THE MUSVIP PROTOCOL: PERSPECTIVES FROM MALAYSIAN OLDER ADULTS WITH PARKINSON'S ON MUSIC THERAPY

Indra V. Selvarajah[1]
Ang Mei Foong[1]

Abstract

Parkinson's Disease is a chronic degenerative neuromuscular disease that is caused by a sudden drop in the neurotransmitter dopamine and associated with the disintegration of the basal ganglia in the brain. Symptoms of the disease are characterized by both motor and non-motor problems marked by uncontrollable tremors, muscular rigidity and slow imprecise movements. In addition, people with Parkinson's typically suffer voice impairments which worsen over time. Research reports that 90 percent of all people with Parkinson's Disease will manifest voice impairments. This seriously affects patients' quality of life and often causes patients to develop secondary co-morbidities such as anxiety disorder and depression. Research shows that pharmacological and surgical treatments such as brain stimulation surgery are standard treatments for this disease. Unfortunately, where these treatments are partially successful in improving motor symptoms, they have not reported any significant improvements to voice impairments. Research further indicates that loss of communication is both life-threatening and psychologically devastating. In its final stages, Parkinson's Disease can leave the patient totally unable to swallow and speak, causing many patients to cease regular activities of daily living and withdraw from socializing. Current medical research champions emerging non-pharmacological treatments such as therapeutic singing as a non-surgical and non-invasive way to intervene with voice impairments. A growing body of research has recorded promising effects. This includes the results of a pilot study conducted at the Malaysian Parkinson's Disease Association (MPDA) which have demonstrated a range of positive benefits from the perspective of the MPDA patients. This article introduces the context for the development of the MusVIP voice rehabilitation protocol based on the benefits of a music therapy-based therapeutic singing approach for voice rehabilitation as evidenced from patients' self-reports.

Keywords: Parkinson's Disease; Music therapy; Older adults

[1] Department of Music, Faculty of Human Ecology, Universiti Putra Malaysia

Introduction

Speech voice impairments (SVI) is a common symptom of Parkinson's Disease (PD). As many as 90% of People with Parkinson's (PwP) will experience SVI which creates major setbacks in the treatment and management of the disease. As PD is degenerative and incurable, PD patients living with SVI are forced to face the slow and painful deterioration of their speech and communication abilities, followed by a loss of self-expression, self-identity and sense of dignity. Not surprisingly, this often leads to the development of comorbidities such as depression and anxiety disorders in PwP, which further complicate treatment (Marsh, 2013; Chen & Marsh, 2014).

This article introduces the context of an exploratory strand of voice rehabilitation research which merges the strengths and techniques from two fields: medical music therapy and classical voice technique, into a treatment intervention for SVI in PwP. The end result of this merger is an original therapeutic singing protocol known as the Music Based Voice Intervention Protocol, or MusVIP. This article focuses on the sharing of perspectives by PwP with regards to the potential for using the MusVIP to support vocal rehabilitation, based on their experiences during a pilot trial. Patients' perspectives were generated from their self-reports and gathered through a series of structured interviews. Patient responses were collected during the pilot study to help determine the viability of adopting the MusVIP into future medical treatment programmes for SVI in PwP as seen from twelve patients' perspectives. Respondents were all members of the Malaysian Parkinson's Disease Association (MPDA) who had volunteered to participate in the four-week voice rehabilitation pilot study. The PwP had lived with PD between one to twelve years.

Integrating the patient perspective into the development of the voice rehabilitation protocol was seen as vital for six major reasons: (1) it was a means to gather critical information regarding the main source of patients' challenges coping with SVI; (2) analysis of patient feedback enabled the study to determine the validity of the MusVIP as a treatment option for SVI for PwP; (3) direct patient feedback allowed the study to ascertain the practicality and viability of introducing the voice rehabilitation protocol into the current treatment arsenal for PwP in medical settings, as viewed from patients' perspectives; (4) the study needed to ascertain the psychosocial impact of the MusVIP protocol on the quality of life of PwP. This was because quality of life had been identified by a senior neurologist from a well-established government hospital as a factor of motivation for patients to follow through with treatment and adhere to prescribed treatment regimens; (5) integrating patient perspectives into the pilot study was a way to identify the key risks and benefits of using the MusVIP as a point of intervention for SVI in PwP and an opportunity to balance the desired effects or benefits of the voice protocol against any undesired effects or unforeseen risks; and (6) it was a means to pinpoint culturally specific biases and concerns that might affect

the validity of MusVIP. To date, no studies in voice rehabilitation have been conducted with PwP in Malaysia.

In short, not only would patients' feedbacks allow the study to anticipate the types of challenges PwP in Malaysia face in dealing with SVI, it would also enable them to incorporate insights gained from patients towards refining the protocol in lieu of future application into clinical treatment settings.

Literature Review

Parkinson's disease (PD) is a progressive, degenerative brain disorder triggered by a sudden unexplainable reduction in the production of dopamine, an important neurotransmitter that helps nerve cells to send signals to each other (Lim, Puvanarajah, & Ibrahim, 2011; Schulz & Grant, 2000).The biomechanism responsible for sparking the dopamine deficiency remains unknown. What is known is that the decrease in dopamine levels leads to the disintegration of the basal ganglia which controls the processing of movement related impulses in the brain such as voluntary motor skills, procedural learning, and eye movement, apart from cognitive and emotional functions such as motivation and emotional regulation. PD causes irreversible damage to the brain and primarily affects adults aged 65 and older (Lim *et al.*, 2011). At present, there is no known cure for PD and there is no way to predict individual progression. Where PD ranges in scope from mild to severe stages, it is typically divided into five stages:

Table 1: Primary Stages and Symptoms of Parkinson's Disease (PD)

Stage	Motor symptoms	Non-motor symptoms
1	Unilateral, mildly noticeable, does not yet interfere with daily tasks;	Cognitive changes • Memory problems • Executive functioning problems Emotional changes • Mood disorders • Anxiety • Depression Insomnia Fatigue Constipation Vision issues Swallowing problems Difficulties with smells
2	Bilateral, stiffness begins, mild tremors, slight change in facial expression, onset of bilateral symptoms, possible onset of speech difficulties;	
3	Mild to moderate bilateral, loss of balance, decreased reflexes, slower movements overall, increased risk of falls, speech difficulties increase;	
4	Severe, movement begins to require a walker or other assistive device, significant decreases in movement and reaction times, cannot live alone, possible onset of hallucinations and delusions; speech is severely compromised;	

5	freezing while standing due to advanced stiffness in legs, wheelchair bound, bedridden, twenty-four seven care needed, possible hallucinations and delusions; loss of speech and communication abilities; swallowing problems.	Speech and communication difficulties * *Symptoms are incremental but unpredictable in sequence.*

Source: Zhao, Wee, Chan, Seah, Au, Lau, Pica, Li, Luo, & Tan (2010).

In 1967, two neurologists at Columbia University, New York, Melvin Yahr and Margaret Hoehn introduced a method of classifying Parkinson's Disease that would help physicians to better diagnose and treat the disease. In their paper, Yahr and Hoehn described a broad spectrum of rates of progression in PD and established that PD was associated with an increased mortality rate with the average age of onset in the 6th decade i.e., between ages 50–59 years (Zhao *et al.*, 2010).

The Hoehn and Yahr scale is the most established rating scale for identifying and categorizing the level of severity of Parkinson's in patients (Zhao *et al.*, 2010). The term "Parkinson's" refers to all forms of the disorder. The order of rating from Stage 1 to Stage 5 describes the typical stage by stage unfolding of symptoms expected through the course of the disease (the original scale is presented in Table 1).

However, the Hoehn and Yahr scale should be viewed as a guideline rather than a cardinal rule. In reality, manifestation of symptoms in PD is unpredictable and does not always follow a logical or set sequence. There are times when Stage 1 is skipped, and the onset of symptoms is immediately bilateral. Other PwP may experience advanced tremor which causes instant incapacitation without experiencing balance issues. In some cases, people with this disorder never reach Stage V. As one can imagine, such unpredictability wreaks havoc in their daily lives. Hence, coping with PD is an ongoing source of stress and challenge to PwP.

Symptoms of PD present themselves as a string of neuromuscular challenges affecting memory, executive thinking, behaviour, emotions and activities of daily living. This cocktail of symptoms falls into two major categories i.e., non-motor and motor symptoms. Common non-motor symptoms include constipation, weight loss, sleep disturbances, cognitive deficits, psychosis and mood disorders such as depression and anxiety (Munhoz, Moro, Silveira-Moriyama, & Teive, 2015). Motor symptoms include *bradykinesia* (slowness of movement), *hypokinesia* (reduced movements), postural instability, problems with coordination and balance, and voice impairments such as *hypokinetic dysarthria* (Pacchetti, Mancini, Aglieri, Fundaro, Martignoni, & Nappi, 2000).

In order to attenuate symptoms, patients and their caregivers are advised to stringently monitor symptoms and watch for signs that may indicate a worsening of symptoms. While patients should not live in fear of symptoms, it is imperative that

PwP and their caregivers receive regular medical counselling and psychosocial support. Moreover, PwP under treatment need to follow a strict medication regime and care plan to manage and treat symptoms throughout the course of the disease. This includes the need to have a contingency plan to prepare for the eventuality that PwP will become disabled and fully dependent on others for sustenance and care (Zhao *et al.*, 2010).

Speech voice impairments (SVI) are an inevitable outcome of PD. The extant research demonstrates that SVI are amongst the most prominent symptoms of PD which will worsen over time with no forewarning or predictable sequence. Among the most common SVI, PwP are prone to develop hypokinetic dysarthria (HD), also known as Parkinsonian dysarthria (Miller, Noble, Jones, & Burn, 2006; Ramig, Fox, & Sapir, 2007). HD occurs when the movements of the larynx are reduced due to inadequate muscle activation. Typical symptoms of HD include softness in speech (hypophonia), monotone (dysprosody), imprecise articulation (slurred in speech), vocal tremor, as well as a hoarse and breathy quality of voice. Inactive movements in the lungs and respiratory system result in decreased breath support. (Buetow, Talmage, McCann, Fogg, & Purdy, 2014; Cochavit Elefant, Baker, Lotan, Lagesen, & Skeie, 2012; Fogg-Rogers *et al.,* 2015; Haneishi, 2001; Ramig *et al*., 2007; Schulz & Grant, 2000).

History reveals that there has been a rising prevalence of SVI in PD since the 80's. A study conducted in 1983 reported that at least 50% of PD sufferers worldwide presented communication difficulties (Scott & Caird, 1983). However, by 2006 the percentage of PwP who contracted SVI had risen to almost 80% (Miller *et al.*, 2006). Another study in 2007 conducted by Ramig and Fox predicted that nearly 90 percent of PwP demonstrated deficits in speech (Ramig *et al.*, 2007). The overall trend indicates a growing incidence of speech vocal impairments in PwP.

The impact of speech voice impairments on PwP

The symptoms of SVI leave a devastating impact on PwP. In the beginning, early symptoms such as slurred speech and mumbling of words might constitute a minor source of irritation. Small inconveniences eventually escalate into larger challenges as the disease progresses. Strained conversations turn into outbursts of frustration and decreased loudness turns into hoarse whispers as PwP struggle to communicate and loved ones struggle to understand.

Coming from a clinical perspective, older adults with Parkinson's have aired grievances and shared feelings of hopelessness with this study due to the changes in their vocal quality and loss of speech intelligibility in their daily lives. Some have confessed to opting out of speaking as they are tired of repeating themselves in order to be understood. Losing their volume projection (loudness) in daily speech weakens

their voice and compromises their ability to be heard or verbally interact and hold meaningful conversations with other people in their lives. As a result, PwP with pronounced SVI live in a state of constant anxiety and worry, fearing that they will someday lose their ability to express themselves and communicate altogether. This in turn causes them to lose self-confidence and self-esteem. Some patients have shared that they have a morbid fear of suffocating to death in their sleep. This is due to their inability to control their tongues if their tongues were to ever flip back during periods of deep sleep. The chronic mental anguish that accompanies advanced SVI leads PwP to experience helplessness and desperation.

Coming from the research perspective, a qualitative study by Miller et. al (2006) identified four main areas of impact affected by SVI from the PwP perspectives: (i) interaction with others; (ii) problems with conversations; (iii) feelings about intelligibility; and (iv) the voice. Miller et.al found that the main concern of PwP was not the change of voice itself but the poor communication that resulted in their loss of dignity (Miller *et al*., 2006). This set of findings give us important insight into the impact of SVI as seen from the perspective of PwP.

Due to the severe and unpredictable nature of symptoms including SVI, it is common for PwP to gradually withdraw from their regular social activities and stay at home. Degenerating symptoms directly interfere with activities of daily living. The meticulous self-management routine that PwP have to endure in order to better cope with symptoms on a daily basis is restrictive, awkward and socially interfering. Many stop conversing (due to difficulties being heard and maintaining conversations), are forced to stop work and cease going out with friends as well as hobbies and activities that they used to enjoy with other people as the disease progresses and SVI symptoms worsen. This in turn leads to loneliness and social isolation.

As a final devastating blow, PD in its final stages often leaves patients unable to speak and swallow, making eating and breathing difficult. These effects are life threatening and psychologically demoralizing. As PwP gradually lose their independence, they are forced to become fully dependent on caregivers. As a result, PwP sense of dignity is shattered and they lose their sense of self-identity and personhood. Not surprisingly, older adults with PD frequently develop secondary comorbidities such as anxiety disorder and depression. Research indicates that as many as 50 percent of PwP will go into depression because of the insurmountable challenges that they face (Ramig & Fox, 2007).

The negative repercussions of having SVI are not limited to PwP. Family members and caregivers are also directly impacted. Research shows that the majority of care for Parkinson's patients is provided by caregivers such as family members or friends who offer physical, emotional support for patients as well as perform an important economic role to prevent placement in unspecialized nursing homes (mostly not

catered to Parkinson's care). Having a caregiver has been shown to improve the quality of life of patients, as well as create better outcomes for morbidity and mortality (Miller, Berrios, &Politynska,1996).

The level of commitment required for Parkinson's care is intensive and often requires round the clock supervision particularly during the final stages. Extended caregiver duties increase caregiver-burden and distress and is associated in the literature with persistent stress and impaired psychosocial functioning of caregivers. Consequently, caregiver distress is a major predictor for institutionalization. Caregiver strain has been found to escalate as the disease progresses and SVI i.e. poorer communication abilities increases caregiver distress (Schraga, Hovris, Morley, Quinn, & Jahanshahi, 2006). Other research found that loss of speech functions and lack of speech intelligibility in PwP was a major cause of frustration to caregivers and a frequent source of family friction (Aarsland *et al*., 1999; Miller, Deane, Jones, Noble, & Gibb, 2011; Miller, Noble, Jones, & Burn, 2006; Ramig *et al.,* 2007). In short, PwP quality of life and success in disease management is highly dependent on caregiver resources and status of well-being.

Current status of treatment for PD and its impact on SVI in PwP

Management of symptoms is the main focus of medical treatment for PD to control motor symptoms as well as treat SVI (Lim, Puvanarajah, & Ibrahim, 2011). This is because at present there is no cure for PD and no means to waylay the disease. Surgical options such as deep brain stimulation surgery (DBS) are sometimes sought by patients but have been found to potentially aggravate SVI as stated above. Current treatments for PD are mainly pharmacological and medications such as levodopa (L-dopa) are often used to treat motor symptoms in PD. L-dopa is primarily used to restore dopamine levels in the brain, where the sudden reduction of dopamine has been identified as the main cause of the disease. Common levodopa-containing drugs such as *Madopar*® and *Sinemet*® are administered during the initial stages of PD, while medications such as selegiline, amantadine, dopamine-agonists are commonly prescribed as the disease progresses (Consensus Guidelines for the Treatment of Parkinson's Disease, 2012).

While pharmacological treatments have been reported to be generally successful in improving motor symptoms in people with PD, they have not been as efficacious in treating SVI. For treatments related to speech impairments in PD, there are studies which have reported unsatisfactory outcomes from both pharmacological and surgical treatments (Pinto et al., 2004; Schulz, Greer, & Friedman, 2000). More recent research indicates that PwP who underwent Deep Brain Surgery (STN-DBS, deep brain surgery of the subthalamic nucleus) one of the available treatments for PD, displayed a tendency to manifest SVI *(Wertheimer et al*., 2014).

Speech impairments are also a frequent adverse side effect of taking Dopamine Agonist (DA), a common pharmacological treatment for PwP (Boravac, 2016). Even though both treatments reported significant improvements to the limbs' motor functions, they did not report significant improvements in speech intelligibility. In short, where current mainstay treatments noted improvements in limb functioning, they were not associated with any improvement in SVI. Pre-existing treatments also do not address the psychosocial needs of people with PD as part of a comprehensive treatment regimen. As a result, the mental health needs of PwP are frequently neglected.

In search of better solutions – behavioural treatments for SVI in PwP

The extant research champions emerging treatment interventions that are non-pharmacological, non-surgical, and non-invasive as an intervention for voice impairments. Over the course of the last two decades, behavioural treatments, such as speech therapy and music therapy that focus on targeted systematic training of vocal muscles, have emerged on the treatment horizon as potentially more effective ways to treat HD without the side effects of medication (Atkinson-Clement, Sadat, & Pinto, 2015; Pinto *et al*., 2004; Schulz & Grant, 2000).

Lee-Silverman Voice Treatment (LSVT) programme

At present, the best solution for treating SVI from the field of speech therapy is the Lee Silverman Voice Treatment® (LSVT) proven to be highly positive in treating speech impairments in PwP. Numerous studies and meta analyses have documented a steady stream of positive results using LSVT to treat HD among PwP. The majority of these studies reported positive outcomes in the parameters of vocal loudness, phonatory process, articulation and respiration. The classic LSVT treatment programme is highly intensive, conducted over a period of 4 weeks, four times a week. Following LSVT treatment, it has been claimed by the creators of LSVT that improvements on vocal loudness, phonatory process, articulation and respiration could last up to two years after treatment (Ramig & Fox, 2007).

However, as the LSVT programme was developed in the USA for use by trained and qualified speech therapists with implications of international licensing fees and limited access to certified LSVT trainers in Malaysia, access to the LSVT programme in Malaysia is highly limited. Hence, the need to find homegrown solutions that are viable, cost-effective and sustainable.

Music Therapy as an emerging solution

A growing body of research reports the promising effects of therapeutic singing as a means to attenuate voice impairments measured in the changes of various physical

parameters of vocal quality as well as patient self-report data. In the last two decades, several research studies have demonstrated the promising positive effects of music therapy (MT) focusing on singing as an intervention to improve motor functions, speech impairments, facial expressions, and mood among PwPs. (Elefant, Lotan, Baker, & Skeie, 2012; Evans, Canavan, Foy, Langford, & Proctor, 2012; Haneishi, 2001; Pacchetti *et al.,* 2000). In treating speech impairments using MT, studies have shown that singing techniques help to extend chest capacity, improve respiratory muscle movements thereby improving breathing, leading to significant improvements in voice productions. (Evans *et al*., 2012; Lewis, Cave, Stern, Welch, Taylor, Russell, Lewis, Cave, Stern, Welch, Taylor, Russell, Doyle, Russell, McKee, Clift, Bott & Hopkinson, 2016).

However, a more recent study by Elefant *et al.* (2012) reported significant positive effects in singing quality and vocal range, but reported no changes to quality of speech. The intervention was based on group singing, participants received 60-minutes of singing intervention in a small group setting for 20 consecutive weeks. There were 10 PwPs who participated in this one-group repeated measure design study, who were stable responders to Levodopa, and in Hoehn and Yahr stage 2 or 3. Results showed significant improvements in several singing qualities (fluency, singing accuracy, intensity of volume and consistency of volume, as well as voice range (Elefant *et al*., 2012).

Another two year longitudinal study from the UK reported small but significant improvements in laryngeal elements and a small degree of improvements in participants' self-rating quality of life, suggesting that group singing helps to prevent deterioration in the voice and to maintain voice quality among the PwPs. (Evans *et al*., 2012)**.** In addition to this, a recent study of PwPs' experience in Choral Singing Therapy (CST) in New Zealand reported that choral singing helped PwPs to self-manage some consequences of their conditions, which included low mood, social isolation and communication difficulties. *(Fogg-Rogers et al.*, 2015).

Based on these results, it appears that the prospects are positive for further researching and developing therapeutic singing as a mechanism to intervene with SVI in PwP. This includes the results of the current pilot study conducted at the Malaysian Parkinson's Disease Association (MPDA). This study investigated the impact of their self-designed voice rehabilitation protocol (MusVIP) on twelve participants with Parkinson's. Results indicated a range of positive benefits using the voice rehabilitation protocol as seen from the participants with Parkinson's perspective. What follows is an elucidation of PwP perspectives following the four-week pilot study intervention with the MusVIP. Data was derived from twelve participants with mild to moderate PD.

MusVIP – Medical Music Therapy with Western Classical Voice Technique

Following an extensive literature review which pointed out gaps in the current efficacy of voice based interventions for SVI in PD and the potential for therapeutic singing to be further harnessed for voice rehabilitation, this study combined a medical music therapy approach for voice rehabilitation with advanced Western classical singing technique. The result was the MusVIP voice rehabilitation protocol, which featured various layers of therapeutic singing activities.

Beginning with a structured voice training programme which was designed to be progressive and accumulative, the MusVIP also included voice and movement activities to enhance sensory processing (a common problem for PwP), daily vocal exercises and bi-weekly group sessions. The outcome was a rigorous voice rehabilitation curriculum that required a very high level of commitment from patients. In anticipation of the level of rigour required for PwP to adhere to the MusVIP intervention, one of the primary objectives of the study was to gauge if the level of intensity would be too arduous and tiring for patients to comply with in view of its future conversion into a clinical treatment protocol. This was another major impetus for soliciting PwP perspectives regarding their experience of using the MusVIP.

The level of frequency and intensity necessitated by the programme was required and intentional. Prior research conducted on the Lee-Silverman Voice Treatment programme from speech therapy (which is at present the treatment gold standard for SVI in PD), had indicated that a minimum intensity threshold was needed to register a significant difference in vocal outcomes for PwP. This was due to the natural deterioration in vocal quality over time that was typically expected as the patient regressed. The level of frequency and intensity of involvement was designed to counter the inevitable side effects of voice deterioration in the course of treatment while at the same time spurring potential improvements in vocal quality, volume and control.

A personal glimpse into PwP experiences of using the MusVIP was also critical in discerning the range of challenges and benefits the participants experienced undergoing the MusVIP. We sought to determine how participants in the pilot study made decisions in the midst of healthcare treatment choices. We attempted to identify the factors that motivated patients towards greater personal agency in directing and managing their own healthcare health outcomes. Last but not least, we wanted to better predict the potential efficacy of the research- based intervention as well as identify what factors might enhance PwPs' adherence to the MusVIP's treatment recommendations. This included the incorporation of daily homework intended to maximize the benefits of the voice training.

Method

A survey interview was conducted with twelve PwPs', individually, following completion of the MusVIP pilot intervention to elicit participants perspectives on changes in their voice, identify any vocal problems they had faced, as well as gauge their perceptions on how the music and singing had impacted their everyday lives based on participants' self-report. The interview was administered orally as a series of uniform open-ended questions posed to each participant. Questions centred around what the MusVIP group singing experience was like for participants, what kind of home practice did they initiate (if any) as an extension to weekly sessions, what were the kinds of challenges they experienced at home which prevented practice and how did they manifest, whether they perceived if the MusVIP had impacted their everyday speech in any way, and ultimately, if the MusVIP singing classes had increased or decreased the levels of contentment, joy or motivation in their daily life. This journal article presents the results of this interview, post-intervention, which summarizes PwP's feedback on their overall experience using the MusVIP.

Results

PwP' perspectives on using the MusVIP protocol

Presentation of participants responses unfold according to the sequence of questions orally presented during weekly post-session interviews. To make the responses equitable and standardized, participants were asked a set of common questions. What ensues are the verbatim statements given by the twelve interviewed participants as presented in quotations.

What was the MusVIP group singing experience like for you?

All participants indicated that they "liked it (the sessions) very much", derived "a sense of joy", felt "definitely happy, can sing whole day", "enjoy(ed) the music", "so far has been fun", "so far so good", "enjoy the session very much", they "look(ed) forward to class", felt that they had "less *off* days when they sang more", the "activities were fun and that improved (their level of) happiness", "(experience) more joy" and the sessions "generated an interest to continue (beyond the four weeks)". Two participants indicated that they had sung in choirs before and the sessions had revived their interest in singing. Following the intervention, the participants and the president of the MPDA association indicated that they would like to continue the sessions beyond the duration of the pilot study. Hence the services of a music student intern were put in place to continue providing weekly therapeutic singing support for the MPDA residents.

Participants clearly enjoyed the opportunities for social interaction and support that the MusVIP programme facilitated. The data from their responses revealed that the group singing setting seemed to increase participants motivation to adhere to and follow through with the voice rehabilitation program, which is one of the major challenges of existing treatment interventions for SVI that contribute towards their failure to follow through. Their interest in psychosocial opportunities provided by the MusVIP program was evidenced by statements such as “We come and sing, we talk about (singing) to friends”, “(the sessions) provide support, encouragement to us”. It was observed in this study that participants would sometimes complement each other during sessions, and spur each other to do better. They also expressed the desire to reach out to others within the singing group as well as beyond the singing group evidenced by statements such as “like to see more people come to join” and “so looking forward to see everyone, being involve and engaged”, “(I) feel happy and support(ed) through singing. Feel lively”, and “Before I was still trying to fit in, now (I) feel the encouragement and support”. The range of responses were spontaneous and entirely unsolicited in this study.

Were you able to practice at home? If so what did you practice?

At the beginning of the four-week pilot, less than one-quarter of participants followed through on their daily practice. Over time, however, participants started to experience the benefits of using the MusVIP singing activities. They gradually increased their home practice and even devised creative ways to incorporate daily singing practice into their home routines as evidenced by participants’ responses to this question.

Responses were initially less favorable towards daily practice, even indicative of resistance, “(need to) do more physical exercise (rather than voice exercises)”, “hard to do more singing as there is housework”, and “no time”. But over the course of the sessions responses evolved to “no time, but try to sing in public, during physiotherapy sessions as IMU”, “singing helps me to cope better when on the exercise treadmill, not so boring”, “feel like practicing is doing the right thing (to help my voice)”, “sing at home”, “sing when sometimes (traffic) jam”, and “homework is important”.

Other creative ways that participants more effectively incorporated daily voice practice (their MusVIP homework) into their activities included “(I) sing with my daughter”, “(my) husband practices with me every day after breakfast, helps with my pitching and breathing”, “(I called my grandchildren in Sydney the other day and) taught my grandchildren to sing *Naughty pussy cat!*”, “(My) Husband is happier, (the activity song has had an) influence on him, (now) he sings naturally (with me)!”

Based on the participants responses, it appears that once they had experienced some tangible benefits from the bi-weekly singing sessions and understood the important implications of doing their daily vocal practice, participants found their own

fun socially interactive ways to incorporate vocal exercises into their daily activities. They did this either to ease boredom during routine events such as exercise or being stuck in a traffic jam, or to use the singing exercises as a means to bond with and engage with family members. We noted that some of these interactions had also been initiated by the family caregivers and incorporated as a family ritual.

What were some of the challenges you faced in trying to practice? Did you have days when you couldn't practice this week? If so how did it affect your ability to practice?

The participants indicated that the very real challenge that they experienced on a regular basis centred around the instability of medication effects, as expressed in their own words: "I don't know how it (my Parkinson's) triggers my medication. It sometimes goes "ON", helping to keep symptoms under control. Other times it goes "OFF", when for whatever unknown reason the medication does not kick in and we are left to cope with a range of terrible symptoms".

The symptoms they refer to include, not being able to get out of their houses, not being able to talk, uncontrollable tremors, getting suddenly stuck while walking, and falling. This "ON/OFF" phenomenon which is a reality for PwP frequently occurs, and it is highly distressing and disruptive to their daily lives.

However, the motivation to participate in the MusVIP weekly session was high and participants devised their own ways to circumvent problems with medication by planning their medication intake beforehand and having medication on standby in case they went "OFF" during a session.

The other challenge mentioned by PwP came in an unexpected form. Wearing false teeth made it hard to sing. But that did not stop the participant from attending sessions and adhering to the programme. He also diligently practiced the vocal exercises at home.

Do you think the vocal training you received this week has affected your daily speech outside of singing class? If so how?

Initially the participants indicated that it was too early to know which was to be expected following the first session. But slowly across the four weeks, they began to indicate positive changes as evidenced by the following responses reported in their own words: "(My) voice is louder"; "(I) can throw out (my) voice"; "Singing has been helpful with my daily speech"; "(I can now) sustain my breath speaking to the end of speech"; "Now I can sing (and speak with) higher voice"; " I have learned that singing is related to (the) voice"; "Worth the effort being involved as more aware of voice control and how to better compensate for our voice deficits in our everyday interactions with others"; "(I) have more control (over my speech)"; "(I) have

improve(d) in pitch range"; "(My) voice is more stable, more in control"; "I have learned that slowing down (my singing) helps to make (my) speech clearer"; and I am now more alert. It guides against falling". Participants in this study also indicated that they felt good when people tell them they could understand them, as opposed to feeling isolated when their voice was not comprehensible.

Overall, has the MusVIP singing classes increased or decreased your level of contentment, joy or motivation in daily life?

Participants indicated that the classes had given them an opportunity to experience achievement. This was apparently very important to them and contributed towards their level of contentment, as related in their own words: "Achievement is important (to) prevent you from sliding down", "Give me confiden(ce)", "Great sense of achievement", "Opportunity to work on a goal: experience achievement", and "Opportunity to increase sense of achievement".

Setting an attainable goal and working towards that goal was a motivating factor that helped to facilitate participants' sense of achievement. The progressive nature of the MusVIP curriculum set regular goals to work on, which was equally important to them. Another factor of motivation was the development of a heightened sensitivity toward their current vocal quality and being equipped with sufficient vocal knowledge to help them practice and exercise conscious control over their voices. Statements such as "I was told I can reach higher"; and "Still lots of room for improvement" and "Sometimes I feel discouraged", "Feel motivated because I thought singers are born to be"; "Change is I feel eager to come to the class. I want to improve my pitch" were reflected in their growing vocal knowledge, heightening aural sensitivity combined with a desire to improve vocal quality. By the end of the pilot intervention participants also demonstrated an increased personal consciousness of their vocal clarity and quality, as well as pronunciation and enunciation.

The challenges set within the MusVIP curriculum were designed to incrementally stretch their vocal abilities, sensory awareness and physical coordination of study participants. One example was the use of the Malay *Masri* rhythm, which was introduced via a traditional Malay folk song. Although study participants initially struggled to coordinate the rhythm with their singing, they indicated that the challenge was fun and exciting for them. Statements such as "(I) Never knew singing and *Masri* can be challenging", "Singing is not a problem, but *Masri* rhythm (is)", "Very exciting experience" demonstrated that participants relished the challenge.

Another factor that contributed towards their motivation to practice and improve was social connectivity. The structure of the group singing classes embodied within the MusVIP provided participants with structured opportunities to sing together, stay socially connected and receive social support. As they struggled, triumphed and

supported each other throughout the course of their singing journey, it was important that the older adults with PD felt safe and accepted to practice their singing skills among sympathetic peers. This enabled them to share their joys and struggles, as well as spur and encourage each other in their respective PD journeys. By the end of the pilot study intervention, the MusVIP singing group organically evolved into their own support group, an unexpected but meaningful outcome of this homegrown pilot study.

Conclusion

The extant research indicates that although access to healthcare services is now available on an unprecedented scale, a large number of patients fail to follow through with recommendations given by healthcare professionals (Vivian & Wilcox, 2000). There exists a discrepancy between patients' knowledge of available treatment options, level of patient awareness and education, and treatment adherence. This includes adherence to speech therapy for SVI among PwP.

Personal management of healthcare outcomes from the vantage point of the patient is particularly serious because many disease conditions can be controlled and complications forestalled via patients improved personal management of their health care behaviours and strict adherence to their therapeutic regimes (Liberman & Rotarius,1999).

The music therapy based MusVIP protocol was developed to not just provide a targeted intervention for vocal rehabilitation in PwP but was also aimed at tackling the age-old problem of poor treatment adherence and a high attrition rate in treatment, both of which are common problems for older adults already labored with a chronic debilitating disease. Older adults with PD find it particularly difficult to stay the course in treatment due to the loss of independence, restricted physical mobility, loss of communication and negative side effects of medication. Based on the results of the pilot study as reported from PwP perspectives, it appears that the MusVIP voice rehabilitation protocol holds promise and potential for further development into a clinical treatment protocol as it not only boosts interest and motivation in regular group singing but also following through with important daily voice exercises in a fun, supportive and non-stigmatizing way.

Acknowledgement

This research study would not have been possible without the cooperation and support of the MPDA, PwP and caregivers who had graciously committed their effort and time to the four-week pilot study. It presented us with a rare opportunity to better understand the experience of PwP from their individual perspectives as well as observe the impact of the protocol on their psychosocial well-being. Although patient

self-reports are subjective and highly individual, and hence do not represent the wider majority of patients who suffer from the disease, other research has indicated that patient compliance during the course of treatment is often dependent on a variety of subjective personal factors which impinge on patients' ability to adhere to prescribed treatment plans. In the context of the future development of the MusVIP into a clinical treatment intervention, it was important to pinpoint and gain insight into those factors in lieu of future research and development of the protocol.

References

Aarsland, D., Larsen, J.P., Karlsen, K., Lim, N.G., & Tandberg, E. (1999). Mental symptoms in Parkinson's disease are important contributors to caregiver distress. *International Journal of Geriatric Psychiatry*, *14*(10), 866–874. https://doi.org/10.1002/(SICI)1099-1166(199910)14:10<866::AID-GPS38>3.0.CO;2-Z

Atkinson-Clement, C., Sadat, J., & Pinto, S. (2015). Behavioral treatments for speech in Parkinson's disease: meta-analyses and review of the literature. *Neurodegenerative Disease Management*, *5*(3), 233–248. https://doi.org/10.2217/nmt.15.16

Borovac J.A. (2016). Side effects of a dopamine agonist therapy for Parkinson's disease: a mini-review of clinical pharmacology. *The Yale Journal of Biology and Medicine*, *89*(1), 37-47.

Buetow, S.A., Talmage, A., McCann, C., Fogg, L., & Purdy, S. (2014). Conceptualizing how group singing may enhance quality of life with Parkinson's disease. *Disability and Rehabilitation*, *36*(5), 430–433. https://doi.org/10.3109/09638288.2013.793749

Cacciatore, F.M., Simone, D. De, Patrocinio, D., & Sallustio, V. (2012). Adverse drug reaction to dopamine agonists (DA) or appearance of a typical sign of Parkinson's Disease induced by DA. *Basal Ganglia*, *2*(3), e1-e87. https://doi.org/10.1016/j.baga.2012.10.001

Elefant, C., Baker, F.A, Lotan, M., Lagesen, S.K., & Skeie, G.O. (2012). The effect of group music therapy on mood, speech, and singing in individuals with Parkinson's disease: a feasibility study. *Journal of Music Therapy*, *49*(3), 278–302. https://doi.org/10.1093/jmt/49.3.278

Elefant, C., Lotan, M., Baker, F.A., & Skeie, G.O. (2012). Effects of music therapy on facial expression of individuals with Parkinson's disease: a pilot study. *Musicae Scientiae*, *16*(3), 392–400. https://doi.org/10.1177/1029864912458917

Evans, C., Canavan, M., Foy, C., Langford, R., & Proctor, R. (2012). Can group singing provide effective speech therapy for people with Parkinson's disease? *Arts and Health*, *4*(1), 83–95. https://doi.org/10.1080/17533015.2011.584883

Fogg-Rogers, L., Buetow, S., Talmage, A., McCann, C. M., Leao, S.H.S., Tippett, L., …, & Purdy, S.C. (2015). Choral singing therapy following stroke or Parkinson's disease: an exploration of participants' experiences. *Disability and Rehabilitation*, *8288*(November), 1–11. https://doi.org/10.3109/09638288.2015.1068875

Haneishi, E. (2001). Effects of a music therapy voice protocol on speech intelligibility, vocal acoustic measures, and mood of individuals with Parkinson's disease. *Journal of Music Therapy*, *38*(4), 273–290. https://doi.org/10.1093/jmt/38.4.273

Hoehn, M.M. & Yahr, M.D. (1967). Parkinsonism: onset, progression, and mortality Parkinsonism: onset, progression, and mortality. *Neurology*, *17*(5), 427–442. https://doi.org/10.1212/WNL.17.5.427

Lewis, A., Cave, P., Stern, M., Welch, L., Taylor, K., Russell, J., Lewis, A., Cave, P., Stern, M., Welch, L., Taylor, K., Russell, J., Doyle, A.M., Russell, A.M., McKee, H., Clift, S., Bott, J., & Hopkinson, N.S. (2016). Singing for Lung Health-a systematic review of the literature and consensus statement. *NPJ Prim Care Respir Med*. 2016 Dec 1;26:16080. doi: 10.1038/npjpcrm.2016.80.

Liberman, A. & Rotarius, T. (1999). Managed care evolution: where did it come from and where is it going? *The Health Care Manager*, *18*(2). Retrieved from https://journals.lww.com/healthcaremanagerjournal/Fulltext/1999/12000/Managed_Care_Evolution_Where_Did_It_Come_from_and.9.aspx

Lim, S.Y., Puvanarajah, S., & Ibrahim, N.M. (Ed. . (2011). *Parkinson's Disease-Information for people living with Parkinson's*.

Lim, S.-Y., Puvanarajah, S., Lee, M.K., Chee, K.Y., Viswanathan, S., Tan, A.H., … Azrin, K. (2012). 2012 Consensus Guidelines for the Treatment of Parkinson's Disease.

Miller, E., Berrios, G.E., & Politynska, B.E. (1996). Caring for someone with Parkinson's disease: Factors that contribute to distress. *International Journal of Geriatric Psychiatry*, *11*(3), 263–268. https://doi.org/10.1002/(SICI)1099-1166(199603)11:3<263::AID-GPS316>3.0.CO;2-P

Miller, N., Deane, K.H.O., Jones, D., Noble, E., & Gibb, C. (2011). National survey of speech and language therapy provision for people with Parkinson's disease in the United Kingdom: therapists' practices. *International Journal of Language and Communication Disorders / Royal College of Speech & Language Therapists*, *46*(2), 189–201. https://doi.org/10.3109/13682822.2010.484849

Miller, N., Noble, E., Jones, D., & Burn, D. (2006). Life with communication changes in Parkinson's disease. *Age and Ageing*, *35*(3), 235–239. https://doi.org/10.1093/ageing/afj053

Munhoz, R.P., Moro, A., Silveira-Moriyama, L., & Teive, H.A. (2015). Non-motor signs in Parkinson's disease: a review. *Arquivos de Neuro-Psiquiatria*, *73*(5), 454–462. https://doi.org/10.1590/0004-282X20150029

Pacchetti, C., Mancini, F., Aglieri, R., Fundarò, C., Martignoni, E., & Nappi, G. (2000). Active music therapy in Parkinson's disease: an integrative method for motor and emotional rehabilitation. *Psychosomatic Medicine*, *62*, 386–393. https://doi.org/10.1097/00006842-200005000-00012

Pinto, S., Ozsancak, C., Tripoliti, E., Thobois, S., Limousin-dowsey, P., & Auzou, P. (2004). Review Treatments for dysarthria in Parkinson's disease. *Neurology*, *3*(September), 547–556.

Ramig, L. & Fox, C. (2007). Speech disorders in Parkinson's disease and the effects of pharmacological, surgical and speech treatment with emphasis on Lee Silverman voice treatment (LSVT). *Parkinson's Disease Foundation News and Review*.

Ramig, L.O., Fox, C., & Sapir, S. (2007). Speech disorders in Parkinson's disease and the effects of pharmacological, surgical and speech treatment with emphasis on Lee Silverman voice treatment (LSVTÒ) LORRAINE. In *Handbook of Clinical Neurology*, *83*, 385-399). https://doi.org/10.1016/S0072-9752(07)83017-X

Schrag, A., Hovris, A., Morley, D., Quinn, N., & Jahanshahi, M. (2006). Caregiver-burden in parkinson's disease is closely associated with psychiatric symptoms, falls, and disability. *Parkinsonism and Related Disorders*, *12*(1), 35–41. https://doi.org/10.1016/j.parkreldis.2005.06.011

Schulz, G.M. & Grant, M.K. (2000). Effects of speech therapy and pharmacologic and surgical treatments on voice and speech in Parkinson's disease: a review of the literature. *Journal of Communication Disorders*, *33*, 59–88. https://doi.org/10.1016/S0021-9924(99)00025-8

Schulz, G.M., Greer, M., & Friedman, W. (2000). Changes in vocal intensity in Parkinson's disease following pallidotomy surgery. *Journal of Voice: Official Journal of the Voice Foundation*, *14*(4), 589–606. https://doi.org/10.1016/S0892-1997(00)80015-6

Scott, S. & Caird, F.I. (1983). Speech therapy for Parkinson' s disease. *Journal of Neurology, Neurosurgery, and Psychiatry*, *46* (October 1982), 140–144. Retrieved from http://jnnp.bmj.com/content/46/2/140.full.pdf+html

Vivian, B.G. & Wilcox, J.R. (2000). Compliance communication in home health care: a mutually reciprocal process. *Qualitative Health Research*, *10*(1), 103–116. https://doi.org/10.1177/104973200129118273

Wertheimer, J., Gottuso, A.Y., Nuno, M., Walton, C., Duboille, A., Tuchman, M., & Ramig, L. (2014). The impact of STN deep brain stimulation on speech in individuals with Parkinson's disease: the patient's perspective. *Parkinsonism and Related Disorders*, *20*(10), 1065–1070. https://doi.org/10.1016/j.parkreldis.2014.06.010