phase of this research. Additionally, they chose to not have their videotaped conversations shown during the social validity portion of the study. Their communication-related QoL data for the preand post-treatment phases, however, were included in the analyses.

Treatment

Setting

The LSVT was administered individually in a laboratory at the School of Human Communication Disorders (SHCD). Treatment also included talking in various settings throughout the community (e.g., coffee shop, supermarket, drug store), and the completion of daily homework tasks (i.e., voice exercises and functional tasks, such as phone calls or asking for assistance in a store).

Procedures

The LSVT was administered to all participants with IPD using the standard Ramig and Fox (2005) protocol. Speech-language pathology graduate student researchers, who had completed the LSVT course, conducted the treatment under the supervision of a SLP who was certified in LSVT. As per the LSVT protocol, each participant with IPD received four 1-hour sessions each week for 4 weeks, for a total of 16 hours of treatment. Each session consisted of three components: (1) completion of three types of vocal exercises (i.e., maximum sustained "ah," and high/low pitch loud "ah"), (2) production of 10 individualized functional sentences using a loud voice, and (3) elicited and spontaneous speech using a loud voice (starting with words/phrases and progressing to conversation). Specific feedback about vocal intensity and quality was provided to participants within each session. Additionally, participants were asked to complete daily homework, including loud sustained and high/low pitch "ah," oral reading, and spontaneous speaking, which increased in complexity over the course of the treatment.

Equipment and Materials

The LSVT manual (Ramig & Fox, 2005) was followed to ensure consistent treatment delivery of daily tasks, carryover exercises, and homework activities. During each session three visual cues were placed on the table in front of the participant: a 'THINK LOUD!' card, an illustration highlighting the need for individuals with IPD to use a loud voice, and digitalized biofeedback from a sound-level meter indicating the loudness level obtained during treatment. For LSVT sessions and homework exercises, a variety of stimuli were used to elicit speech, such as oral reading materials (e.g., word and phrase lists, sentence lists, books), picture cue cards, and conversational topics/questions. The reading materials and conversational topics were individualized for each participant to reflect their communication needs and interests. Additionally, participants were provided with at least five 'THINK LOUD!' signs, a copy of

the sheet explaining the need for a loud voice, and a treatment notebook. Participants were encouraged to place the signs in settings where communication was important and/or frequent (e.g., office, kitchen). The treatment notebook included homework assignments.

Delivery of LSVT entailed the use of various equipment and materials in every session. A digital sound-level meter was placed on a tripod at a distance of 30 centimetres from the participant's mouth. This enabled the clinician to record progress in treatment and to provide specific feedback regarding intensity (i.e., loudness) of the participant's voice. An audiotape and videotape recorder were used to record portions of the LSVT sessions. These materials were played for the participants at different points across the treatment period to allow for feedback and self-evaluation of progress. Messages saved on voice mail as part of homework exercises were also played back periodically throughout treatment for feedback and self-evaluation of progress.

Data Collection and Procedures

Setting

Outcome measures were collected in the participants' homes during each phase. Participants identified a room of choice, preferably sitting at a table, for data collection (i.e., conversation probes). All possible extraneous noise was eliminated. To minimize discomfort and promote a more natural setting, the research assistant (RA) left the room during each conversation while allowing the videotape to capture the interaction. *Conversation Probes*

During each phase, there were five visits to each participant's home to collect conversational speech data. In each session, conversational speech data were taken three times, arranged around the participant's medication cycle to account for variability due to medication. One third of the conversations were recorded while the individual with IPD was doing a motor task (e.g., conversing while setting the table) to increase the probability that speech was 'automatic,' as the participant had to focus on the motor task in addition to conversing (G. Turnbull, personal communication, September 22, 2005).

For the first conversation of each session, participants were provided the following instructions: "You will have a conversation for about 3 minutes. You can talk about anything you want, including current events, plans, your family, your hobbies, or your daily activities. Please keep conversing until I ask you to stop." After the instructions were provided, the video recordings were started and the RA left the room, and returned when a stop-watch reached 3 minutes. For subsequent conversations, participants were simply reminded to keep talking until the RA re-entered the room. The RA did not provide conversational stimuli, but participants could choose to use any materials (e.g., photos, magazines) that they might normally talk about. These conversation probes were used as stimuli for the social validity portion of the study. Consent (see Appendix J) was obtained by participants with IPD and their FMs to allow the unfamiliar judges to view their conversational probes.

Communication-Related Quality of Life Measures and Interviews

To examine potential changes in the participants with IPDs' communicationrelated QoL, participants completed QoL scales and open-ended interviews during one visit within each phase. A RA, who was not otherwise involved in the study, and was unfamiliar with LSVT and the hypotheses of the study, conducted this visit to minimize bias in the participants' responses. Prior to completing the communication-related QoL measures, participants with IPD were asked to complete a mood indicator (Paul et al, 2004). Depression is often a comorbid condition for individuals with IPD (Kuopio et al., 2000; Tickle-Degnen & Lyons, 2004). Although the presence of depression could alter a participant with IPD's perceived effectiveness of LSVT, it was not among the exclusion criteria based on recommendations of the Dalhousie Ethics Committee. Thus a mood indicator, based on self-report, was obtained. Participants with IPD were asked to quantify their emotional state on the day of data collection by answering the question "Is today an especially good, especially bad, or an average day for you?" Subsequently, participants with IPD completed the QCL scale (Paul et al.) and the VHI (Jacobson et al., 1997). The FMs completed the PRF (Ramig & Fox, 2005).

After administering the communication-related QoL scales, the RA conducted a semi-structured, open-ended interview (see Appendix K) with the participants with IPD and their FMs. Persons with IPD and their FMs were interviewed separately and responses were confidential. The RA used interview protocols that consisted of open-ended questions and follow-up probes, as per Hickey (2000, 2006). All interviews were audio-recorded. The RA had interview experience, and was trained to conduct the interviews for this research by the research supervisor. All interview protocols were transcribed verbatim by another RA who was not otherwise involved in the study. Four of 14 (or 28.5%) of randomly selected interviews were transcribed by a third RA to ensure interrater reliability. Transcription reliability was calculated for overall utterance-by-utterance agreement, using the formula (# agreements/ # agreements + # disagreements) x 100 = % reliability. Mean percentage of utterance agreement was 89.9 %, with a range of

85.7% to 91.8%. The second and third RA discussed all discrepancies and came to agreement.

Equipment

The pre-, post-, and maintenance phase conversation probes were videotaped using a Sony DVR-33 digital video camera and QoL interviews were audio recorded using a Panasonic digital voice recorder. Conversation probes were downloaded from a SONY VAIO desktop computer using Movie Maker.

Social Validity

Unfamiliar Judges: Members of the Extended Community

Ten participants were recruited from the extended community, via posters (see Appendix L), to participate in social validity measures. Participants met the following inclusion criteria: (1) had minimal knowledge or experience with IPD, (2) had normal vision and hearing (may be corrected), (3) had no known communication deficits, based on self-report, (3) were at least 18 years of age, (4) spoke English as their primary language, and (5) had no history of major psychiatric diagnoses (e.g., schizophrenia), as per self-report. See Table 3 for an overview of demographic information for members of the extended community.

All members of the extended community completed a brief questionnaire (see Appendix M) to screen for their knowledge and previous experience with IPD. Although most participants had heard of IPD, usually through the media (e.g., interviews with Michael J. Fox), and could state some symptoms of the disease, they lacked detailed knowledge or experience with the disease. There were no restrictions regarding race or gender of the participants. Members of the extended community were blind to the hypotheses of the study and signed a consent form (see Appendix N).

Table 3

MEC Judge	Sex	Age range	Occupation	Education	Score on Awareness of PD Questionnaire
1	F	18-30	Student	Undergraduate degree	11/19
2	F	18-30	Student	Undergraduate degree	9/19
3	F	18-30	Student	Undergraduate degree	8/19
4	F	18-30	Student	Undergraduate degree	12/19
5	F	18-30	Student	Undergraduate degree	9/19
6	F	18-30	Student	Undergraduate degree	13/19
7	M	18-30	Student	Undergraduate degree	15/19
8	F	41-50	Administration	College degree	7/19
9	М	41-50	Electronics	College degree	11/19
10	F	18-30	Student	Undergraduate degree	13/19

Demographic Information of Members from the Extended Community

Note: MEC = Members of the Extended Community; F = female; M = maleThe mean score on the Awareness of IPD Questionnaire was 10.8/19 or 56% with a standard deviation of 2.5.

Unfamiliar Judges: Peers with Idiopathic Parkinson Disease

Peers with IPD were recruited via purposeful sampling by posting announcements in the Maritime Parkinson Society Newsletter (see Appendix O). Additionally, an administrator from the Maritime Parkinson Society informed, via email, associated Chapters across the Maritimes about the study. In an effort to recruit further, a poster was placed in the Maritime Parkinson's Clinic at Dalhousie University. Interested persons were asked to contact the investigator by phone or email to learn more about the study. If an individual was interested in participation, an appointment was scheduled to obtain informed consent (see Appendix N), screen for inclusion criteria, and collect data. The inclusion criteria for this group included: (1) a diagnosis of IPD, (2) vision and hearing within functional limits (may be corrected), (3) ages between 50 to 75 years, (4) cognitive abilities within normal limits to mildly impaired, based on the Montreal Cognitive Assessment (Nasreddine et al., 2005), (5) no known neuropsychiatric deficits, (6) spoke English as primary language, (9) were medically stable to participate, and (10) were strangers to those who participated in the LSVT portion of the study.

After 3 months of recruitment across the Maritimes, three persons with IPD who did not receive LSVT consented to being unfamiliar judges. Peer with IPD were blind to the hypotheses of the study. Refer to Table 4 to review the demographic information of the peer judges.

Table 4

Peer Judge	Sex	Age range	Occupation	Education	Score on cognitive assessment
1	Μ	61-70	Retired	Grade 10	25/30
2	F	61-70	Retired	Undergraduate degree	29/30
3	F	61-70	Retired	Grade 12	30/30

Demographic Information of Peers with Idiopathic Parkinson Disease

Note: F = female; M = male

Materials and Equipment

Stimuli consisted of conversation probes that took place between each dyad (i.e., participants with IPD and their FMs) during each phase (pre-treatment, immediately post-treatment, and maintenance). One clip was randomly selected from each phase for viewing by the judges. The last 2 minutes of each clip was burned onto a digital video disk (DVD); all clips for one dyad were grouped together, with the order of clips from each phase randomized across dyads. The video clips were shown in a classroom at the SHCD at Dalhousie University using a DVD player, a Panasonic projector, and a white screen. During all data collection sessions, the projector was placed 2 meters from the screen to ensure consistent size and light intensity of the picture. Two peers with IPD were unable to commute to the SHCD for data collection, thus the investigator showed the clips at the judge's home (using the same equipment). A visual analog scale (see Appendix P) was used to rate the quality of the communication seen on the video clips (Hickey, 2000; Hickey & Rondeau, 2005).

Conversational Viewing and Rating

All unfamiliar judges watched the clips from each phase for each dyad twice. For the first viewing, all conversational probes were watched in their entirety without interruption. During the second viewing, the video was stopped after each clip at which time the judges were asked to complete their ratings and answer the open-ended question (see Appendix P). Judges were given as much time as needed to complete the form. Ratings of the conversations were conducted with respect to various dimensions of quality of the communication exchange on a visual analog scale. The visual analog scales contained 7 dimensions: (1) comfort level during the conversation, (2) loudness of the person with IPD, (3) intelligibility of the individual with IPD, (4) communication adequacy of the FM, (5) balance of turn taking in the conversation, (6) degree of quality of communication. The form contained eleven 15-centimetre visual analogue scales, with each dimension rated from *Never* to *Always*. There was no communication between judges or the investigator during the viewing and rating of the clips.

Design

A quasi-experimental repeated measure pre-post design was employed to examine the clinical significance of LSVT outcomes (Barlow, Hayes, & Nelson, 1984) using mixed methods from quantitative and qualitative methodologies. The study design included three phases: (a) immediately pre-LSVT, (b) immediately post-LSVT, and (c) maintenance. The immediate pre- and post-treatment phases were conducted within two weeks before and after LSVT, respectively. The maintenance phase was conducted approximately 6 months after the completion of LSVT (in accordance with the availability of the participants). Data were compared across the pre- and post-treatment, and maintenance phases.

Data Analyses

Quantitative Analyses

Research questions 1 and 2 examined the impact of LSVT on communicationrelated QoL, as judged by the participants with IPD and the FMs. Research question 3 examined the social validity of LSVT outcomes, based on ratings by members of the extended community and peers with IPD. First, descriptive statistics were calculated for all data for the group and for each individual. For all measures, quantitative analyses were conducted by examining data for main effects across the pre- and post-treatment and maintenance phases. Due to the limitations of the sample size and the type of data collected, a non-parametric approach was taken to statistically analyse the communication-related QoL data. Group and individual means from the QCL scale, the VHI, and the PRF were subjected to the Friedman analysis of variance by ranks test. If main effects were identified, a Wilcoxon matched-pair signed ranks test was conducted post-hoc to determine whether the differences were from pre-treatment to post-treatment or from pre-treatment to the maintenance phase. Data for IPD4 and FM4 were only collected during the pre- and post-treatment phases, due to attrition; thus, the Wilcoxon matched-pair signed-ranks test was the only test used for this participant's data.

Mean ratings and standard deviations were calculated for each of the seven dimensions for all ratings in each phase. For members of the extended community, analyses were computed using the Friedman analysis of variance by ranks test. If main effects were found, a Wilcoxon matched-pair signed ranks test was used for post-hoc analyses.

Due to the small, purposeful sample size of peers with IPD, statistical analyses were not possible, nor appropriate. Total means and standard deviations for ratings of each item and across the phases were calculated and compared.

Qualitative Analyses

Qualitative data were explored for all research questions. Inductive analyses were employed to determine themes that emerged from the qualitative data. For research questions 1 and 2, these data included the audio-recordings and transcripts of the openended interviews from persons with IPD and their FMs, respectively. For research questions 3, data included the unfamiliar judges' open-ended written comments about pre- and post-treatment, and maintenance phase conversations. Themes were developed through a cyclical approach (Fox, Poulsen, Bawden, & Packard, 2004; Luborsky, 1994; Strauss & Corbin, 1990). First, all transcripts were read through without being coded. During the second reading, open coding was used to develop codes for identifying concise words or phrases to summarize the content in the transcripts; these codes were written in the margins by the corresponding content. Then, the investigator re-read the data and determined whether the codes precisely reflected the information. Finally, codes that reoccurred, reflected underlying patterns, or indicated significance/importance for the participants were organized into themes, or overall categories of comments. To determine the reliability of the categorization, an independent observer categorized the comments into the various themes that were identified by the investigator. The independent observer was given the category names and a brief description and then

categorized each open-ended utterance according to the themes. Reliability was calculated using the following formula, (# agreements/ # agreements + # disagreements) x 100 = % reliability. Overall, there were 229 open-ended utterances to categorize and 26 disagreements between the primary investigator and the independent observer. Therefore, the total percentage agreement was (203/229) x 100 = 88.8%. The primary investigator and the independent observer discussed all discrepancies and came to agreement.

Chapter 3: Results

Overview

The results are presented in two sections. Research questions 1 and 2 are answered within the first section. Quantitative results are presented to describe participants with IPDs' and FMs' perceptions of communication-related QoL and voice of the person with IPD immediately post-, and 6 months post-LSVT. Then, themes obtained during the interviews across each phase are explored. In the second section, research question 3 is answered using quantitative analyses of social validity ratings and qualitative analyses of emerging themes from the unfamiliar judges' comments.

All quantitative data were analysed for main effects using the Friedman two-way analyses of variance by ranks (reported as χ^2 values) to compare test scores across phases (e.g., pre-treatment, post-treatment, and maintenance phase). If significant main effects were identified, then a 2-tailed Wilcoxon matched-pair signed ranks test (reported as Z values) was used post-hoc to determine whether differences were from pre- to post-treatment or from pre-treatment to the maintenance phase. These analyses were conducted first for the group scores and then for each participant's scores. Due to IPD4's attrition from the study, his pre- and post-treatment scores were calculated using a 2-tailed Wilcoxon matched-pair signed ranks test.

All qualitative data were examined using inductive analyses to determine themes that emerged from interviews (IPDs and FMs) and open-ended written observations (unfamiliar judges). Themes were developed through a cyclical approach to identify recurrent, significant patterns, which were then organized into themes (Fox et al., 2004; Luborsky, 1994; Strauss & Corbin, 1990).

Objective LSVT Measures

To ensure that the treatment provided in the present study was consistent with the LSVT conducted in the literature, sound pressure levels (SPL) of sustained phonation (i.e., 'ah') were recorded pre- and post-treatment and compared to the findings by Ramig and colleagues. As can be seen in Table 5, the means and standard deviations are comparable; suggesting that participants with IPD in the present study benefited from LSVT in a manner consistent with the efficacy literature.

Table 5

Comparison of Sound Pressure Level of Sustained Phonation to Studies by Ramig at al.

	Present study Mean SPL "AH" (SD)	Ramig et al. (2001a) Mean SPL "AH" (SD)	Ramig et al. (2001b) Mean SPL "AH" (SD)
Pre-treatment	65.7 (4.44)	68.3 (4.45)	69.1 (5.10)
Post-treatment	81.3 (6.80)	82.4 (3.92)	82.4 (3.90)

Communication-Related Quality of Life Measures

A mood indicator, based on self-report, was obtained on the days of the communication-related QoL interviews. As seen in Table 6, 76% of responses across all phases indicated that participants' were having an 'average' day at the time of QoL data collection. Thus, it can be assumed that the communication-related QoL outcomes should be representative of a typical day for participants with IPD.

Table 6

							Pa	rticipa	nts						
		IPD1	1		IPD2			IPD3			IPD4			IPD5	
	Pre	Post	MP	Pre	Post	MP	Pre	Post	MP	Pre	Post	MP	Pre	Post	MP
Especially good day	v		,	,	,	,	,	✓		,			~		,
Average day Especially bad day		✓	V	✓	•	•	~	a ti	~	V	~	n/a		~	~

Participants with Idiopathic Parkinson Disease's Rating of Emotional State at the Time of Quality of Life Data Collection

Note: IPD = Specific participant with IPD; Pre = pre-treatment; Post = post-treatment; MP = maintenance phase; n/a = non-applicable.

Quality of Communication Life (QCL) Scale

The QCL scale (Paul et al., 2004) was completed by each participant with IPD at each phase. Participants with IPD were asked to rate, by intersecting a line containing a 5-point scale, the quality of their communication life through a series of questions (see Appendix B). Test scores were calculated by measuring the distance (maximum of 7.6 centimetres) from the bottom of the scale to the mark made by the participant. Test scores were then averaged across the 18 items for a mean score for each participant, as well as for the group, in each phase.

Results of the group QCL scores revealed no main effect for phase ($\chi^2 = 1.98$, p > 0.05). Exploratory analyses of the trends in the group means, however, suggested that scores on the QCL scale improve from pre- to post-treatment, but decreased to near pre-treatment levels during the maintenance phase (see Table 7).

With respect to individual data, results of the QCL across the phases were variable, with some findings in the direction of the hypothesis posed above. See Table 6 for means and standard deviations for each participant. Most notably, IPD1 and IPD2 showed main effects ($\chi^2 = 12.4$, p < 0.05; $\chi^2 = 17.2$, p < 0.05, respectively); post-hoc analyses revealed significant improvements from pre- to post-treatment (Z = 2.59, p <0.05; Z = 3.27, p < 0.05, respectively), and from pre-treatment to maintenance phase for IPD1 (Z = 3.22, p < 0.05). Contrary to expectations, there was a significant decrease in IPD3's QCL scores ($\chi^2 = 19.0$, p < 0.05) from pre-treatment to post-treatment (Z = 3.91, p< 0.05) and to the maintenance phase (Z = 3.18, p < 0.05). Main effects were not found for IPD4 (Z = 1.27, p > 0.05) and IPD5 ($\chi^2 = 0.90$, p > 0.05).

Table 7

Mean Scores and Standard Deviations for the Quality of Communication Life (QCL) Scale from the Pre-treatment, Post-treatment, and Maintenance Phase

Participant	Pre-Treatment Mean Score (SD)	Post-Treatment Mean Score (SD)	Maintenance Mean Phase Score (SD)
IPD1	4.44 (.9474)	*5.30 (.959)	*5.72 (.814)
IPD2	5.18 (1.20)	* 6.92 (.097)	5.14 (1.22)
IPD3	6.84 (.887)	*5.68 (1.41)	*5.67 (1.83)
IPD4	5.84 (2.10)	6.29 (1.33)	N/A
IPD5	4.76 (2.24)	4.63 (2.29)	4.84 (2.04)
Group	5.41 (.955)	5.76 (.883)	5.34 (.426)

*Significant at p < .05, using the Friedman analysis of variance by ranks.

Note: IPD = Specific participant with IPD; IPD4 was analysed using 2-tailed Wilcoxon matched-pair signed ranks test (significance at p < .05).

Voice Handicap Index (VHI)

The VHI (Jacobson et al., 1997) was completed by each participant with IPD across all phases. Participants rated themselves on 30 questions using a 5-point discrete variable scale with possible answers ranging from *Never* to *Always* (see Appendix C). Each rating was assigned a score from 0 to 4, with lower scores indicating better perceived voice function or less voice handicap. Total test scores were obtained from the sum total of the 30 items and then averaged across the group in each phase, as follows: M = 42.4 (SD = 28.5) for pre-treatment, M = 35.2 (SD = 27.6) for post-treatment, and M = 45.5 (SD = 15.1) for the maintenance phase. Additionally, mean item scores were calculated by averaging across the 30 VHI items for each participant, and for the group, in each phase (see Table 8).

As hypothesized, results for group scores revealed a main effect in self-perceived voice handicap across the three phases ($\chi^2 = 9.37$, p < 0.05). Post-hoc analyses indicated significance immediately post-LSVT (Z = 3.31, p < 0.05), but not at the maintenance phase (Z = .409, p > 0.05), with scores on the VHI at maintenance decreasing to baseline levels.

Individual scores on the VHI were in accordance with hypotheses for some participants. Results for IPD1 and IPD2 revealed a main effect in perceived voice handicap across phases ($\chi^2 = 24.0, p < 0.05; \chi^2 = 13.1, p < 0.05$, respectively), while posthoc tests showed significance from pre-treatment to post-treatment (Z = 2.83, p < 0.05) and maintenance phases for IPD1 (Z = 3.76, p < 0.05), and significance from pre-treatment to the maintenance phase for IPD2 (Z = 3.31, p < 0.05). Results for IPD3 revealed a main effect ($\chi^2 = 32.1, p < 0.05$), with a significant perceived decrease in voice

handicap from pre- to post-treatment (Z = 2.53, p < 0.05) and a significant increase in perceived voice handicap from pre-treatment to the maintenance phase (Z = 3.68, p < 0.05). Results for IPD4 showed a significant improvement in perceived voice from pre- to post-treatment (Z = 2.83, p < 0.05). Contrary to the hypothesis, results for IPD5 indicated a main effect for phases ($\chi^2 = 32.1$, p < 0.05), but with a significant increase in voice handicap from pre-treatment to maintenance phase (Z = 1.96, p = 0.05).

Table 8

Mean Scores and Standard Deviations for the Voice Handicap Index (VHI) from the Preand Post-treatment Phase, and Maintenance Phase

Participant	Pre-Treatment Mean Score (SD)	Post-Treatment Mean Score (SD)	Maintenance Mean Phase Score (SD)
IPD1	1.87 (.819)	*1.47 (.860)	*.900 (.885)
IPD2	2.80 (1.24)	2.47 (.730)	*2.03 (.850)
IPD3	.367 (.667)	*.100 (.305)	*1.33 (.884)
IPD4	.767 (.897)	**.500 (.731)	N/A
IPD5	1.30 (1.46)	1.33 (1.155)	*1.80 (1.42)
Group	1.42 (1.35)	* 1.17 (1.15)	1.51 (1.11)

*Significant at p < .05, using the Friedman analysis of variance by ranks.

** Significant at p < .05, using 2-tailed Wilcoxon matched-pairs signed ranks test.

Note: IPD = Specific participant with IPD

Perceptual Rating Form (PRF)

The PRF (Ramig & Fox, 2005; see Appendix D) was completed by FMs' in each phase to obtain perceptions of voice function of their counterpart with IPD. Scores for each item were calculated by using a ruler to measure the distance of the mark along the visual analog scale and then computing a percentage of the total length of the scale (with lower scores representing a better perception of voice function). Mean scores were then averaged across the 10 items for each participant, and for the group during each phase (see Table 9).

Analyses of the group data using the Friedman test revealed a main effect for voice perception across the three phases ($\chi^2 = 6.73$, p < 0.05). The Wilcoxon test showed a significant perceived improvement in voice from pre- to post-treatment (Z = 4.02, p < 0.05), but not from pre-treatment to maintenance phase (Z = 1.64, p > 0.05).

Results for the individual participants revealed no main effects for FM1 and FM3 across the three phases ($\chi^2 = 3.21, p > 0.05; \chi^2 = 1.08, p > 0.05$, respectively). Findings for the other three participants (FM2, FM4, and FM5) showed main effects of improvement in voice perception ($\chi^2 = 7.94, p < 0.05; Z = 2.80, p < 0.05; \chi^2 = 9.39, p < 0.05$, respectively). For FM2, this difference was seen from pre-treatment to the maintenance phase (Z = 2.38, p < 0.05). For FM4 and FM5, this difference was from pre-to post-treatment (Z = 2.80, p < 0.05; Z = 2.81, p < 0.05, respectively).

Table 9

Mean Scores and Standard Deviations for the Perceptual Rating Form (PRF) from the Pre-treatment, Post-treatment Phase, and Maintenance Phase, as Rated by the Family Members

Participant	Pre-Treatment Mean Score (SD)	Post-Treatment Mean Score (SD)	Maintenance Mean Phase Score (SD)
FM1	38.0 (20.8)	30.9 (19.6)	39.7 (18.7)
FM2	63.3 (13.4)	64.0 (15.6)	* 50.4 (18.6)
FM3	50.5 (26.2)	41.7 (31.4)	49.9 (13.1)
FM4	44.2 (10.1)	**31.7 (7.69)	N/A
FM5	36.2 (22.7)	*13.6 (18.2)	31.8 (23.6)
Group	46.46 (21.2)	* 36.4 (25.4)	43.0 (20.0)

*Significant at p < .05, using the Friedman analysis of variance by ranks.

**Significant at p < .05 using 2-tailed Wilcoxon matched-pairs signed ranks test Note: FM = Family member of the participant with IPD.

Interviews with Participants with Idiopathic Parkinson Disease

Refer to Appendix Q for the themes and quotes from the pre-treatment interviews. Table 10 lists the themes and provides example quotes from the posttreatment and maintenance phases. At post-treatment, qualitative inductive analyses revealed several themes that emerged consistently, including: program satisfaction, recommendations to others, improved loudness of voice, and not adhering to practice protocols. Specifically, all participants with IPD commented that they enjoyed the program and appreciated its usefulness. IPD3 liked that the program was tailored to his interests. Several participants commented that they would recommend LSVT to other individuals with IPD. All participants reported that their voice had improved; most suggested that vocal improvements were related to increased loudness. Additionally, IPD4 mentioned that the program increased his confidence in speaking. The majority of participants with IPD stated that they did not follow the practice protocol as prescribed (i.e., completing the post-treatment LSVT homework for about 10-15 minutes every day).

At post-treatment phase, the following themes were derived from more variable responses: third parties noticing voice improvements post-treatment, using strategies to improve communication, and the consistency of LSVT experiences compared to the expectation. Specifically, IPD1 and IPD4 discussed that others have commented on their communication and voice improvements. Conversely, IPD2, IPD3, and IPD5 disclosed that they had not received such comments. IPD1, IPD2, and IPD5 mentioned that they use a louder voice as their primary strategy to improve communication when others are having difficulty understanding. IPD3 reported not doing anything to be better understood by others, despite mentioning earlier in the interview that he speaks louder since the LSVT treatment. The expectations of LSVT were consistent with the experience for IPD2, IPD3, and IPD4. In contrast, IPD1 thought the experience was more demanding and time consuming than she had originally anticipated. IPD5 was not expecting the content and practice required by doing LSVT.

At maintenance, themes that emerged were less consistent and revealed some changes compared to the post-treatment phase. For instance, participants with IPD seemed less enthusiastic about their satisfaction with the program. With the exception of IPD1 and IPD2, it appeared that participants with IPD were less likely to recommend the LSVT program. For example, IPD3 went from saying that he would recommend LSVT during the post-treatment phase, to not recommending it during the maintenance phase. Similarly, IPD1 changed her response from post-treatment to maintenance regarding using specific strategies to promote communication. At post-treatment, IPD1 reported speaking slower and "from the chest area" to improve communication. At the maintenance phase she reported not using any strategies to facilitate communication. IPD2, IPD3, and IPD5 maintained that they thought their voice was louder compared to pre-treatment. When asked if the experience of LSVT was consistent with expectations, IPD3 changed his answer. At post-treatment, he reported that his experience was consistent with expectations, but at maintenance, IPD3 suggested that LSVT did not meet his expectations.

Themes	Quotes	Quotes
	(Post-treatment)	(Maintenance phase)
General satisfaction with nrooram	"When I put it all into perspective it was a worth while venture." [IPD1]	"My experience with the program was not bad." [IPD2]
	"It [the program] went by really fastI enjoyed it." [IPD2]	
- Good	"I appreciated the factthat they encouraged me, even copied down, pages reproduced from the BibleIt was an open expression of my faith." [IPD3]	
	"This experience was a positive experience." [IPD4]	
- Moderate/ poor		"I found it [LSVT] frustrating to do and really time consuming. I had to keep telling myself that it was for my benefit and the benefit of all other people and the person doing the study. It wasn't a real pleasure to do." [IPD1]
		"I may [participate in this program again], I won't say yes or no, maybe." [IPD3]
		"You're just sitting there [saying] 'ah' [with the] lady across the table looking down your throat, that's what it seemed like to me." [IPD5]

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Themes	Quotes (Post-treatment)	Quotes (Maintenance phase)
Would recommend program to others - Yes	"If [communication] was important to that person, I would say go for it." [IPD2] "If somebody is thinking about the treatment I would encourage that person to go." [IPD3]	"Absolutely [I would recommend this program to others]." [IPD1] "[I would] definitely, definitely, [recommend it to others]" [IPD2] "I might [recommend program to others]. It might help them" [IPD5]
- No		"Well not particularlyI suppose it would depend if they were actually losing vocal capacity, then I could see it being more valuable to them than to myself." [IPD3]
Improved communication after treatment - <i>Voice is</i> <i>louder</i>	"When I want to call on a louder voice, I can manage to do that." [IPD1] "It helped me." [IPD2] "I think I'm speaking louderMy wife doesn't have to say 'what' as often as she used to say itI'm speaking louder on a normal basis to clerks or to people at random." [IPD3] "I feel like it had changed a bit. I feel a little more confident about my speech in a meetingnow I raise my voice without feeling like I'm shouting." [IPD4] "I think it's helped. I try to talk loud when I'm talking to people."	"[When] I'm at a meeting at work and I have to talk loud and clear and it helped me a little bit. Mind you it's not perfect, my speech isn't perfect, but it has helped me a little bit." [IPD2] "I'm making a genuine effort to speak louder." [IPD3] "I'm louder; my voice is louder I think." [IPD5]

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Themes	Quotes (Post-treatment)	Quotes (Maintenance phase)
Others have noticed an improvement in voice - Yes	"Both my sister-in-laws have said 'I think you voice is a lot better, I think you have more clarity'one of my friends said he though my voice was better. [FM1] thinks my projection is better." [IPD1] "[FM4] and my daughter have mentioned that my voice sounded better." [IPD4]	"The people who were aware that my voice was getting weaker thought that my voice had improved a lot." [IPD1] "I was talking to [X] this morning and he understood most of what l was saying. So whereas before I would have a hard time talking all the time." [IPD2]
- No	"Other people have not really commented that it is easier to understand me." [IPD2] "nor has anybody commented on the volume of my voice since I have completed the treatment." [IPD3] "No, no [others have not commented that it is easier to understand me]." [IPD5]	
Use strategies to be better understood by others - <i>No</i>	"I think about it before I speak, I speak a little slower and I take a little more time tostart speaking from the chest area." [IPD1] "I talk loud and clear." [IPD2] "I try to raise my voice a little more than I used to." [IPD5] "I don't make any special effort to do anything to make myself understood." [IPD3]	"No [I do not use any strategies]." [IPD1]

Themes	Quotes	Quotes
-	(Post-treatment)	(Maintenance phase)
Experiences were consistent with what was expected - Ves	"It was pretty much what I expected." [IPD2] "I guess it was pretty well what I expected." [IPD3] "The treatment was not totally unexpected." [IPD4]	"Yes they [experiences] were [as expected] but I was hoping that I could speak perfect after the programbut we don't live in a perfect world" [IPD2]
- <i>No</i>	"It was definitely a bit more of a time commitment than I thoughtit had a stricter protocol than what I ever thought it would be." [IPD1] "The 'ahs' for example, I never thought it would be something like that, or reading the sentencesSo I never thought it would be like that." [IPD5]	"A lot less than what I expected. I expected something more, I don't know what, dramatic or moreintense." [IPD3] "I didn't have any idea what it was going to be like at all. I wasn't disappointed I guess you might say, I never had a clue." [IPD5]
Not practicing according to protocol	"No [1'm not practicing], not as much as I should be." [IPD2] "T'm trying to do this [practice] here day by day, mind you the last few days was pretty rushed it seems and so I didn't get it done the last few days." [IPD3]	"And the voice exercisesI was able to keep those up at the start pretty well but I ran into some troubles over the winter when I got 3 colds in a row." [IPD1]
	"So far I haven't been doing it [practicing] very diligently." [IPD4] "[I have] not [been practicing] as much as I should." [IPD5]	

Interviews with Family Members

Refer to Appendix R for themes that emerged from the pre-treatment interviews. Qualitative inductive analysis revealed several themes from FMs' post-treatment and maintenance phase interviews, including: the value of the program, recommendations to others, time commitment requirements, changes in vocal quality, the lack of automaticity when using a loud voice, third party perceptions of intelligibility, and the extent to which the LSVT experience met previous expectations. Table 11 provides examples of each theme.

At post-treatment phase, all FMs reported that the program was useful, although most said it was overly time consuming. All FMs, with the exception of FM3, reported that the vocal quality of their spouse with IPD had improved. FM4 added that her spouse seemed to have more endurance when speaking. Several FMs commented that their spouse must concentrate to use the loud voice; speaking loudly was reportedly not automatic. FM1, FM2, and FM3 alluded that others seemed to understand better their spouse immediately after LSVT. FM2 elaborated that their neighbour was amazed at how loud and clear IPD2 was post-treatment. Only two FMs commented about the consistency of their experiences with the program versus initial expectations. FM2 disclosed that LSVT was exactly what she expected, whereas FM1 commented that it was more involved than predicted.

At maintenance, themes that surfaced in the interviews were generally consistent with the post-treatment interviews. FM1, FM2 and FM5 reported that participation in the program was worthwhile; however, FM3 commented that it was a nuisance. Several FMs continued to report improved vocal quality and loudness during the maintenance phase.

Only FM2 mentioned that the loud voice was not automatic. FM2 and FM3 noted that the program was consistent with their expectations.

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Qualitative Themes and Quotes from Family Members Regarding their Experiences with the Lee Silverman Voice Treatment at the Post-treatment and Maintenance Phase

Themes	Quotes	Quotes
	(Post-treatment)	(Maintenance phase)
Program was useful/worthwhile - Ves	"What she's got now are some of the tools to keep the voice going and in the future if she finds anything getting worse, to strengthen it." [FM1]	"I think she picked up how to speak with a loud voice when she feels under stress with Parkinson's." [FM1]
	"[The program] would definitely be worth it." [FM2] "Yes [I would recommend itl." [FM3]	"I think that it [the program] was really good and that it helped [IPD2]." [FM2]
	"I would recommend it to anyone who has Parkinson." [FM4]	"For someone whose problem is that their voice is low, I mean I think you would see an incredible difference in them." [FM2]
	"Initially I was a bit apprehensivebut this [program] seemed very favourable because it's not invasive and it's something that a person can practice to make yourself better." [FM4]	"It's worth going through, worth doing it." [FM5]
	"Oh yes I would [recommend this program to others.]" [FM5]	
- Moderate		"Well, it [the program] is a nuisancethere's nothing wrong with it, it might help some" [FM3]

I for timeIt was far MI] t into his rest time." t into his rest time." ite a lot of time." s voice] was always s voice] was always s voice] was always if he tries to say it of the tries to say it for the tries to say it if he tries to say it let [He's got] to into a nag in other med to use her loud need to use her loud is better" [FM2] let. There's times dly]he has			
 as time "It's just the time factor[IPD1] is stressed for timeIt was far more involved that what [we] thought." [FM1] "It was time consuming." [FM2] "It was a bit gregarious [sic] because it went into his rest time." [FM4] "You would have to get used to taking quite a lot of time." [FM5] "You would have to get used to taking quite a lot of time." [FM6] "You would have to get used to taking quite a lot of time." [FM6] "You would have to get used to taking quite a lot of time." [FM6] "You would have to get used to taking quite a lot of time." [FM6] "You would have to get used to taking quite a lot of time." [FM6] "You and clear like he's supposed to." [FM1] "I definitely notice that his speech is better if he tries to say it loud and clear like he's supposed to." [FM6] "I think it was very beneficial because his voice seems to have improved You can hear him a little bit better I think that he can talk for little longer than before." [FM4] "I do think that it has helped him speak louder." [FM5] "I do think that it has helped him speak louder." [FM5] "I do think that it has helped him speak louder." [FM2] "I do think that it has helped him speak louder." [FM2] "I do think that it has helped him speak louder." [FM2] "I do think that it has helped him speak louder." [FM2] "I do think that it has helped him speak louder." [FM2] "I do think that it has helped him speak louder." [FM2] "I do think that it has helped him speak louder." [FM2] "I do think that it has helped him speak louder." [FM2] "I do think that it has helped him speak louder." [FM2] "I do think that it has helped him speak louder." [FM2] "I do think that it has helped him speak louder. There's times words." [FM2] 	Themes	Quotes (Post-treatment)	Quotes (Maintenance phase)
 "You would have to get used to taking quite a lot of time." [FM5] ed vocal "[IPD1] is speaking a little clearer[IPD1's voice] was always breaking up before." [FM1] "I definitely notice that his speech is betterif he tries to say it loud and clear like he's supposed to." [FM2] "I think it was very beneficial because his voice seems to have improved You can hear him a little bit betterI think that he can talk for little longer than before." [FM4] "I do think that it has helped him speak louder." [FM5] Ioud voice "What has changed is that[IPD1] has learned to use her loud voice at the appropriate time." [FM1] "I'l have to say 'say it again, louder and clearer'[He's got] to get in the habit of doing thatI've turned into a nag in other words." [FM2] "If [IPD2] really concentrates his speech is better" [FM2] "He's working at it and trying to speak louder. There's times when he is not conscious of it [speaking loudly]he has [trouble] remembering to speak up." [FM3] 	Program was time consuming	"It's just the time factor[IPD1] is stressed for timeIt was far more involved that what [we] thought." [FM1] "It was time consuming." [FM2] "It was a bit gregarious [sic] because it went into his rest time." FMA1	I just get back to the timeIt just put more of a constraint on her." [FM2]
 ed vocal "[IPD1] is speaking a little clearer[IPD1's voice] was always breaking up before." [FM1] "I definitely notice that his speech is betterif he tries to say it loud and clear like he's supposed to." [FM2] "I think it was very beneficial because his voice seems to have improvedYou can hear him a little bit betterI think that he can talk for little longer than before." [FM4] "I do think that it has helped him speak louder." [FM5] "What has changed is that[IPD1] has learned to use her loud voice at the appropriate time." [FM1] "I'l have to say 'say it again, louder and clearer'[He's got] to get in the habit of doing thatI've turned into a nag in other words." [FM2] "If [IPD2] really concentrates his speech is better" [FM2] "He's working at it and trying to speak louder. There's times when he is not conscious of it [speaking loudly]he has [trouble] remembering to speak up." [FM3] 		"You would have to get used to taking quite a lot of time." [FM5]	
 "I definitely notice that his speech is betterif he tries to say it loud and clear like he's supposed to." [FM2] "I think it was very beneficial because his voice seems to have improved You can hear him a little bit better I think that he can talk for little longer than before." [FM4] "I do think that it has helped him speak louder." [FM5] "I do think that it has helped him speak louder." [FM5] "I do think that it has helped no before." [FM4] "I do think that it has helped him speak louder." [FM5] "I do think that it has helped no before." [FM4] "I do think that it has helped him speak louder." [FM2] "What has changed is that [IPD1] has learned to use her loud voice at the appropriate time." [FM1] "Thave to say 'say it again, louder and clearer' [He's got] to get in the habit of doing that I've turned into a nag in other words." [FM2] "If [IPD2] really concentrates his speech is better" [FM2] "He's working at it and trying to speak louder. There's times when he is not conscious of it [speaking loudly]he has [trouble] remembering to speak up." [FM3] 	Improved vocal quality and/or	"[IPD1] is speaking a little clearer[IPD1's voice] was always breaking up before." [FM1]	"I don't know what the data will show, but just from watching him, I'd say definitely [he has improved]" [FM2]
 Turnk It was very beneficial because his voice seems to have improved You can hear him a little bit better I think that he can talk for little longer than before." [FM4] "I do think that it has helped him speak louder." [FM5] "What has changed is that [IPD1] has learned to use her loud voice at the appropriate time." [FM1] "T'Il have to say 'say it again, louder and clearer' [He's got] to get in the habit of doing thatI've turned into a nag in other words." [FM2] "If [IPD2] really concentrates his speech is better" [FM2] "He's working at it and trying to speak louder. There's times when he is not conscious of it [speaking loudly]he has [trouble] remembering to speak up." [FM3] 		"I definitely notice that his speech is better if he tries to say it loud and clear like he's supposed to." [FM2]	"He participates in conversations more than he used to. Because you know he can talk better and so he tries to talk where before he might not say anything." [FM2]
"I do think that it has helped him speak louder." [FM5] "What has changed is that[IPD1] has learned to use her loud voice at the appropriate time." [FM1] "T'll have to say 'say it again, louder and clearer'[He's got] to get in the habit of doing thatI've turned into a nag in other words." [FM2] "If [IPD2] really concentrates his speech is better" [FM2] "He's working at it and trying to speak louder. There's times when he is not conscious of it [speaking loudly]he has [trouble] remembering to speak up." [FM3]		"I think it was very beneficial because his voice seems to have improvedYou can hear him a little bit betterI think that he can talk for little longer than before." [FM4]	"It helped him to realize that he wasn't speaking uphe is aware that he can speak too softly and that helped tremendously." [FM3]
"What has changed is that[IPD1] has learned to use her loud voice at the appropriate time." [FM1] "T'll have to say 'say it again, louder and clearer'[He's got] to get in the habit of doing thatI've turned into a nag in other words." [FM2] "If [IPD2] really concentrates his speech is better" [FM2] "He's working at it and trying to speak louder. There's times when he is not conscious of it [speaking loudly]he has [trouble] remembering to speak up." [FM3]		"I do think that it has helped him speak louder." [FM5]	"His voice is loudernow he speaks up louder." [FM5]
to	Using a loud voice is not automatic	"What has changed is that[IPD1] has learned to use her loud voice at the appropriate time." [FM1]	"I think she picked up how to speak with a loud voice when she feels under stress with Parkinson's." [FM1]
"If [IPD2] really concentrates his speech is better" [FM2] "He's working at it and trying to speak louder. There's times when he is not conscious of it [speaking loudly]he has [trouble] remembering to speak up." [FM3]		"1'll have to say 'say it again, louder and clearer'[He's got] to get in the habit of doing thatI've turned into a nag in other words." [FM2]	"I think it really helps him when he stops, like when he's not thinking about it or not conscious about trying to talk loud, then not so much." [FM2]
"He's working at it and trying to speak louder. There's times when he is not conscious of it [speaking loudly]he has [trouble] remembering to speak up." [FM3]		"If [IPD2] really concentrates his speech is better" [FM2]	
		"He's working at it and trying to speak louder. There's times when he is not conscious of it [speaking loudly]he has [trouble] remembering to speak up." [FM3]	

Quotes	(Maintenance phase)	b it's	d at,		"I knew what it [the program] was going to be like, so I would say the sameIt was what I expected." [FM2] "I guess [it was what I expected]I took vocal [lessons] so it was of the same ideas." [FM3]	"I just didn't really have any expectations because I didn't know what he was going to be doing." [FM5] ac	
Quotes	(Post-treatment)	"[IPD1] hasn't had anyone asking to repeat. So in that sense it's good." [FM1]	"He was over at our neighbours one day and she was amazed at, when he spoke really loud, how clear it was." [FM2]	"He's fine when he's talking one-on-one." [FM3]	"It was sort of almost exactly what I thought." [FM2]	"It was probably a little more physicaland involved than [IPD1] was expecting." [FM1] "I didn't have any expectation because I didn't know what he would be doing." [FM5]	
Themes		Others understand speech better			Experiences were consistent with what was expected - Yes	- No/unsure	

Social Validity

Social validation measures were obtained to determine whether the effects of LSVT were noticeable and socially desirable to judges who were unfamiliar with LSVT and with the participants who completed the treatment. Because one IPD & FM dyad did not give permission for their videos to be used, social validity was examined for four dyads. The ten members of the extended community and three peers with IPD, who served as unfamiliar judges, rated and provided written observations of randomly selected videotaped conversations of participants with IPD and their FMs from each phase. *Findings from Members of the Extended Community*

Descriptive statistics were calculated for each question and for each dyad and were then averaged across dyads (see Table 12). Results of a Friedman two-way analysis of variance by ranks revealed a main effect for phases in the non-predicted direction, for the group data across items ($\chi^2 = 8.10, p < 0.05$) (see bottom right corner of Table 11). Results of a Wilcoxon matched-pairs signed ranks test revealed that members of the extended community rated the overall quality of the conversations more poorly posttreatment (Z = 3.80, p < 0.05), and 6 months post-LSVT (Z = 2.60, p < 0.05), compared to pre-treatment.

Next, the ratings for each individual dyad were examined across phases (see last row in Table 12 for each dyad). Contrary to hypotheses, results revealed a main effect for Dyad 1 ($\chi^2 = 28.2, p < 0.05$) such that ratings significantly decreased from pre-treatment to the maintenance phase (Z = 5.29, p < 0.05). Ratings for Dyad 3 demonstrated a main effect for phase ($\chi^2 = 38.5, p < 0.05$) indicating significant decreases in perceived quality of communication from pre- to post-treatment (Z = 5.97, p < 0.05) and from pretreatment to the maintenance phase (Z = 2.05, p < 0.05). Main effects were not revealed for the ratings of Dyad 2 and Dyad 5 ($\chi^2 = 5.23$, p > 0.05; $\chi^2 = 5.27$, p > 0.05, respectively).

Subsequently, analysis of ratings for each item across dyads revealed that only item 2 ("The FM appeared to feel comfortable during the conversation") showed a main effect ($\chi^2 = 8.47$, p < 0.05) from pre-treatment to post-treatment (Z = 2.34, p < 0.05); in other words, FMs appeared less comfortable during the conversation post-treatment. Analyses revealed no other main effects across phases for any of the item ratings across dyads.

Finally, various items were significant within the different dyads. Results for Dyad 1 revealed a main effect in the non-predicted direction for item 3 ("The person with IPD spoke loudly enough") ($\chi^2 = 12.7, p < 0.05$) during the maintenance phase (Z = 2.53, p < 0.05). Likewise, results for Dyad 3 showed a main effect in the non-predicted direction for item 2 ($\chi^2 = 8.97, p < 0.05$) during the post-treatment (Z = 2.52, p < 0.05) and maintenance phase (Z = 1.96, p = 0.05), as well as for items 5 ("The person with IPD expressed a lot of information") ($\chi^2 = 12.2, p < 0.05$) and 8 ("The voice quality of the person with IPD was good") ($\chi^2 = 11.5, p < 0.05$) immediately post-LSVT (Z = 2.81, p <0.05; Z = 2.67, p < 0.05, respectively). Dyad 5 showed a main effect for item 3 ("The person with IPD spoke loud enough) ($\chi^2 = 13.2, p < 0.05$) and item 7 ($\chi^2 = 11.0, p <$ 0.05) ("The pair contributed equally to the conversation"). Post-hoc analyses revealed significant differences in the predicted direction for item 3 from pre- to post-treatment (Z= 2.67, p < 0.05) and from pre-treatment to the maintenance phase (Z = 2.43, p < 0.05). Significant improvements for item 7 were seen from pre-treatment to the maintenance phase (Z = 2.68, p < 0.05). There were no main effects for the mean of the ratings from Dyad 2.

Table 12

ean (SD) .6 (13.0) .2 (16.5) .6 (14.6) .0 (14.3) 8.9 (18.8) .0 (18.8) .1 (15.9) .5 (16.6) .4 (15.7) .3 (30.8)
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.7 (19.5)
.8 (20.3)
.7 (25.0)
.1 (23.3)
.8 (19.4)
.9 (22.8)
.0 (23.6)
.7 (19.2)
.9 (21.9)
.8 (19.9)
9.2 (19.2
5.7 (22.6
6.8 (21.6
1 1 2 5

Members of the Extended Community Mean Ratings for Dyads' Conversation Quality for Each Phase Within and Across Dyads

*Significance at p < .05, using a Friedman analysis of variance by ranks.

Qualitative inductive analyses were used to determine themes that emerged from the written observations provided by the unfamiliar judges in response to an open-ended question. Table 12 provides the themes and example quotes from each phase. Members of the extended community consistently commented on the general quality of the communicative interaction, as well as the volume and vocal quality of the participants. In general, members of the extended community reported that Dyad 1 had good communication interactions across all phases. Comments related to the quality of the communication interaction for Dyad 2 and Dyad 5 were mixed across all phases. Dyad 3 was reported to have poor communication interaction during the post-treatment phase. Statements regarding the volume of participants with IPD varied for IPD2 and IPD3 across all phases. Members of the extended community reported good volume for IPD1 in each phase and remarked improved volume immediately post-treatment and during the maintenance phase for IPD5. Remarks relevant to vocal quality were mixed for all individuals with IPD across each phase. Overall comments suggested that vocal quality was poor (e.g., scratchy or hoarse) for all participants with IPD across all phases. Refer to Table 13 for specific quotes regarding each theme.

Table 13

Qualitative Themes and Quotes from Members of the Extended Community Based on Viewing Conversational Probes across Phases

		Dyad 1	
Theme	Quotes (Pre-treatment)	Quotes (Post-treatment)	Quotes (Maintenance phase)
Quality of the communication interaction	"The pair interacted and communicated quite wellthe conversation seemed natural."[MEC1]	"[IPD1] was more confident in this conversation [compared to pre-treatment]." [MEC7]	"This conversation seemed more natural and had better flow than [pre- treatment]". [MEC1]
-0000	"[IPD1] could express well with good speech speed and clarity." [MEC2]		
	"They could clearly and easily communicate with each other" [MEC10]		
- Poor		•	"Person with [Parkinson] disease dominated the conversation." [MEC9]
Spoke with loud voice - Yes	"[[PD1] spoke clearly and loudly." [MEC4] "[[PD1's] voice was quite loud." [MEC5]	"Speech speed, clarity, volume, and her ability to express, were all good." [MEC3]	"[IPD1] still spoke loud enough." [MEC4]

	(Pre-treatment)	(Post-treatment)	(Maintenance phase)
Vocal quality -Good		"[IPD1's] voice seemed clean." [MEC1]	"[IPD1] had more expression and emphasis in her voice." [MEC1]
-Poor		"[IPD1's] voice sounded a little hoarse in [this] conversation." [MEC6]	"[IPD1's] voice seemed a bit more hoarse than [the pre-treatment] conversation." [MEC2]
•		"[IPD1's] voice [was] not as scratchy as in [maintenance-phase] conversation." [MEC4]	"[IPD1's] voice was weaker, hoarser [than pre-treatment]." [MEC3]
			"[IPD1's] voice quality was diminished compared to [pre-treatment]." [MEC4]
			"[IPD1's] voice was a little crackly and hoarse sounding." [MEC5]
			"[IPD1's] voice was a little more hoarse." [MEC10]

		Dyad 2	
Theme	Quotes (Pre-treatment)	Quotes (Post-treatment)	Quotes (Maintenance phase)
Quality of the communication interaction	"[IPD2] spoke more slowly which made it easier to pick up on words."[MEC2]	"They had a comfortable interaction."[MEC2]	"[FM2] did a great job of continuing the flow of the conversationand always responded in a comfortable and
- Good	"[I was] able to understand his speech more clearly than [during the maintenance phase]."[MEC5]	"Spouse provided contextual cues so that I could reference what they were talking about."[MEC5]	encouraging way."[MEC1] "They interacted quite well and carried the conversation." [MEC2]
	"[IPD2] seemed to appear more comfortable in this conversation [compared to maintenance phase]."[MEC6]	"Overall [IPD2] appeared to be more communicative compared to [pre- treatment]". [MEC6] "Conversation seemed more	"[FM2] is doing a great job of listening and both are keeping up the flow of the conversation."[MEC4]
	"[IPD2] brought up more conversation [compared to maintenance phase]."[MEC9]		other." [MEC6]
	"This conversation was more natural [compared to maintenance hhase] "IMFC101		
- Poor		"This conversation seemed to be the worst of the three."[MEC1]	"The conversation seemed a little forced and unnatural."[MEC10]
		"Spouse appeared to not understand parts of his speech."[MEC5]	
		"Only clip where wife had difficulty understanding" [MEC7]	
		"Difficult for the family member to understand."[MEC8]	

Theme	Quotes (Pre-treatment)	Quotes (Post-treatment)	Quotes (Maintenance phase)
Spoke with loud voice			"He was loudbut not easier to understand."[MEC1]
- 168	· · · · ·		"The man's voice quality was fairlyloud."[MEC6]
			"Volume [of voice] is good."[MEC3]
- No	"[IPD2's] voice wasn't as loud in this clip." [MEC1]		
Vocal quality - <i>Good</i>	"The quality of his voicedoesn't seem too scratchy and he's still pretty loud."[MEC4]		"His voice quality was fairly good."[MEC6]
- Poor	"His voice quality seemed a little worse in this conversatic [compared to maintenance phase]".[MEC6]	"The voice seems a bit more scratchy in this [clip]."[MEC4]	"The man's voice was a little on the harsher side." [MEC5]

	Quotes (Maintenance phase)	"The man was easy to understand, overall."[MEC6]				really "The pair didn't really seem engaged."[MEC2] "This conversation seemed a little		infortable." treatment]."[MEC7]	
Dyad 3	Quotes (Post-treatment)					"This conversation seemed really forced and uncomfortable." [MEC1]	"The couple did not seem completely comfortable sitting and talking with on another."[MEC2]	"The spouse appeared uncomfortable." [MEC5]	"The sponse seemed a bit
	Quotes (Pre-treatment)	"Compared to [post-treatment] this conversation seemed less strained."[MEC2]	"This conversation seemed more relaxed for both man and wife [compared to post-treatment]." [MEC3]	"I was able to understand the person with Parkinson's disease speech better."[MEC5]	"Conversation was fluid." [MEC8]	"They seemed more at ease and less forced [compared to post- treatment]."[MEC10]			
	Theme	Quality of the communication interaction	-Good			-Poor			

		Dyad 3	
Theme	Quotes (Pre-treatment)	Quotes (Post-treatment)	Quotes (Maintenance phase)
Quality of the communication interaction		"Person with Parkinson disease looked more comfortable than the spouse." [MEC7]	
- Poor		"The conversation was strained." [MEC8]	
		"They seemed awkward and forced." [MEC10]	
Spoke loud enough - Yes	"The man's conversation was clearer than [post-treatment] and volume was better, although some word svllables were milet "		"I think this was the man's best conversation. He spoke clearly and loudly enough." [MEC1]
	[MEC3]		"Volume was still tricky with some syllables but generally good." [MEC3]
			"He was speaking at a reasonable volume." [MEC5]
- No	"I had difficulty understanding the man with Parkinson disease and he didn't talk loud enoughthis seemed worse [compared to post- treatment]" [MEC1]	"The man was sometimes difficult to understand and he often trailed off and became quiet at the end of sentences." [MEC1]	"He spoke quite softly at times." [MEC4]
	"The man spoke softly." [MEC3]	"Volume was quiet in some words or word parts." [MEC3]	
	"The man's voice seemed to be a little more quiet [compared to post- treatment] and he was more difficult to understand." [MEC6]	"The man hadslightly low voice volume [and] poor articulation of speech." [MEC6]	

		Dyad 3	
Theme	Quotes	Quotes	Quotes
	(Pre-treatment)	(Post-treatment)	(Maintenance phase)
Vocal quality			"Clarity was good." [MEC3]
- Good			"Person with Parkinson spoke more clearly than the other two conversations."[MEC5]
- Poor		"His voice was muffled and his speech seemed a bit slurred." [MEC4]	"The man's voice was still muffled and even more slurred." [MEC4]
		"The speech of the person with PD was muffled and not always easy to understand." [MEC5]	"[IPD3] had a slight mumble to his voice." [MEC9]
		"The person with PD had a mumble to his speech."[MEC9]	

		Dyad 5	
Theme	Quotes (Pre-treatment)	Quotes (Post-treatment)	Quotes (Maintenance phase)
Quality of the communication		"I felt they communicated pretty well."[MEC2]	"They communicated and interacted quite well."[MEC2]
- Good			"[IPD5] had improved articulation." [MEC7]
			"The conversation seemed a little awkward, but overall the quality was good." [MEC6]
- Poor	"This conversation seemed more uncomfortable than the	"[IPD5's]lacked clear articulation."[MEC7]	"This conversation seemed a bit more choppy."[MEC5]
	otners. [MEC1] "[Conversation] seemed a bit forced		"Conversation was repetitive and seemed a little difficult."[MEC9]
			"Conversation seemed unnatural and forced."[MEC10]

		Dyad 5	
Theme	Quotes	Quotes	Quotes
	(Pre-treatment)	(Post-treatment)	(Maintenance phase)
Spoke with loud voice		"His voice was consistently loud enough to hear."[MEC1]	"Sentences seemedfairly clear with good volume."[MEC3]
- 16S		"Volume was good." [MEC3]	"[IPD5] slurred his speech, but it was
		"[IPD5] spoke loudly but not very clearly." [MEC4]	quite loud. [NIEC4]
		"[IPD5] was easily heard."[MEC5]	
		"[IPD5] was easy to understand and spoke quite loudly."[MEC6]	
- No	The spoke a lot sorter in this clip compared to the othersalthough he was quieter I felt that his voice seemed more natural." [MEC1]		
	"[IPD5] spoke much more quietly." [MEC4]		
	"[IPD5's] voice was not as loud in this conversation as it was in the first two conversations." [MEC6]		

		Dyad 5	
Theme	Quotes (Pre-treatment)	Quotes (Post-treatment)	Quotes (Maintenance phase)
Vocal quality - <i>Good</i>	"[IPD5's] voice wasless scratchy." [MEC4]	"[IPD5's] voice sounds very clear." [MEC6] "The person with PD spoke clearly." [MEC5]	"The man spoke clearer, and his voice wasn't as loud and hoarse as [post- treatment]." [MEC1]
- Poor	"His voice seemed a little hoarse, but this could be because he was speaking loudly."[MEC1]	"[IPD5's] voice was bit scratchy and shallow." [MEC4] "(TPD5's] has a clicht mumble to his	"[IPD5's] voice quality was not as clear as [post-treatment] but I was still able to understand him." [MEC5]
	"Man's voice seemed a little hoarse."[MEC3]	voice."[MEC9]	
	"[IPD5's] voice was noticeable higher pitched." [MEC4]		
	"[IPD5's] voice quality was different compared to the other two; he appeared to speak at a bit of a higher pitch." [MEC5]		
	"[IPD5's] voice sounded a bit hoarse and crackling."[MEC6]		

Findings from Peers with Idiopathic Parkinson Disease

Descriptive statistics (means and standard deviations) were computed for exploratory visual inspection of social validity ratings from peers with IPD (see Table 14). Statistical analyses, or direct comparison to the members of the extended community, were not completed due to the small sample size of peers with IPD. Overall mean results suggested no differences in the mean ratings from pre-treatment (M = 58.9, SD = 22.7) to post-treatment (M = 61.5, SD = 24.0) or maintenance (M = 62.9, SD = 22.3).

Table 14

Peers with Idiopathic Parkinson Disease's Mean Ratings for Dyads' Conversation Quality for Each Phase

	Pre-treatment	Post-treatment	Maintenance Phase
Item 1	65.9 (19.0)	67.5 (18.7)	70.3 (18.6)
Item 2	67.7 (18.1)	65.0 (18.1)	63.1 (20.1)
Item 3	56.8 (18.8)	61.9 (23.4)	65.4 (19.3)
Item 4	50.5 (28.9)	53.0 (32.3)	54.5 (30.9)
Item 5	58.0 (24.0)	69.3 (20.6)	66.7 (21.2)
Item 6	64.7 (13.7)	63.8 (16.2)	65.8 (15.2)
Item 7	61.4 (20.7)	65.1 (19.5)	66.2 (18.5)
Item 8	48.1 (24.7)	55.8 (28.4)	53.4 (26.4)
Item 9	62.8 (27.8)	59.7 (30.4)	65.3 (25.0)
Item 10	52.8 (26.3)	53.8 (29.3)	58.8 (25.0)
Mean across items	58.9 (22.7)	61.5 (24.0)	62.9 (22.3)

As with the other qualitative data, a cyclical approach (Fox, et al., 2004; Luborsky, 1994; Strauss & Corbin, 1990) was used to determine emerging themes from written observations obtained from the open-ended question for peers with IPD. Table 15 summarizes themes across the three phases. Peers with IPD consistently reported on the quality of the communication interaction between the dyad and the overall intelligibility of the person with IPD. In general, peers with IPD noted that Dyad 1 had good communication interactions across all phases. Comments on the quality of the communication interaction for Dyad 3 suggested that the quality was better pre-treatment compared to post-treatment, and reports for Dyad 5 implied that the quality of communication interaction was better after LSVT. Remarks related to the intelligibility of the person with IPD varied across dyads and phases. Peers with IPD reported good intelligibility for IPD1 during the post-treatment and maintenance phases. Statements pertaining to intelligibility for IPD2 suggested that all peers with IPD had difficulty understanding him regardless of the phase. Comments related to IPD3 indicated that he was easiest to understand during the maintenance phase. One unfamiliar judge specifically stated that he seemed "clearer compared to [the post-treatment phase]". Reports for IPD5 suggested that he was louder after LSVT, thus making him easier to understand. Refer to Table 15 for specific quotes regarding each theme.

Table 15

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Qualitative Themes and Quotes from Peers with Idiopathic Parkinson Disease based on Viewing Conversational Probes across Each Phase

Theme			
Theme		Dyad 1	
	Quotes	Quotes	Quotes
	(Pre-treatment)	(Post-treatment)	(Maintenance phase)
Quality of the communication interaction	"I felt it was a normal conversation." [Peer1]		"[It was a] good conversation." [Peer2]
- Good	"[It was] a good normal conversation." [Peer2]		
	"Equal communication between both [partners]." [Peer3]		
Intelligibility of person with IPD		"[Person with IPD was] very very clear; easy to understand." [Peer3]	"Person with Parkinson was very clear." [Peer3]
- Good			
		Dyad 2	
Theme	Quotes (Pre-treatment)	Quotes (Post-treatment)	Quotes (Maintenance phase)
Quality of the communication interaction			"Seemed [like a] more one-sided [conversation]." [Peer3]
- Poor			

		Dyad 2	
Theme	Quotes	Quotes	Quotes
	(Pre-treatment)	(Post-treatment)	(Maintenance phase)
Intelligibility of person with IPD	"[I] couldn't understand [IPD2]" [Peer1]	"[I] couldn't understand [IPD2]" [Peer1]	"[I] couldn't understand [IPD2]" [Peer1]
- Poor	"IPD2 was loud enough but not clear."	"I did not understand one word." [Peer2]	"I could not understand what [IPD2] was saving." [Peer2]
	[Peer2]	"[This conversation was the] hardest to	"([]DDD) "
	"[IPD2] was very difficult [to understand]would have to lip read to		[IFD2] was very unificant to understand. [Peer3]
	understand." [Peer3]		
		Dyad 3	
Theme	Quotes	Quotes	Quotes
	(Pre-treatment)	(Post-treatment)	(Maintenance phase)
Quality of the	"This couple seemed to contribute		
communication interaction	equally." [Peer1]		
	"This [conversation] seemed better than		
- Good	[the post-treatment] conversation." [Peer2]		
	"A more equal conversation." [Peer3]		
- Poor		"The FM seemed to control the conversation." [Peer1]	
		"Both [partners] seemed uncomfortable; not a natural conversation." [Peer2]	

		Dyad 3	
Theme	Quotes (Pre-treatment)	Quotes (Post-treatment)	Quotes (Maintenance phase)
Intelligibility of person with IPD			"[IPD3] seemed clearer [compared to post- treatment]." [Peer3]
- Good			"[IPD3] was mumbling again, but quite understandable." [Peer3]
- Poor		"[IPD3] was mumbling and hesitant." [Peer3]	-
		Dvad 5	
Theme	Quotes	Quotes	Quotes
	(Pre-treatment)	(Post-treatment)	(Maintenance phase)
Quality of the communication interaction		"Both people were equally comfortable." [Peer1]	"Good [conversation]!" [Peer2]
- Good		"[The couple] had good humour and good give and take." [Peer2]	
Intelligibility of person with IPD		"[IPD4] was loud and clear." [Peer3]	"[IPD4] was loud enough." [Peer3]
- Good		•	•
- Poor	"[IPD4] was at times a bit difficult to understand." [Peer1]	"[IPD4] was having trouble with /s/." [Peer2]	
	"This was not as clear as the other conversations." [Peer2]		
	"[IPD4] had a loud voice but was hard to understand " [Peer3]		

Summary of Findings

A summary of results of the for each research question are displayed in Table 16.

Answers to each research question are provided based on both quantitative and

qualitative analyses.

Table 16

Summary of Results for Each Research Question

Research Questions	Results
1) Does LSVT impact the participants with IPDs' perceptions of voice and communication-related QoL immediately post-treatment, as well as 6 months post- LSVT, based on QoL scales and open- ended interviews?	• The QCL scale did not yield significant group results.
	• Participants with IPD perceived improvements in voice handicap from pre-treatment to post-treatment, but not to the maintenance phase.
	• Participants with IPD were more positive about LSVT and perceived increased volume immediately after LSVT. These effects decreased during the maintenance phase.
(2) Does LSVT impact FMs' perceptions of their spouse's voice and communication- related QoL immediately post-treatment, and 6 months post-LSVT, based on open QoL scales and ended interviews?	 Family members perceived an improved vocal quality immediately post-treatment. This effect was not found in the maintenance phase. Themes suggested that FMs noted improved vocal quality and/or loudness post-treatment and during the maintenance phase.
3) Will social validity ratings reflect changes in voice and communication quality immediately post-LSVT, and 6 months post-treatment, based on observations of two groups of unfamiliar judges: (a) members of the extended community who have minimal knowledge and experience with PD, and (b) peers with IPD with no experience with LSVT or knowledge of the study.	• Members of the extended community did not perceive improvement in the quality of communication immediately after LSVT or during the maintenance phase.
	• Overall themes from members of the extended community were mixed.
	• Peers with IPD noted no differences in the quality of communication across phases.
	• Overall themes from Peers with IPD were mixed.

Chapter 4: Discussion

Overview

The efficacy of LSVT for persons with IPD has been demonstrated repeatedly in ideal laboratory settings, including several RCTs (e.g., Fox et al., 2002; Ramig et al., 1994; 1995; 1996; 2001a; 2001b). The present study sought to investigate aspects of the clinical significance of LSVT. There were two main goals involved in this research: (1) to determine whether participants with IPD and their respective FMs would report improved voice and communication-related QoL immediately after LSVT and 6 months post-treatment, and (2) to examine whether unfamiliar judges would rate conversations between participants with IPD and their FMs as improved immediately post-LSVT and 6 months post-treatment. Results of quantitative and qualitative analyses are interpreted below, beginning with communication-related QoL outcomes and followed by social validity outcomes.

Communication-Related Quality of Life Measures

Research questions 1 and 2 examined the impact of LSVT on perceptions of voice and communication-related QoL for participants with IPD, as rated by the participants with IPD and their FMs. Quantitative measures completed by participants with IPD included the QCL scale (Paul et al., 2004) and the VHI (Jacobson et al., 1997). The FMs completed the PRF (Ramig and Fox, 2005). Overall results for participants with IPD and FMs suggested improvements in perceived voice function and communication-related QoL immediately after LSVT, but these gains were not revealed in the maintenance phase. Generally, themes that emerged from the QoL interviews were consistent with the quantitative data.

Perceptions of Participants with Idiopathic Parkinson Disease

Group results on the QCL scale (Paul et al., 2004) showed that LSVT failed to demonstrate a statistically significant impact on the participants' perceptions of communication-related QoL. Group trends in the predicted direction were noted for the post-treatment phase; with ratings returning to near baseline levels at the maintenance phase. One possible explanation for lack of statistically significant increases in perceived quality of communication life may be explained by Koplas and colleagues' (1999) theory of control over parkinsonian symptoms. The authors surmised that a sense of control over symptoms may positively contribute to one's QoL. As a group, participants with IPD may not have perceived enough of a gain in control over the voice to translate to improved QoL as measured by the QCL scale. Similarly, statistically significant decreases in perceived quality of communication life, as was noted for IPD3, may be attributed to a lack of actual or perceived improvement in communication from LSVT, leading to disappointment in the LSVT program and the magnitude of its outcomes. Such disappointment may manifest as a decreased sense of control over parkinsonian symptoms, which may be related to an overall reduction in communication-related QoL.

Another plausible explanation for the QCL results is that the QCL scale was not sensitive enough to detect changes in quality of communication life due to a voice treatment. Alternatively, because exploratory results demonstrated a trend toward significance in the predicted direction immediately post-treatment, it is possible that the sample size was inadequate for the statistical power required to demonstrate significant changes on the QCL scale.

Although significant group findings were not seen for the QCL scale, group analysis for the VHI (Jacobson et al., 1997) showed that participants with IPD perceived a decreased voice handicap immediately after LSVT. The group total mean VHI score prior to LSVT was correlated with a moderate voice handicap (Jacobson et al., 1997), whereas the post-treatment group total mean score decreased to a mild voice handicap, and the maintenance phase mean total score returned to a moderate voice handicap. Findings on the VHI were similar to other reports in the literature. Recently, Speilman et al., (2007) examined an extended version of $LSVT^7$ in which FMs completed the VHI prior to, immediately after, and 6 months post-treatment. The reported mean total scores were similar to the current study in immediate pre- (M = 44, SD = 22) and post-treatment phases (M = 30, SD = 17), but not 6 months post-treatment (M = 32, SD = 14). These values are associated with a moderate, mild, and mild level of voice handicap, respectively (Jacobson et al.). While Speilman and colleagues' results cannot be compared directly with those of the present study due to differences in LSVT protocol, statistical analyses, and number of participants, converging results imply that clients with IPD may perceive a decrease in voice handicap immediately after LSVT. The levels of perceived voice handicap 6 months after treatment appear more variable.

Several important themes emerged from the open-ended interviews which provided additional insight into the effect of LSVT on communication-related QoL for participants with IPD. In general, participants commented that they were satisfied with the program and would recommend it to others; however, satisfaction appeared to have decreased when asked at the maintenance phase. Participants reported that LSVT was

⁷ An extended version of LSVT (termed LSVT-X) involved two 1-hour sessions of LSVT treatment per

time consuming and required a significant commitment. Additionally, improved voice quality primarily related to increased loudness and clarity immediately after treatment and during the maintenance phase (but to a lesser degree) was reported.

Another theme that emerged involved the lack of compliance with the recommended daily homework upon the completion of LSVT. To maintain treatment gains, the developers of LSVT prescribe daily homework. As early as the post-treatment interviews, 80% of participants with IPD reported not completing homework tasks. Anecdotal observations have suggested that many clients with IPD seem to have difficulty adhering to the homework protocol upon the completion of LSVT (Lorraine Ramig, personal communication, November 17th 2006). To address this problem, it was recommended that clients of LSVT have follow-up sessions with their SLP approximately every 6 months and/or use a home-based LSVT software program (Lorraine Ramig, personal communication, November 17th 2006). The effectiveness of these recommendations has yet to be reported in the literature.

Perceptions of Family Members

Group analysis of the PRF (Ramig and Fox, 2005) showed that FMs perceived improvements in their spouses' voice immediately after LSVT, but not 6 months posttreatment. Likewise, Ramig et al. (1995) used a similar perceptual rating scale and found that FMs rated statistically significant voice improvements in their counterparts with IPD from pre- to post-treatment, but not 6 months after LSVT. Based on these ratings, Ramig and colleagues surmised that LSVT has the potential for a functional impact on

week for 8 consecutive weeks.

communication. Similar post-treatment results using a perceptual scale have been identified in the literature (e.g., Countryman et al., 1997; Fox et al., 2002).

Important themes that emerged from FMs' open-ended interviews included general satisfaction with the program post-treatment, and in the maintenance phase, but to a lesser extent. Family members also said that the LSVT regime was time consuming. This theme was especially evident immediately post-treatment. For both post-treatment and maintenance phase, FMs mentioned improved voice quality and/or increased loudness. These comments are consistent with the efficacy literature on improved loudness after LSVT. A primary goal of LSVT is to recalibrate the auditory system of the client with IPD such that a louder voice is achieved automatically (Ramig & Fox, 2006). Results of this study, however, are inconsistent with this goal and with the efficacy literature. Family members reported that using a loud voice was not automatic for their spouses; participants with IPD had to concentrate to achieve additional volume. Persons with IPD may find it difficult to maintain a natural or lengthy conversation, even after LSVT, if continuous concentration on speaking loudly is required. Thus, the likelihood that a loud voice will be used in daily situations is decreased because of the significant effort and awareness that must accompany it. This may help to explain why the efficacy of LSVT in the laboratory setting has been demonstrated repeatedly, but may not carry over into "real world" situations. In most efficacy studies (e.g., Ramig et al., 1996; 2001a; 2001b), participants were asked to sustain a loud phonation, say a few phrases, and read a passage. In these artificial situations, it would be easier for participants to concentrate on maintaining a loud voice, especially given their likely awareness of the investigator's desires for improved vocal function. Generalization of this loud voice and

improved communication to real life situations cannot be captured by the efficacy studies.

General Interpretations of Communication-Related Quality of Life Outcomes

As a whole, the aforementioned findings provided evidence for the clinical significance immediately after LSVT, but not 6 months post-treatment. These results are inconsistent with the efficacy literature which shows that LSVT is efficacious not only 6 months after treatment (e.g., Ramig et al., 1996, 2002) but up to 2 years post-treatment (Ramig et al, 2001a). There are several potential explanations for these results. The focus and measures of the present study differ from those of the efficacy literature in that the latter uses measures of vocal function as primary indicators of improvements. For example, in the efficacy studies, sound-level meters are used to provide decibel readings of loudness during short non-functional speech tasks (e.g., maximum sustain phonation). In contrast, this study uses measures of perceived vocal function, handicap, and QoL.

Another noteworthy issue with respect to the types of measurements and settings in which the efficacy studies collect data is that individuals with IPD are susceptible to cueing in order to achieve a movement goal. For example, a goal of taking longer steps can be facilitated by placing a transverse line on the floor (i.e., a visual cue) thus promoting greater push off force and higher velocity (Jiang & Norman, 2006). Likewise, Turnbull (personal communication, October 2005) reported that a laser pointer directed at the floor can serve as a visual cue for larger steps, and that this effect does not require training. During the efficacy studies, therefore, it is possible that participants with IPD were cued externally by seeing the therapist that administered LSVT, by having a soundlevel meter in front of them, or by returning to the laboratory environment where the treatment was administered. In order to examine the effects of LSVT in natural contexts, the present study attempted to avoid external cueing confounds. For instance, LSVT was provided in the laboratory, whereas measures were taken in the participant's homes. Research assistants who conducted the communication-related QoL measures and interviews were not otherwise involved in the study, and voice was measured perceptually by self-report and FMs. It is not surprising, therefore, that results of the present study are not entirely in keeping with the efficacy literature.

When interpreting the results of this study, one might also consider that LSVT may have protected the voice from the additional deterioration that could have happened if LSVT was not completed. Efficacy literature on LSVT suggests that vocal function of LSVT can be maintained up to 2 years post-treatment due to LSVT compared to other voice treatment strategies (Ramig et al., 2001a). Investigating the protective potential of LSVT on functional communication may be achieved by incorporating a control group to the present design and comparing the ratings of the treatment group to the control group. The inclusion of a control group, however, was deemed unethical by the investigator as LSVT has been demonstrated repeatedly as the most efficacious voice treatment for persons with IPD. Additionally, researchers (e.g., Cullen, 1986; Gehan, 1961; Greenwald & Cullen, 1984; 1985) highlighted that when attempting to determine the effectiveness of a treatment (i.e., phase IV and V of EBP), a control group is no longer necessary. This is because changes due to treatment have already been confirmed within the efficacy literature.

Social Validation

Members of the Extended Community

Ratings from members of the extended community were gathered to provide information on the types of improvements, if any, seen in conversations over the course of the LSVT study. Contrary to the hypotheses, group data showed statistically significant declines in communication performance across phases as rated by members of the extended community. Hence, the quality of the conversations was perceived more poorly after LSVT compared to before. If LSVT was minimally effective in changing aspects of communication for participants with IPD, a trend toward decreased conversation quality may be expected due to the progressive nature of IPD. Interestingly, there were no statistically significant differences in ratings from pre- to post-treatment versus pre-treatment to the maintenance phase, as may be expected due to the 6 month gap between data collection periods. One might speculate, therefore, that although completion of LSVT may not have generated socially valuable treatment effects as perceived by members of the extended community, it may have provided a protective benefit on the vocal mechanism for the LSVT participants.

A noteworthy group trend toward significance was seen for item 3 ("The person with PD spoke loud enough."), indicating that increased volume may be noticeable to members of the extended community after LSVT. Based on social validity ratings, however, it is unlikely that members of the extended community would rate the overall quality of the communication interaction as improved, even with increased loudness of the person with IPD. There are a variety of potential explanations for these results. For example, the social validity judges watched only one 3-minute conversation from each phase of the study that were randomly selected from 15 possible conversations in each phase. Perhaps if a larger sample or a different sample of conversational probes was viewed, members of the extended community would have detected a significant group difference in volume after LSVT. Alternatively, the particular social validity questions posed to the unfamiliar judges may not have reflected the aspects of communication or potential improvements in the quality of the communication interaction that were important to the judges. The social validity rating scales were adapted from aphasia research, and have only been validated for unfamiliar judges rating the communication of individuals with aphasia and their partners (Hickey, 2000; Hickey & Rondeau, 2005). The methods used in social validity research for treatment of progressive dysarthrias have not been established previously, as they have in aphasia and other areas of research (e.g., special education, applied behavioral analyses).

In addition to the quantitative ratings, unfamiliar judges completed an open-ended question (see Appendix P). Themes that emerged from this measure included: quality of the communication interaction, vocal volume, and vocal quality. Most qualitative comments regarding the quality of the communication interaction and vocal quality were mixed (i.e., good and poor) across phases for all dyads except Dyad 1. Members of the extended community agreed that quality of communication for Dyad 1 was good and that IPD1 had consistently good vocal quality across all experimental phases. Such comments may reflect that LSVT did not contribute to improved vocal quality for IPD1, but may have helped to protect her voice over time. Comments related to the volume of the participants with IPD were mixed for all IPDs other than IPD1 and IPD5. Remarks suggested that IPD1's voice was quieter during the maintenance phase. A trend in ratings

suggested that IPD5's volume had improved immediately after treatment and was sustained to the maintenance phase.

Conclusions based on the aforementioned findings reflect that members of the extended community, who were unfamiliar with the dyads, were unable to quantitatively detect socially valuable group changes pertaining to aspects of overall quality of communication as a consequence of LSVT. Similarly, qualitative comments to an open-ended question did not yield significant group patterns for communication among dyads across the three experimental phases.

Peers with Idiopathic Parkinson Disease

Three unfamiliar raters with a diagnosis of IPD served as peers with IPD in the social validity portion of this study. The small sample size of this group precluded the use of rigorous statistical analysis from which firm conclusions could be drawn. Comments related to qualitative themes were mixed. Caution is warranted when interpreting results from peers with IPD as the validity and reliability are lacking at this stage. More data are needed to be able to compare these ratings with those of members from the extended community.

Clinical Implications

Results from this study may have several important clinical implications. Consistent with previous efficacy studies of LSVT, the current investigation implies potential for the effectiveness of LSVT, as perceived by clients and their FMs, and potentially by other individuals with IPD. Specifically, results from the VHI, the PRF, and the open ended interviews suggested noticeable improvements in vocal loudness and general quality of communication immediately after LSVT; results were variable at 6 months post-treatment. Thus, LSVT may be a useful tool to enhance and/or protect the voice function of persons with IPD.

An important implication for clinical practice involves consideration to the individual differences in attitude and motivation for treatment and follow-up exercises. One potential explanation in the decreased perceptions of communication during the maintenance phase involves a failure to practice according to protocol. Within the open-ended questions, several comments were made regarding the lack of participants' adherence to the recommended post-treatment homework, suggesting that clients are not likely to practice once the treatment has been completed. Ramig and colleagues have also found similar patterns among their participants (L. Ramig, personal communication, November 22nd 2006). It is possible, and perhaps likely, that many LSVT clients will not be committed to practicing and are therefore less likely to maintain treatment gains over time.

Information from members of the extended community provided several important clinical implications. Results suggested that the general public may be more likely to detect deterioration in communication, presumably due to the progression in symptoms from IPD, than to observe positive treatment effects from LSVT. A study conducted by Hickey and Rondeau (2005) found that unfamiliar judges representative of the general public may provide the most robust social validity findings in treatment outcomes for aphasia. This might imply that LSVT is not clinically significant. Further social validity research is warranted for communication disorder treatments, such as LSVT. Social validity is a measure of ecological validity (Kenedy, 1992). Professionals have an obligation to show 'value for money' when considering provisions of treatments (Carding, 2000). Chwalisz (2003) reported that treatments with little evidence for effectiveness are less likely to receive federal or provincial financial support. Due to clinician training requirements, the intensive nature of the treatment, and the clinician to client ratio requirements, LSVT is an expensive program. Thus, it must be questioned whether having the individual with IPD and their FM notice significant improvements immediately post-treatment only, while members of the extended community cannot observe treatment effects, is cost effective. Based on the results of this study, it is unlikely that government agencies would fund LSVT for persons with IPD. As this was a pilot study, however, further research on issues of effectiveness and clinical significance remains necessary before any conclusions that would influence policy can be drawn.

Recommendations

Based on the results of this pilot study, several preliminary recommendations can be made. To maximize treatment outcomes, the LSVT protocol should include guidelines for treatment candidacy, which extend beyond having IPD, hypokinetic dysarthria, and absent or minimal cognitive deficits. Such guidelines may include an intrinsic desire to participate in the treatment, commitment to the protocol, and enduring motivation to continue the protocol over time. Several potential clients may feel required to take part because their FMs or other counterparts want them to do so. For example, during the post-treatment QoL interview, FMI stated "It [was] me that kind of got her into it [the LSVT study]. [IPD1] wasn't mentally onboard to the proper extent...it's the caretaker that may push them into it [LSVT]." Clients of LSVT must be willing to give up a significant amount of time during the treatment phase and must be motivated to complete daily homework post-treatment for as long as possible. With each potential LSVT client, specific guidelines for appropriate treatment candidacy should be screened by the clinician prior to commencing and committing to LSVT.

Furthermore, the clinician should have a good understanding of the client's individual goals and reasons for taking part LSVT. A realistic communication goal for LSVT may be to improve communication with the spouse, versus with members of the extended community. To ensure realistic goals and to avoid disappointment with treatment outcomes, the clinician must give the appropriate counselling prior to the treatment. The client should be informed that LSVT will not guarantee an improvement in voice for communication in typical daily situations. Additionally, unfamiliar people may be unable to notice an improvement after treatment. The LSVT protocol and outcomes may not suit the needs and wants of all individuals; other treatment options should be identified and discussed with the client and FMs. Clients should understand that LSVT requires long-term commitments to practicing if treatment gains are more likely to be sustained. Proper counselling will help the potential LSVT client make an informed decision. If an individual chooses to complete LSVT, it is recommended that the client has regular contact with the SLP to ensure that treatment gains are being maintained within daily life, as well as to help with motivation and commitment to the program; this could be accomplished through telephone calls, e-mails, video conferencing, and/or office visits.

Limitations of the Study

There were several limitations to consider when interpreting the results of this research. One inherent weakness included the small sample size of those who completed LSVT as well as the attrition of one participant at the maintenance phase. Despite the power analysis requiring five participants, and although the sample was not uniform (e.g., male, female, different stages of IPD, working and retired participants), it was unlikely that most of the population variability was captured, thus limiting generalization of the results. Additionally, communication-related QoL measures were collected on a single day for each phase. Hence, the information obtained represents a 'snapshot' in time and may not necessarily provide accurate representation of voice function or overall communication-related QoL.

A primary goal in conducting research investigating the clinical significance of a treatment is to record data in a natural setting. Within the boundaries of ethical procedures, however, this remained a difficult task. For instance, individuals cannot be videotaped without their knowledge, thus, the data collection situation remained somewhat artificial. Although most participants reported feeling at ease during tapings, one dyad reported not being accustomed to having conversations with one another on a regular basis. Consequently, they experienced some discomfort in having "forced" conversations for the duration of 3 minutes, three times in each of the five sessions per phase.

The Hawthorn effect⁸ may have influenced the communication-related QoL measures obtained, despite the preventative steps that were taken to minimize it. Due to the nature of this study, participants were generally aware of the hypotheses. Thus, in a subconscious effort to please the investigator, participants may have overestimated voice improvements related to LSVT. This may contribute to the explanation of why significant changes were yielded in the VHI and PRF, which are more specific to voice, but not on the QCL scale, which is more related to general communication and participation.

Obtaining hearing and otolaryngological assessments prior to initial data collection would have improved the control of the study. Hearing impairments can negatively impact successful communication. Participants involved in the LSVT portion of the study were asked whether their, and their spouse's, hearing was normal or corrected-to-normal. Therefore, hearing was subjectively screened based on self and spousal report. The methodology would have had more rigor if hearing was objectively screened using an audiometer. Similarly, vocal impairments were assumed to be a result of hypokinetic dysarthria from IPD, based on expert opinion of the research supervisor. As this was not objectively confirmed by an otolaryngologist prior to the study, it is possible that laryngeal status was not consistent with IPD and could not have been impacted by LSVT. Unfortunately, available resources did not permit a laryngeal assessment for this pilot study.

The purpose of the social validity measures was to add information about the clinical significance of a treatment. This was done by recruiting unfamiliar judges (i.e.,

⁸ The Hawthorne Effect is a phenomenon which can occur when a participant is being observed during a research study. It is thought that the participant's behavior may change temporarily due to this observation.

members of the extended community and peers with IPD) to determine if people who were unknown to those who completed LSVT would detect changes in the conversations across phases. Due to limitations in resources and responses to recruitment efforts, only three peers with IPD participated in this study. Thus, statistical analyses and comparison to the data obtained from members of the extended community were inappropriate for the peers. Efforts to increase the sample size of peers with IPD are ongoing.

Future Considerations

The results of the current study are promising and highlight the need for additional research in this and related areas. This study was the first, to the author's knowledge, to specifically address the clinical significance of LSVT through communication-related QoL measures and social validation. Although LSVT has demonstrated efficacy, knowledge related to effectiveness is necessary to determine the extent to which LSVT is beneficial under ordinary conditions (Carding, 2000). Such information may be useful in planning resource utilization and policy.

The previous discussion outlined various potential positive outcomes resulting from LSVT, especially immediately post-treatment. In addition to replications of this methodology, future studies may wish to expand the scope of this line of research. For instance, investigating the clinical significance of LSVT by incorporating a larger sample size may improve generalizability of the outcomes. Determining whether LSVT yields benefits in real-life settings to individuals in specific stages of IPD or with other types of PD, would be a valuable endeavour. It would also be worthwhile to investigate the extent to which LSVT protects from the degeneration of the voice in natural settings. Therefore, future studies may consider including a control group and comparing communicationrelated QoL and social validity measures between the groups.

At this time, approximately 20 years worth of data exists to support the efficacy of LSVT. Future studies are needed to shift the focus of research of this treatment to consider its effectiveness. Expansion and replication of this study may provide additional and/or converging evidence regarding the clinical significance of LSVT.

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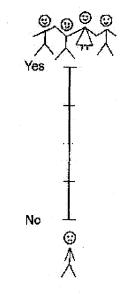
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Appendix A: Levels of Research for Evidence Based Practice Incorporating Efficacy and	
Effectiveness	

Phase	Description	Typical research design
Phase I	 Develop a critical research hypothesis for later testing Establish safety of new treatment Detect activity of a treatment 	Small sample sizesNo control groups
Phase II	 Preliminary stages of efficacy testing Formulating and standardizing treatment protocols Observations to detect activity 	• Samples from target population
Phase III	 Efficacy testing Hypotheses are refined	 Large samples Control groups
Phase IV	 Continuation of efficacy studies Initial efforts into conducting effectiveness studies 	SubpopulationsFollow-up testing
Phase V	• Continuation of effectiveness research	 Control samples not used

Appendix B: Examples of Quality of Communication Life Scale Items



People include me in conversations.

Other QCLS items include the following categories and statements:

Socialization/Activities

I like to talk with people.

I meet the communication needs of my job or school.

People include me in conversations

I follow news, sports, and stories on TV/movies.

I use the telephone.

People understand me when I talk.

I get out of the house and do things.

Confidence/Self-Concept

It's easy for me to communicate.

I like myself.

I see the funny things in life.

I keep trying when people don't understand me.

I am confident that I can communicate.

I speak for myself.

Roles and Responsibilities

My role in the family is the same. I stay in touch with family and friends. I make my own decisions. I have household responsibilities.

General

In general, my quality of life is good.

Consistency

It's easy for me to communicate. My role in the family is the same. Name: Session: Session:

Voice Handicap Index (VHI)

Instructions: These are statements that many people have used to describe their voices and the effects of their voices on their lives. Check the response that indicates how frequently you have the same experience.

		Never-	Almost	Sometimes	Almost	Always
			Never		Always	
EI	My voice makes it difficult for people to hear me					
22	P2 I run out of air when T talk are see					
EX.	Péople haye difficulty understanding me in a noisy room					
P4 -	The sound of my voice varies throughout the day					
F5	My family has difficulty hearing me when I call them throughout the house					
F6.	I use the phone less often than I would like					
E7	Pim tense when talking with others because of my voice					
F8	I tend to avoid groups of people because of my voice					
Eð	People seem irritated with my voice					
010	P10 People ask, "What's wrong with your voice?"					* .
II.	F11 I speak with friends, neighbors or relatives less often because of my voice					
F12	People ask me to repeat myself when speaking face-to-face					
PIS	My voice sounds creaky and dryverses					
14	P14 I feel as though I have to strain to produce voice					
					······································	and a survey of the second

Jacobson, Johnson, Grywalski, Sübergleit, Jacobson, Benninger, & Newman (1997). The Voice Handicap Index (VHI). American Journal of Speech Language Pathology, 6, 66-70. Page 1 of 2

Appendix C: Examples of Items from the Voice Handicap Index

Appendix D: Perceptual Rating Form

Perceptual Rating Form

<u>Client:</u>	Date:	Relation to Client:		
Please mark the place on the line that best represents the client's typical speech:				
Always loud enough			Never loud enough	
Never a "shaky" voice			Always a "shaky" voice	
Never a hoarse "scratchy" voice			Always a hoarse "scratchy" voice	
Never monotone			Always monotone	
Never Slurs	- - -		Always Slurs	
Never a "strained" voice		· · ·	Always a "strained" voice	
Never mumbles			Always mumbles	
Always Speaks so others can understand			Never Speaks so others can understand	
Always Participates In a Conversation			Never Participates In a Conversation	
Always Starts A Conversation			Never Starts A Conversation	

Appendix E: Notice Digest Advert for Persons with Idiopathic Parkinson's Disease and Family Members

Notice Digest Advert

From the School of Human Communication Disorders Ellen Hickey, Ph.D. (Principal Investigator) Laura Boland, B.Sc. (Graduate Student Research Assistant)

PERSONS WITH PARKINSON'S DISEASE ARE NEEDED FOR A RESEARCH STUDY

"Effectiveness of Lee Silverman Voice Treatment for Parkinsonian Dysarthria: Generalization and maintenance"

What is the purpose of this study?

We want to find out if a particular speech treatment for persons with Parkinson disease (PD) is useful in everyday life, or "real world" situations.

- This study will use a speech treatment for persons with Parkinson disease that has been shown to work quite well in large-scale studies. However, the treatment effects outside of the laboratory environment have not been studied.
- This study will examine whether there is a benefit in "real world" situations, and if the benefit lasts after treatment stops.
- We will also study whether there is any impact on your quality of life.

What's involved? You will be asked to

- Participate in data collection sessions in your home.
- These sessions will take place immediately before and after treatment, and 6 months after treatment.
- Participate in treatment sessions, 4 times per week for 4 weeks (a total of 16 sessions).
- Complete daily homework assignments.

Participation in this study is strictly voluntary. You may choose not to participate or to withdraw from the study at any time. All information will be kept confidential.

To talk more about the study, and to find out if this study is right for you, please contact either:

Dr. Ellen Hickey – by phone at **494-1072**, or by e-mail at <u>ehickey@dal.ca</u> **Laura Boland** – by phone at **453-1841**, or by e-mail at <u>lauraboland@dal.ca</u> Information and consent forms will be mailed to you.

Appendix F: Recruitment Letter for Persons with Idiopathic Parkinson Disease and Family Members

PERSONS WITH PARKINSON'S DISEASE ARE NEEDED FOR A RESEARCH STUDY

"Effectiveness of Lee Silverman Voice Treatment for Parkinsonian Dysarthria: Generalization and maintenance"

Ellen Hickey, Ph.D. (Principal Investigator) Laura Boland, B.Sc. (Graduate Student Research Assistant) School of Human Communication Disorders, Dalhousie University

What is the purpose of this study?

We want to find out if a particular speech treatment for persons with Parkinson disease (PD) is useful in everyday life, or "real world" situations.

- This study will use a speech treatment for persons with PD that has been shown to work quite well in large-scale studies. However, the treatment effects outside of the laboratory environment have not been studied.
- This study will examine whether there is a benefit in "real world" situations, and if the benefit lasts after treatment stops.
- We will also study whether there is any impact on your quality of life.

Who can participate?

You may take part in this study if the answer is YES to all of the following;

- ✓ You are 50- to 70-years old.
- ✓ You were diagnosed with idiopathic Parkinson disease about 2 years ago.
- ✓ You have speech difficulties due to PD.
- ✓ Your cognitive abilities (or thinking skills) have not been affected by PD, or are only mildly impaired.
- ✓ You speak English as your primary language.
- ✓ Your hearing and vision are normal or corrected to normal.
- ✓ You live with someone who wants to participate in the study with you (may be spouse, partner, or other family member or friend referred to as family member from now on).
- ✓ Your family member has normal speech and language, with English as his/her primary language.

BUT, if the answer to any of the following is YES, you cannot take part;

- \varnothing You have a diagnosis of Parkinson-plus syndrome.
- You or your family member have or have had a history of other neurological (brain-related) or major psychiatric disorders (for example, Alzheimer disease, cerebral palsy, stroke, schizophrenia).
- Ø You have psychiatric problems from PD (for example, hallucinations, major depression).
- You or your family member have or have had poor medical status that would prohibit ability to pay attention and participate in the study protocol

What's involved? You will be asked to ...

- **Screening:** If you want to be in this study, you will have to have some tests done to see if you can take part. This is called "screening". It is possible that the tests will show that you can't be in the study. This will include speech and cognitive testing. The screening will be conducted in the School of Human Communication Disorders at Dalhousie University (in Fenwick Tower).
- The study: If you participate in the study, you will do the following...

1) One pre-treatment and one post-treatment interview/information sessions in your home, with a research assistant (about 30-45 minutes, each). Your family member will also be interviewed. These sessions will be scheduled within 2 weeks before and after the treatment, and again about 6 months after treatment ends.

2) Five pre-treatment and ten post-treatment data collection sessions in your home. You will be asked to read sentences aloud and to have 3-minute conversations with your family member. These sessions will be scheduled 5 times within 2 weeks before and after treatment, and again 5 times about 6 months after treatment ends. Each visit will take approximately one hour.
 3) Treatment: You will participate in speech therapy - 1-hour treatment sessions 4 times per week for 4 weeks, for a total of 16 sessions. The treatment will be conducted in treatment rooms at the School of Human Communication Disorders at Dalhousie University.

4) Daily homework: You will be asked to complete homework in speaking tasks every day during the 4-week period of treatment. Homework will be individualized to meet your needs and goals.

What will it do for you?

There may be no direct benefit to you, but possible benefits include...

• You will receive free speech treatment services using a procedure that has been shown to be have good results in the clinical setting. You are likely to benefit from this treatment, at least on measures taken in the clinic. There is no guarantee that you will benefit from treatment in "real world" situations.

What will it do for others?

The researchers will gain information that might help to develop further the treatment and to benefit other people with PD in the future. This research is also likely to benefit speech-language pathologists who treat persons with PD.

Are there risks involved?

There are no significant safety risks to participating in this study. The treatment has been extensively researched and the procedures are safe. Most of the tasks that we ask you to do are similar to tasks that you do every day, such as talking to your family members or using the telephone.

- Because this therapy involves working on your speech, it is possible that you might feel frustrated during the study. A possible unpleasant effect is the potential for feeling sad when the study is over. However, you are encouraged to continue to practice what you learned during the therapy with your conversation partner after the study is over.
- You may be disappointed if you do not feel that you benefited from the treatment.
- It may be inconvenient to have the researchers come to your home.

What about my privacy?

All information will be kept confidential.

To talk more about the study, and to find out if this study is right for you, please contact either:

Dr. Ellen Hickey – by phone at **494-1072**, or by e-mail at <u>ehickey@dal.ca</u> **Laura Boland** – by phone at **453-1841**, or by e-mail at <u>lauraboland@dal.ca</u> Information and consent forms will be mailed to you.

Appendix G: Consent Form for Persons with Idiopathic Parkinson Disease and Family Members



Human Communication Disorders 5599 Fenwick Street Halifax, Nova Scotia B3H 1R2

Effectiveness of LSVT for Parkinsonian Dysarthria: Generalization and Maintenance

Principal Investigator(s): Ellen Hickey, Ph.D., CCC-SLP

Dalhousie University School of Human Communication Disorders 5599 Fenwick St. (902) 494-1072 FAX: (902) 494-5151 e-mail: ehickey@dal.ca Certified Speech-Language Pathologist, Assistant Professor

Contacts: For more information about this study, please contact at any time: Dr. Ellen Hickey (at above phone number/e-mail), or Laura Boland, B.Sc. School of Human Communication Disorders 5599 Fenwick St. (902) 453-1841 FAX: (902) 494-5151 e-mail: lauraboland@dal.ca Graduate Student Research Assistant

INTRODUCTION

We invite you to take part in a research study at Dalhousie University. We are doing this trial to find out better ways of caring for people with speech problems due to Parkinson disease (PD). The study is described below.

Taking part in this study is voluntary and you may withdraw at any time without penalty. Participating in the study might not benefit you, but we might learn things that will benefit others. You should discuss any questions you have about the study with Dr. Ellen Hickey and/or Laura Boland.

WHAT WILL I LEARN FROM READING THIS?

We will explain why we are doing the study. It tells you what will happen, and about any potential inconvenience, discomfort or risk. There is also a brief description of the treatment. This information will help you decide whether you want to be part of the trial.

Please read this carefully. Take as much time as you like. If you wish, think about it for a while. Mark anything you don't understand, or want explained better. After you have read it, please ask questions about anything that is not clear.

WHAT IS THE PURPOSE OF THE STUDY?

Research studies are done on speech treatments to improve our ability to help people with communication problems. In this study, we want to find out if a particular speech treatment for persons with PD is useful in everyday life, or "real world" situations.

This study will use a speech treatment for persons with PD that has been shown to work quite well in large-scale studies. However, the treatment effects outside of the laboratory environment have not been studied. This study will examine whether there is a benefit in "real world" situations, and if the benefit lasts after treatment stops. We will also investigate the impact of this treatment on quality of life, if any.

HOW IS THE STUDY BEING DONE?

This study is a clinical research study. Persons with PD will receive speech therapy. In order to study the impact of the treatment in "real world" situations, the researchers will come to your home immediately before and after the treatment to assess your speech abilities and to assess your quality of life. You will be asked to say a list of sentences and have conversations with your family member. You will also be asked to fill out some rating scales about your quality of life, and to participate in interviews with a research assistant. Further details of what you will be asked to do are below. These evaluations will be completed again six months after treatment. Thus, evaluations will be done three times in total.

WHY AM I BEING ASKED TO JOIN THE STUDY?

The Maritime Parkinson Society indicated that you are a member and that you have PD. If you also have speech problems from PD, you may be able to participate. See below for more details.

WHO CAN TAKE PART IN THIS STUDY?

You may take part in this study if the answer is YES to <u>all</u> of the following;

- \checkmark You are 50- to 70-years old.
- \checkmark You are at least 2 years post-diagnosis.
- ✓ Your have speech difficulties that are the result of PD (You will be asked to take a test to assess this).
- ✓ Your cognitive (thinking skills) have not been affected by PD, or are only mildly impaired. (You will be asked to take a test to assess this.)
- ✓ You speak English as your primary language.
- \checkmark Your hearing and vision are normal or corrected-to-normal.
- ✓ You live with someone who wants to participate in the study with you (this may be spouse, partner, or other family member or friend – referred to as family member from now on).
- ✓ Your family member has normal speech and language, with English as his/her primary language, and he or she wishes to participate in this study.

BUT, if the answer to any of the following statements is YES, you cannot take part;

- Ø You have a diagnosis of Parkinson-plus syndrome or secondary Parkinson disease.
- You or your family member have or have had a history of other neurological (brain-related) or major psychiatric disorders (for example, Alzheimer disease, cerebral palsy, stroke, schizophrenia).
- \varnothing You have psychiatric problems from PD (for example, hallucinations, major depression).
- \varnothing You or your family member have or have had poor medical status that would prohibit ability to pay attention and participate in the study protocol.
- \varnothing You have a history of speech or language difficulties that are NOT related to PD.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

There will be a total of 6 to 8 persons with PD from the local areas of the Halifax Regional Municipality in this study. In addition, they will each have one family member who participates.

HOW LONG WILL I BE IN THE STUDY?

The study is expected to last about 6 to 8 weeks initially. You will then be asked to participate in the study again in 6 months. See below for further details about the time that you will be expected to participate.

WHO WILL BE CONDUCTING THE RESEARCH?

The following people will be involved in conducting this study.

• **Principal Investigator:** Ellen Hickey, Ph.D., CCC-SLP is an Assistant Professor of speech-language pathology, and a certified LSVT practitioner. She will oversee all aspects of this study. She will be involved in conducting and supervising the treatment and the evaluations.

• **Graduate Student Clinicians:** Laura Boland and Sheena Alexander are Master's students in speech-language pathology and have taken the LSVT certification course. They are able to provide the treatment under the supervision of a certified speech-language pathologist. They will conduct evaluations and treatment sessions.

• **Graduate Student Research Assistants:** Laura Boland, Sheena Alexander, and/or Zuzana Staskova will come to your homes to conduct evaluations and to collect data for Dr. Hickey. They will also work in Dr. Hickey's laboratory to analyze the speech samples and other data that are collected (see further details below).

WHAT WILL I BE ASKED TO DO IF I TAKE PART IN THIS STUDY?

Screening

If you want to be in this study and sign this 'consent' form, you will have to have some tests done to see if you can take part. This is called "screening". It is possible that the tests will show that you can't be in the study. The screening will be conducted by Dr. Hickey and one graduate student (Laura Boland or Sheena Alexander). This will include speech and thinking-skills testing. The screening will be conducted in the School of Human Communication Disorders at Dalhousie University. The research study screening tests that will be done are:

- The Structural-Functional Exam of the Speech Mechanism (you will be asked to use the muscles in your face, mouth, and throat, for example, smile, frown, stick your tongue out, say "ah", cough, swallow).
- The Montreal Cognitive Assessment: For example, you will be asked to:
 - speak in words, sentences, and conversations
 - remember words immediately and after a delay
 - o follow spoken and written directions
 - write and draw

name pictures of objects or animals

Study

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We will do the following as part of the study.

- 1) One pre-study interview/information session (about 30-45 minutes for each the participant and the family member).
- Zuzana Staskova, a research assistant, will come to your home to meet with you and your family member.
- You and your family member will meet with Zuzana separately.
- You will talk about your interests and daily routines.
- The family member will be asked questions regarding the independence, communication abilities, and functionality of the person with PD. They will also be asked their options regarding treatment options and resources available.
- The research assistant will ask you to fill out some questionnaires and will interview you about your feelings about communication and your quality of life (Quality of Communication Life Scale and the Parkinson Disease Questionnaire-39).
- You do not have to answer her questions if you do not want to. You can stop the interview any time.
- The interview will be audio-taped for later transcription and analysis.
- This session will be scheduled at your convenience within 2 weeks before treatment starts.

2). Five pre-treatment data collection sessions.

- A research assistant and/or Dr. Hickey will come to your home five times to collect data on your speech abilities.
- These sessions will be videotaped for later examination in Dr. Hickey's laboratory.
- Data will be taken before and after you take your PD medication(s) at 30 minutes, 15 minutes, and immediately before your medication, and 15 minutes and 30 minutes after your medication.
- You will read ten sentences aloud (for example, "Let's play cards." "What's for dinner?"). These will be related to your interests and needs.
- You will have 3-minute conversations with your family member.
- You and your family member can talk about anything you like (for example, your family, hobbies, sports, magazines, things you need to do, etc.).
- Each visit will take approximately one hour.
- These sessions will be scheduled at your convenience (and around your medication schedule) within 2 weeks before treatment begins.

3). Treatment:

- You will participate in speech therapy, conducted by Ellen Hickey or by Laura Boland or Sheena Alexendar (under the supervision of Dr. Hickey).
 - The treatment will be conducted in treatment rooms at the School of Human Communication Disorders at Dalhousie University.

- You will be asked to attend 1-hour treatment sessions 4 times per week for 4 weeks. There is a total of 16 sessions.
- Every day, you will do 3 different types of speech tasks (for example, read sentences aloud, state your opinion on a topic). Further details will be provided when treatment begins.
- Every day, you will be given feedback about your performance.
- 4). Daily homework:
- You will be asked to complete homework in speaking tasks every day during the 4-week period of treatment.
- The homework will start with relatively easy tasks and get harder as you improve in treatment.
- Homework will be individualized to meet your needs and goals (for example, using the telephone, speaking to store clerks, speaking in groups).

5). Two post-study interview/information sessions (about 30-45 minutes each).

- Zuzana Staskova, will come to your home to meet with you and your family member.
- You and your family member will meet with Zuzana separately.
- You will complete the same procedures as in number 1.
- These sessions will be scheduled at your convenience, within 2 weeks after the treatment ends, and again about 6 months after treatment ends.

6). Ten post-study data collection sessions.

- A research assistant and/or Dr. Hickey will come to your home to collect data on your speech abilities.
- You will complete the same procedures as in number 2.
- These sessions will be videotaped for later examination in Dr. Hickey's laboratory.
- These sessions will be scheduled at your convenience (and around your medication schedule) 5 times within 2 weeks after treatment ends, and 5 times about 6 months after treatment ends.

ARE THERE RISKS TO THE STUDY?

There are no significant safety risks to participating in this study. The treatment has been extensively researched and the procedures are safe. Most of the tasks that we ask you to do are similar to tasks that you do every day, such as talking to your family members or using the telephone.

Because this therapy involves working on your speech, it is possible that you might feel frustrated or fatigued during the treatment regime.

A possible unpleasant effect is the potential for feeling sad when the study is over. However, you are encouraged to continue to practice what you learned during the therapy with your conversation partner after the study is over. You may also feel disappointed if you do not feel that the treatment has been beneficial to you.

You may find the interviews and questionnaires you receive during the course of the study upsetting or distressing. You may not like all the questions that you will be asked. You do not have to answer those questions you find distressing. You can stop discussing any topic or end the interview at any time. Also, you may feel that having researchers come into your home poses an inconvenience.

You are a volunteer. You can withdraw from this research study at any time.

ARE THERE BENEFITS TO THE STUDY?

You will receive free speech treatment services using a procedure that has been shown to have good results in the clinical setting. You are likely to benefit from this treatment, at least on measures taken in the clinic. There is no guarantee that you will benefit from treatment in "real world" situations. In any case, the researchers will gain information that might help to develop further the treatment and to benefit other people with PD in the future. This research is also likely to benefit speech-language pathologists who treat persons with PD.

WILL IT COST ME ANYTHING?

You will not be paid to be in the study. There is no charge for the therapy or for any of the assessments that we administer.

WHAT ABOUT NEW INFORMATION?

It is possible (but unlikely) that new information about some new treatment for your condition may become available while you are in the study. You will be told about any other new information that might affect your health, welfare, or willingness to stay in the study.

WHAT ABOUT MY RIGHT TO PRIVACY?

All results obtained may be published or presented at scientific meetings. You identity, however, will not be revealed. A (code name/ID number) will be assigned to protect your identity. You will not be identified in any publications and presentations of the study findings. In the research report, all information that could be used to identify you and your family will be substituted with fictional names. Identifying personal features will

not be described, or will be disguised to provide confidentiality. All materials containing names (documents, audiotapes, videotapes, etc.) will be kept in locked storage accessible only by the researchers and research assistants during the study. Additionally, direct quotations from you may be used, but only after you give your consent.

Data related to this project will be destroyed five years after publication of research results. If you give your consent, however, videotaped materials will be kept for teaching and research purposes. If you do consent to having your videotaped material kept for teaching purposes, it is possible that you will be recognized by students.

With your consent, we can provide your family physician with information about your participation in the study.

WHAT IF I WANT TO QUIT THE STUDY?

You are a volunteer. You can stop participating in the study at any time if you change your mind. If you wish to withdraw your consent, please inform the investigator. All data collected up to the date you withdraw your consent will remain in the study records. However, if you wish to withdraw your data from the study, this is possible at any time.

DECLARATION OF FINANCIAL INTERESTS

The investigator has no financial interests in conducting this research study. Dalhousie University, Faculty of Health Professions has provided funding to cover the costs of conducting the study. Dr. Hickey is conducting the study as part of her typical research duties and is not being paid beyond her normal salary.

WHAT ABOUT QUESTIONS OR CONCERNS?

In the event that you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, you may contact the Human Research Ethics/Integrity Coordinator at Dalhousie University's Office of Human Research Ethics and Integrity for assistance. The coordinator, Patricia Lindley, can be reached at (902) 494-1462 or by email at patricia.lindley@dal.ca.

Also, please feel free to contact Dr. Ellen Hickey (902) 494-7052 (call collect) or ehickey@dal.ca with any questions you may have.

INVITATION TO PARTICIPATE IN THIS RESEARCH PROJECT

The purpose of this research is to improve interventions for individuals with speech difficulties as the result of PD. Please indicate your decision to participate on the attached consent form. You will find one form for the person with PD and another for the family

member. Both individuals must consent in order to participate. Thank you for your consideration.



Human Communication Disorders 5599 Fenwick Street Halifax, Nova Scotia B3H 1R2

Effectiveness of LSVT for Parkinsonian Dysarthria: Generalization and Maintenance

Consent form for the participant with Parkinson disease.

I have read the explanation about this study. I have been given the opportunity to discuss it and my questions have been answered to my satisfaction. I understand that I will be screened and may not be able to participate if I score below a certain number on the screening assessments. I hereby consent to take part in this study. However, I realize that my participation is voluntary and that I am free to withdraw from the study at any time.

Participant (print name)

I understand that videotaping and audio-taping are a requirement for participation in the study. I give my consent to be videotaped and audio-taped by the researcher.

Participant (signature)

The tapes will be kept by the researcher in a locked filing cabinet. I understand that only the researcher, research assistants, and hired student transcriptionists will have access to these tapes. The tapes will be destroyed five years after publication. If I consent to having the tapes kept indefinitely for teaching and research purposes, however, I can do so here:

I give consent for the tapes to be used for future research (e.g., a study examining the social value of LSVT or developing more effective treatment interventions).

___yes ___no

I give consent for the tapes to be used for teaching purposes. ____yes ____no

Participant (signature)

Date

Date

I give consent for quotes from the conversations or interview to be used in publication.

yes	no

Date

Date

Participant (signature)

I agree to be contacted in the future for participation in this or other affiliated research. For example, this may include the possibility of having a one year post-treatment follow up or developing more effective treatment interventions.

_yes ____no

Participant (signature)

Researcher (print name)

Researcher (signature)

Date

*Note: Please fill in the dates personally.

Thank you for your time and patience!



Human Communication Disorders 5599 Fenwick Street Halifax, Nova Scotia B3H 1R2

Effectiveness of LSVT for Parkinsonian Dysarthria: Generalization and Maintenance

Consent form for participant who is a <u>family member</u> of the person with Parkinson disease.

I have read the explanation about this study. I have been given the opportunity to discuss it and my questions have been answered to my satisfaction. I hereby consent to take part in this study. However, I realize that my participation is voluntary and that I am free to withdraw from the study at any time.

Participant (print name)

I understand that videotaping and audio-taping are a requirement for participation in the study. I give my consent to be videotaped and audio-taped by the researcher.

Signature of Participant

Date

The tapes will be kept by the researcher in a locked filing cabinet. I understand that only the researcher, research assistants, and hired student transcriptionists will have access to these tapes. The tapes will be destroyed five years after publication of results. If I consent to having the tapes kept indefinitely for teaching and research purposes, however, I can do here:

I give consent for the tapes to be used for future research (e.g., a study examining the social value of LSVT or developing more effective treatment interventions).

___yes ____no

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Bive consent for the tapet		ing purposes.	no	
	·			
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Appendix H: Evaluation of Structure and Function of the Speech Production Mechanism (based on Strand, Yorkston, & Miller, 1995)

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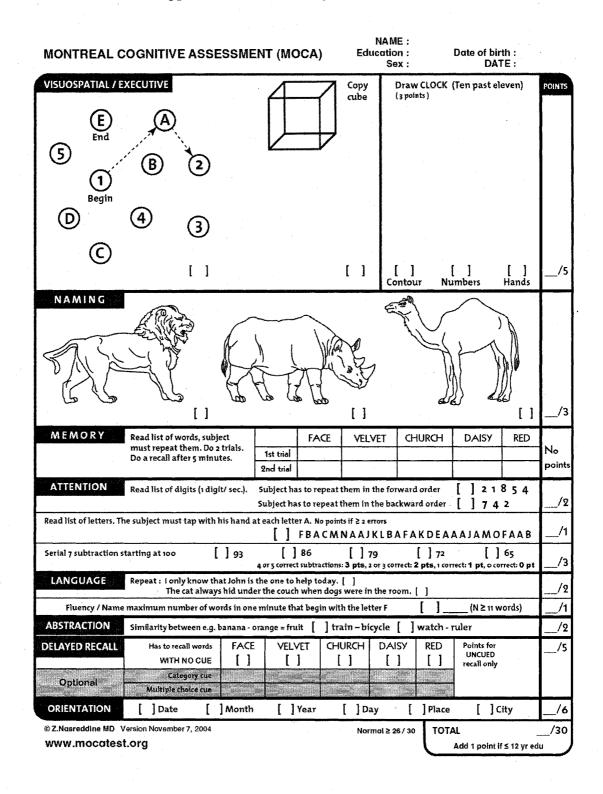
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	SPIRATION/PHONATION (CN X) re/circle as indicated)
	Resting respiration
	Complaints of fatigue (esp. w/ talking, activity)
	Shortness of breath (esp. w/ talking, activity)
	Stridor [inhalation/exhalation]
	Abnormal reflexive cough [weak/absent]
	Abnormal volitional cough [weak/absent]
	Abnormal loudness
	[reduced/exaggerated/uncontrolled]
	Inability to vary loudness
	Wet phonation
	Abnormal voice quality – [breathy/hoarse/harsh]
	Instability
	Phonation breaks
	Pitch breaks
	Inability to vary pitch
-	Fundamental frequency
	Other – specify:
Con	iments, summary statement:

Other comments:

Overall summary statement:



Appendix I: Montreal Cognitive Assessment

Appendix J: Consent for Use of Conversational Probes



DALHOUSIE UNIVERSITY HALIFAX, NOVA SCOTIA CANADA B3H 4R2 SWITCHBOARD: +1 (902) 494-2211

Dear Participants,

This letter is being sent to you because you consented to being contacted for affiliated research after your participation in the *Effectiveness of LSVT for Parkinsonian dysarthria: Generalization and maintenance*. At this time, Laura Boland and Dr. Ellen Hickey are further investigating the Lee Silverman Voice Treatment (LSVT).

This study will examine the social validity of LSVT. Social validity means the extent to which society believes a treatment to be socially 'important' or 'valuable'. These findings may help researchers to get a better idea if non-experts can detect changes (e.g., a louder voice) after treatment.

One way to measure social validity is for unfamiliar people to make observations about a client's communication before and after treatment (in this case, your performance before and after LSVT). We wish to recruit members of the community and individuals with Parkinson's disease to participate in a social validity study. They will rate the quality of the communication (e.g., loudness of voice, clarity of the message, etc.) of persons with Parkinson's disease before and after LSVT.

Twenty people, including 10 members from the community and 10 individuals with Parkinson's disease, will be recruited to be raters for this study. These raters will watch 2-minute conversation segments between individuals with Parkinson's disease and their family members before treatment, immediately after treatment, and several months after treatment. After the raters watch each conversation segment, they will be asked to rate the following:

- a) the comfort level of the conversation
- b) the volume of the voices during the conversation
- c) how well the person with Parkinson's was understood during the conversation
- d) whether the partners contributed equally to the conversation
- e) the overall quality of the conversation

Raters will also be asked to make any additional comments about their observations.

You are being contacted to determine if you will provide consent for us to show short, randomly selected, conversation segments to the raters. Again, these will include one conversation before treatment, one after treatment, and one several months after treatment. They will be shown to 10 members of the community and 10 individuals with Parkinson's disease.

It is possible that you may be recognized by one or more of the raters who are watching the tapes. The raters will sign a confidentiality agreement stating that they will not discuss any aspect of what they have seen or heard outside of the rating sessions. In other words, if a rater recognizes you, he/she will be asked to comply with the confidentiality statement and not reveal your identity or discuss the content of what was seen or heard on the tapes.

Consenting to having the videotapes viewed for the purposes of investigating the social validity of LSVT is voluntary. If you consent and change your mind, you are able to withdraw your decision at any time. Simply call or email Laura Boland or Dr. Hickey. (Laura Boland – 453-1841, lauraboland@dal.ca; Ellen Hickey – 494-1072, ehickey@dal.ca).

As both the individual living with Parkinson's disease and the family member are shown in the video, signatures from both individuals are required before the videotapes will be shown.

If you have any questions, please do not hesitate to contact Laura Boland or Dr. Ellen Hickey, as above.

Thank you for your consideration!



Human Communication Disorders 5599 Fenwick Street Halifax, Nova Scotia B3H 1R2

CONSENT FORM

Clinical Significance of the Lee Silverman Voice Treatment for Person's with Parkinson's Disease

Graduate Researcher: Laura Boland, B.Sc. School of Human Communication Disorders 5599 Fenwick St. Phone : (902) 453-1841 FAX: (902) 494-5151 e-mail: lauraboland@dal.ca Graduate Student

Faculty Supervisor: Ellen Hickey, Ph.D., CCC-SLP Dalhousie University School of Human Communication Disorders 5599 Fenwick St. Phone: (902) 494-1072 FAX: (902) 494-5151 e-mail: ehickey@dal.ca Certified Speech-Language Pathologist, Assistant Professor

Contacts: For more information about this study, please contact: Laura Boland or Dr. Ellen Hickey (at above phone number/e-mail addresses). I have read the explanation of this study. I have been given the opportunity to discuss it and my questions have been answered to my satisfaction. I understand that if I consent to having my videotapes viewed by 10 members of the extended community and 10 individuals with Parkinson's disease, I may be recognized by one or more of the viewers. I also understand that consenting to having my tapes viewed is voluntary, and that I can withdraw my videotapes from this study at any time. I hereby consent to allowing videotapes involving myself to be viewed for the purposes of this study.

Participant (print name)

Participant (signature)

Date:

Participant - family member (print name)

Participant – family member (signature)

Date:

Researcher (print name)

Researcher (signature)

Date:

Appendix K: Quality of Life Interview Protocols

Pre-treatment questions for the participant with Parkinson's disease

1) Can you tell me what it was like to be diagnosed with Parkinson disease?

- 2) What has your life been like since the diagnosis? Have things changed?
- 3) Have there been changes in your level of independence since your diagnosis?
- 4) How does the environment affect your functioning?
- 5) Tell me about the resources that are available to you and your family to help you cope with Parkinson's disease.
- 6) Have you received any treatment for Parkinson's disease? If yes, what has that been like?
- 7) Have you received speech therapy?
- 8) How do you know when you are communicating successfully?
- 9) Is there anything else that I have not asked you that you think would be important for me to know?

Pre-treatment questions for the family member

- 1) Can you tell me what it was like when your family member was diagnosed with Parkinson's disease?
- 2) What has life been like since the diagnosis? How has the diagnosis affected your family and your roles?
- 3) Tell me about your family member's independence. How has that been affected? If it was not, what promotes his or her independence?
- 4) How does the environment affect your family member's functioning?
- 5) Tell me about the resources that are available to you and your family to help you cope with Parkinson's disease.
- 6) In terms of general health care, how has your family member been treated and what has that been like?
- 7) How do you know when your family member's communication is successful?

8) Is there anything else that I have not asked you that you feel would be important for me to know?

Post-treatment and maintenance phase questions for the participant Parkinson's disease

- 1) Tell me about your experience with this study so far.
- 2) Has participating in this study, specifically completing LSVT, affected your daily life?
- 3) If you were talking to someone else who was thinking of having a similar experience, what would you tell them it would be like?
- 4) Are there any changes in your communication since the treatment?
- 5) Have other people commented that it is easier to understand you?
- 6) When you want to be as easy to understand as possible, what do you do?
- 7) Think about what you thought it would be like to participate in this program. Were your experiences similar to what you expected? Or are they different, and if so how?
- 8) Have you been practicing your homework tasks? If so which tasks and for how long?
- 9) Is there anything that I have not asked you that you think is important for me to know in order for me to understand what this experience was like for you?

Post-treatment and maintenance phase questions for the family member

- 1) Tell me about your family member's experience with this study?
- 2) If you were talking to someone else who was thinking of having a similar experience what would you tell them it was going to be like?
- 3) Would you recommend LSVT to other people?
- 4) Now tell me about your family member's communication. Has it changed since the treatment?
- 5) Do think that you understand more of your family member's speech since he or she has completed LSVT?
- 6) Do you think that other people understand your family member's speech better since he or she has completed LSVT?

- 7) Think about what you thought it would be like for your family member to participate in this program. Were the experiences similar to what you expected or were they different?
- 8) Is there anything else that I have not asked you that you think is important for me to know in order for me to understand what this experience was like for you and your family member?

Appendix L: Recruitment Poster for Members of the Extended Community

PARTICIPANTS NEEDED FOR A RESEARCH STUDY

Clinical Significance of the Lee Silverman Voice Treatment (LSVT) for Persons with Parkinson's Disease

Laura Boland, B.Sc. (Graduate Student Researcher)

Purpose

Determine if a voice treatment for persons with Parkinson's disease is deemed valuable in 'real world' situations to the recipient of the treatment and their family.

Compensation

A rate of \$10 per hour

Estimated Time to Complete

Approximately 1 hour to 1.5 hours

Who can participate?

You may take part in this study if the answer is YES to all of the following;

- \checkmark You are 18- to 75-years old.
- ✓ You have minimal knowledge and limited experience with Parkinson's disease.
- ✓ You speak English as your primary language (or very fluently).
- ✓ Your hearing and vision are normal or corrected to normal.

Participation in this study is strictly voluntary. You may choose not to participate or to withdraw from the study at any time. All information will be kept confidential.

What will you be asked to do?

- Answer a short questionnaire.
- Watch video clips of persons with Parkinson's disease, who have completed a voice treatment, conversing with a family member.
- Answer an open-ended question and rating scales.

When?

Wednesday January 23rd, 2008 12:15 pm

Where?

School of Human Communication Disorders, 5599 Fenwick St., Halifax. In the Conference Room Appendix M: Awareness of Parkinson Disease Questionnaire

I. Participant Information

1.) Gender

() Female() Male

2.) Please indicate your age group by marking the appropriate choice.

- () 18 30 years of age
 () 31 40 years of age
- () 41 50 years of age

() 51 - 60 years of age

() 61 or older

3.) Please indicate your occupation

4.) Indicate your highest level of education completed.

() 12th grade or less

() High school graduate or equivalent

() Undergraduate/ College

- () Postgraduate
- () Other:

II. Parkinson Disease – Answer as best you can by marking X in the space provided.

6a.) Have you ever heard of Parkinson disease?

- () yes
- () no

6b.) If yes, where did you learn or hear about Parkinson disease?

7.) Parkinson disease is often caused by (mark X for all that apply)

- () unknown reasons
- () stroke

() head injury

() tumor in/on the brain

() other neurological disorders

() genetics

() drug use

() environmental factors (e.g., toxins)

8.) Have you ever known anyone with Parkinson disease?

- () yes
- () no

9.) If yes, what was your relationship to him or her? (Mark X on all that apply)

- () mother/father
- () grandparent
- () aunt/uncle
- () son/daughter
- () close friend
- () distant relative/family friend
- () other, please specify

10.) Please mark 'X' on all that apply. Parkinson disease can be described as typically causing:

() a reduction of language skills

() a reduction of speech abilities

() a reduction of reading abilities

() a decrease in vocal capacity

() a condition that leads to heart attack

() a condition that leads to respiratory difficulties

() a loss of hearing

() a loss of muscle control

() a loss of cognitive abilities

() a condition associate with dementia

() a condition that is temporary

() reduced balance

() difficulty writing by hand

11a.) Can a person be treated for Parkinson disease?

() yes

() no

11b). If yes, please list the ways in which an individual with PD can be treated.

12). Does Parkinson disease interfere with employment?

() yes

() no

Appendix N: Consent for Social Validity Judges



Human Communication Disorders 5599 Fenwick Street Halifax, Nova Scotia B3H 1R2

Clinical Significance of the Lee Silverman Voice Treatment for Persons with Parkinson Disease

Graduate Researcher: Laura Boland, B.Sc. School of Human Communication Disorders 5599 Fenwick St. (902) 453-1841 FAX: (902) 494-5151 e-mail: lauraboland@dal.ca Graduate Student

Faculty Supervisor: Ellen Hickey, Ph.D., CCC-SLP Dalhousie University School of Human Communication Disorders 5599 Fenwick St. (902) 494-1072 FAX: (902) 494-5151 e-mail: ehickey@dal.ca Certified Speech-Language Pathologist, Assistant Professor

Contacts: For more information about this study, please contact: Laura Boland or Dr. Ellen Hickey (at above phone number/e-mail addresses).

INTRODUCTION

We invite you to take part in a research study at Dalhousie University. We are attempting to find better ways of caring for people with speech/voice problems due to Parkinson disease. The study is described below.

Taking part in this study is voluntary and you may withdraw at any time without penalty. Participating in the study might not benefit you, but we might learn things that will benefit others. You should discuss any questions you have about the study with Laura Boland and/or Dr. Ellen Hickey.

WHAT WILL I LEARN FROM READING THIS?

We will explain why we are doing the study. It tells you what will happen, and about any potential inconvenience, discomfort or risk. This information will help you decide whether you want to take part.

Please read this carefully and mark anything you do not understand or want explained better. After you have read it, please ask questions about anything that is not clear.

WHAT IS THE PURPOSE OF THE STUDY?

Research studies are done on speech treatments to improve our ability to help people with communication problems. In this study, we want to find out if a particular speech treatment for persons with Parkinson disease is useful in everyday life, or "real world" situations.

The purpose of this study is to further our knowledge in the area of speech treatment for persons with Parkinson disease. We are particularly interested in whether or not the Lee Silverman Voice Treatment makes a positive impact in daily situations up to six months after treatment.

HOW IS THE STUDY BEING DONE?

Two groups of 10 individuals each will be recruited to participate in the study, for a total of 20 participants. One group will include persons with Parkinson disease and the other group will include persons without Parkinson disease. Participants will be asked to watch several video clips of conversations between a person with Parkinson disease and their family member. Participants will then be asked to provide descriptions and to rate the conversations that they watched.

WHO CAN TAKE PART IN THIS STUDY?

<u>Person's with Parkinson disease</u> may take part in this study if the answer is YES to <u>all</u> of the following;

 \checkmark You are 50 to 75 years old.

✓ You were diagnosed with idiopathic Parkinson disease (i.e., Parkinson disease of unknown origin).

- Your cognitive (thinking skills) have not been affected, or are only mildly impaired. You will be asked to take a short, private, screening test to assess this. Based on the screening results, it is possible that you will be unable to participate in this study.
- You speak English as your primary language.
- \checkmark Your hearing and vision are normal or you wear glasses or have a hearing aid that enables you to see or hear normally.
- ✓ You have no history of major psychiatric illnesses (e.g., schizophrenia).
- \checkmark You are medically stable enough to participate.

<u>Person's without Parkinson disease</u> may take part in this study if the answer is YES to <u>all</u> of the following;

- \checkmark You are 18 to 75 years old.
- ✓ You have minimal knowledge and/or experience with persons with Parkinson disease.
- \checkmark You have no known communication deficits.
- ✓ You speak English as your primary language.
- \checkmark Your hearing and vision are normal or you wear glasses or have a hearing aid that enables you to see or hear normally.
- ✓ You have no history of major psychiatric illnesses (e.g., schizophrenia).
- \checkmark You are medically stable enough to participate.

BUT, if the answer to any of the following statements is YES, you cannot take part;

- \varnothing You have a diagnosis of Parkinson-plus syndrome.
- Ø You have or have had a history of other neurological (brain-related) or major psychiatric disorders (for example, Alzheimer disease, cerebral palsy, stroke, schizophrenia).
- Ø You have major psychiatric problems from Parkinson disease (for example, hallucinations, major depression).
- \varnothing You have or have had poor medical status that would prohibit ability to pay attention and participate in the study protocol.
- \varnothing You have a history of speech or language difficulties that are NOT related to Parkinson disease.
- \varnothing You are not able to see or to read the rating forms.

HOW LONG WILL I BE IN THE STUDY?

Your participation in this study should take approximately 1.5 to 2 hours.

WHO WILL BE CONDUCTING THE RESEARCH?

The following people will be involved in conducting this study.

• Graduate Student Researcher: Laura Boland is a Master's student in speech-language pathology. She will conduct the experiment.

Faculty Supervisor: Ellen Hickey, Ph.D., CCC-SLP is a Professor of speech-language pathology. She will oversee all aspects of this study.

WHAT WILL I BE ASKED TO DO IF I TAKE PART IN THIS STUDY?

<u>Persons with Parkinson:</u> If you wish to take part in this study, you will be asked to complete a short screening procedure. It is possible that the screening will show that you cannot be in the study. The screening will be conducted by Laura Boland (graduate student) under the supervision of Dr. Hickey. This will include a thinking-skills assessment. The screening will be conducted in the School of Human Communication Disorders at Dalhousie University and will specifically ask you to:

- o speak in words, sentences, and conversations
- o remember words immediately and after a delay
- o follow spoken and written directions
- o write and draw
- o name pictures of objects or animals

Study: If you choose to take part in this study you will be asked to do the following:

- Complete the screening procedures.
- Watch multiple conversations between a person with Parkinson disease and their family member.
- Answer a question about what you observed during the conversation.
- Rate different aspects of the conversation.
- Attend two sessions (to decrease the possibility of fatigue). The total time commitment will be about 2 hours.

<u>Persons without Parkinson Disease</u>: If you are interested in participating in this study, you will be asked to complete a short questionnaire which gives us information about the extent to which you are familiar with Parkinson disease. Depending on the results of the questionnaire, your data may not be used in this study. The questionnaire will be completed prior to viewing the taped conversations.

Study: If you choose to take part in this study you will be asked to do the following:

- Complete a questionnaire.
- Watch multiple conversations between a person with Parkinson disease and their family member.
- Answer a question about what you observed during the conversation.
- Rate different aspects of the conversation.
- Attend two sessions (to decrease the possibility of fatigue). The total time commitment will be about 2 hours.

ARE THERE RISKS TO THE STUDY?

There are no significant safety risks to participating in this study. The tasks should not be stressful (e.g., there are no time limits) and similar to things you may do every day, such as watching TV.

Because this study is somewhat repetitive, it is possible that you might feel frustrated, bored, or fatigued while viewing the clips.

A possible unpleasant effect is the potential for feeling sad or scared when viewing the speech of the person with Parkinson disease. You may also feel disappointed if you did not notice changes in the communication of the person with Parkinson disease.

You are a volunteer. You can withdraw from this research study at any time without consequence.

ARE THERE BENEFITS TO THE STUDY?

There will likely be no direct benefit to you for participating in this study. The researchers, however, will gain information that might help to develop further the treatment for people with Parkinson disease.

WHAT ABOUT MY RIGHT TO PRIVACY?

All results obtained may be published or presented at scientific meetings. Your identity, however, will never be revealed. A (code name/ID number) will be assigned to protect your identity. All materials containing names will be kept in locked storage accessible only by the researchers and research assistants during the study. Additionally, direct quotations from you may be used (without identifying information) only if you give your consent.

Data related to this project will be destroyed 5 years after publication of research results.

RIGHTS TO PRIVACY FOR THE PERSONS IN THE VIDEOTAPES

The persons that you will see on the videotapes have given consent for their tapes to be used in this research. We ask that you please respect their rights to privacy by not discussing any of the details of their identity at any time or the contents of their conversations outside of the viewing sessions. All that you see and hear on the videotapes is confidential information.

WHAT IF I WANT TO QUIT THE STUDY?

You are a volunteer. You can stop participating in the study at any time if you change your mind. If you wish to withdraw your consent, please inform the investigator. All data collected up to the date you withdraw your consent will remain in the study records unless you wish it to be withdrawn. Withdrawing your data from the study is possible at any time.

DECLARATION OF FINANCIAL INTERESTS

The investigator and her supervisor do not have financial interests in conducting this research. Laura Boland is conducting the study as part of her Master's thesis research.

WHAT ABOUT QUESTIONS OR CONCERNS?

In the event that you have any difficulties with, or wish to voice concern about, any aspect of your participation in this study, you may contact the Human Research Ethics/Integrity Coordinator at Dalhousie University's Office of Human Research Ethics and Integrity for assistance. The coordinator, Patricia Lindley, can be reached at (902) 494-1462 or by email at patricia.lindley@dal.ca.

Also, please feel free to contact Dr. Ellen Hickey or Laura Boland by phone or by email (as per below) at any time, with any questions, comments, or concerns. Ellen Hickey: 902-494-7052; ehickey@dal.ca Laura Boland: 902-453-1841; lauraboland@dal.ca

INVITATION TO PARTICIPATE IN THIS RESEARCH PROJECT

The purpose of this research is to improve interventions for individuals with speech difficulties as the result of Parkinson disease. Please indicate your decision to participate on the attached consent form. Thank you for your consideration.



CONSENT FORM

Clinical Significance of the Lee Silverman Voice Treatment for Person's with Parkinson Disease

I have read the explanation about this study. I have been given the opportunity to discuss it and my questions have been answered to my satisfaction. I understand that I will be screened and may not be able to participate if I score below a certain number on the screening assessment. I also understand the need to respect the rights to privacy of the persons on the video by not discussing any of the details of their identity or contents of their conversations outside of the viewing sessions.

I hereby consent to take part in this study. However, I realize that my participation is voluntary and that I am free to withdraw from the study at any time.

Participant (print name)

My data will be kept by the researcher in a locked filing cabinet. I understand that only the graduate researcher, supervisor and research assistants will have access to this information. The tapes will be destroyed 5 years after publication. Direct quotes (without identifying information) may be used in publications if I give my consent, I can do so here:

I give consent for direct quotes to be used in publication

__yes ___no

Participant (signature)

Date

I agree to be contacted in the future for participation in this or other affiliated research.

___yes ___no

Participant (signature)

Researcher (Print)

Date

Date

Researcher (signature)

Date

Appendix O: Recruitment Poster for Peers with Idiopathic Parkinson Disease

PERSONS WITH PARKINSON'S DISEASE ARE NEEDED FOR A RESEARCH STUDY

Clinical Significance of the Lee Silverman Voice Treatment (LSVT) for Persons with Parkinson's Disease

Laura Boland, B.Sc. (Graduate Student Researcher) Ellen Hickey, Ph.D. (Faculty Supervisor) School of Human Communication Disorders, Dalhousie University

Purpose

Determine if a voice treatment for persons with Parkinson's disease is deemed valuable in 'real world' situations to the recipient of the treatment and their family.

Approximate time commitment

1.5 hours

Who can participate?

You may take part in this study if the answer is YES to <u>all</u> of the following:

- \checkmark You have a diagnosis of idiopathic Parkinson's disease.
- ✓ You are 50- to 75-years old.
- ✓ Your thinking skills have not been affected by PD, or are only mildly impaired (there will be a short screening process for this).
- ✓ You speak English as your primary language.
- \checkmark Your hearing and vision are normal, or you wear glasses/hearing aids.

What will you be asked to do?

- Complete a short screening (approximately 10 minutes).
- Watch video clips of persons with Parkinson's disease, who have completed the voice treatment, conversing with a family member.
- Answer an open-ended question and rating scales about the videos.

More information:

To learn more about this study, contact:

- Laura Boland by phone (902-453-1841) or email (lauraboland@dal.ca) OR
- Dr. Ellen Hickey by phone (902-494-1072) or email (ehickey@dal.ca)

Appendix P: Social Validity Ratings for Unfamiliar Judges

Tape segment:

Judge's code name:

This questionnaire is designed for you to evaluate the success of a treatment program designed to help individuals with Parkinson disease improve their communicative abilities. Please read the following statements and indicate to what extent you agree with the statements. Please provide your honest opinions. Your feedback will help in planning future training programs. Mark the lines to show the extent to which you agree with the following statements:

1) The person with Parkinson disease appeared to feel comfortable during the conversation:

Never	Always
2) The family member appeared to feel comfortable	e during the conversation:
Never	Always
3) The person with Parkinson disease spoke loud en	nough.
Never	Always
4) You could understand what the person with Park	kinson disease was saying
Never	Always
5) The person with Parkinson disease expressed a l	ot of information
Never	Always
6) The family member communicated well with the	person with Parkinson disease
Never	Always
7) The pair contributed equally in the conversation	
Never	Always
8) The voice quality of the person with Parkinson d cracking, etc):	isease was good (i.e., not hoarse,
Never	Always

Always

9) This conversation was similar to other typical spousal conversations:

Not at all Definitely

10) The overall quality of this conversation was:

Very poor

Excellent

11) Please write any additional comments about the quality of communication and any differences observed between the conversations for this pair. The physical environment is not of importance; please focus on the interaction and communication.

Themes	Quotes
Life changes after PD diagnosis - No significant changes	"Nothing much has changed, I don't think." [IPD3]
	"Things have changed and things haven't changedlife is still as it was before the diagnosis." [IPD4]
	"Not that there's anything that's changed." [IPD5]
Increased social isolation since diagnosis	"I found that I didn't want to meet people. I found that I socially wanted to pull backI've avoided talking to people socially. I've avoided interaction in social settings" [IPD1]
	"I'm not really involved in that many activities, other than what we do here [at home]." [IPD2]
	"Others seem to add about ten years onto my life, because they know I have Parkinson's, which I don't think is justified." [IPD3]
	"I'm trying to say something to somebody and I just don't make sense sometimesthat's a little embarrassing." [IPD5]
Level of independence since PD - Same level of independence	"Overall I'm independent." [IPD1]
	"[I'm] still independentit's really not been affected, I don't think." [IPD3]
	"I'm totally independent. Everything that I have is here, and I can do everything myself that I need to do." [IPD4]
- Decreased independence	"I used to be independent and now I'm dependent on people." [IPD2]
PD has negatively affected communication	"Already my voice is losing powerit loses volume." [IPD1]
	"I did a lot of phone work with my job and people would say 'what was that you said?' or 'pardon me?' And I would notice that I couldn't even project my voice." [IPD1]
	"I know how to pronounce it, I just can't do it and I don't understand whyI'm frustrated with that." [IPD2]
	"When my speech is slurry it's a real problem for [spouse] to hear what I'm saying, or anybody else." [IPD3]
	"Sometimes I'm on a word I want to use and I cannot get the word out." [IPD5]
	"My voice seems to be the problem." [IPD5]
Medication is the primary source of treatment	"The only treatment I had so far is medicine." [IPD1]
	"All I've received is medication." [IPD3]
	"All I take is a drug for Parkinson's." [IPD5]

Appendix Q: Pre-treatment Qualitative Themes and Quotes from Participants with Idiopathic Parkinson Disease's Interviews about Experiences with Parkinson Disease

Themes	Quotes
Decreased QoL since the onset of PD	"It has been very, very difficulty for a person like me." [IPD1]
	"I've lost some confidence in myself as a person." [IPD1]
	"I'm tired a lot of the time and I never used to get tired. Never. I could go forever." [IPD1]
	"People talk to me like I'm half retarded." [IPD2]
	"I tire out quicker now. It seems to take me a week to get overat one time I would go out in thefield all day and I just couldn't do that now" [IPD5]

Themes	Quotes
Diagnosis of PD: - Expected	"Until you hear the words, you're not totally convinced, but you're not totally surprised." [FM1]
	"I wondered if he might have it, many, many years ago." [FM3]
	"My husband has Parkinson's disease, but his father also had Parkinson's and his father had itthere was no real big diagnosis." [FM4]
Life since the diagnosis - No significant changes	"In some ways [life] is the same." [FM1]
	"No, there's not much change." [FM3]
	"Things are really the same for [IPD5]." [FM5]
Spouse is still independent	"[IPD1] is totally functional. I think with regards to [IPD1] and independence, she wanted to control her future, she didn't want the Parkinson's to control it." [FM1]
	"He does his own thingsI think in terms of his independence right now I would say is almost all the way, you know, is 100% independent." [FM4]
	"He still loves to work; it hasn't affected his ability to work." [FM5]
Family member tries to maintain normalcy	"The best thing I can do is make things as good as possible now and if we have problems with it [IPD] in fifteen years from now, I'll deal with it in fifteen years." [FM1]
	"I [want] for him not to feel like things have really changed much, so we do play golf and he goes and plays golf with his buddies too." [FM4]
	"We take it one day at a time." [FM4]
PD has negatively affected communication	"It's [the voice] breaking up over the phone and its getting soft." [FM1]
	"He's softer spoken. I notice the words aren't clear." [FM3]
	"The speech is affected." [FM4]
	"His speech is not as good." [FM5]

Appendix R: Pre-treatment Qualitative Themes and Quotes from Family Members Regarding Experience with a Spouse with Parkinson Disease