

## **Experiences of persons with Parkinson's disease engaged in group therapeutic singing**

### **Abstract**

**Background:** Parkinson's disease (PD) is a progressive neurodegenerative disorder that leads to altered neural control of movement, including the control of voice, respiration, and swallowing. There is a prevalent need to provide therapy for voice, respiration, and swallowing difficulties because current pharmacological and surgical treatments do not effectively treat these impairments. Previous research has demonstrated that singing may be a treatment option to target voice, respiratory, and swallowing impairments, as well as quality of life. However, participants' perspectives related to reasons for enrolling and engaging in programs as well as evaluation of singing programs have been neglected.

**Objective:** The purpose of this descriptive study was thus to solicit participants' views of their involvement in a group singing intervention (GSI) led by credentialed music therapists.

**Methods:** Twenty persons with PD were interviewed 4 to 6 months after completing the singing intervention. Participants were asked about 1) why they chose to participate, 2) what were the beneficial and non-beneficial aspects of participating, and 3) how to improve overall design and delivery of the GSI.

**Results:** Using content analysis procedures, we learned that participants regarded their involvement in the study as mutually beneficial, fun, and engaging. Participants appreciated the fellowship with other persons with PD and offered minimal constructive criticism.

**Conclusions:** This study provided greater insight into how a therapeutic singing program may benefit participants and positively impact their lives.

**Keywords:** Parkinson's Disease, Singing, Qualitative Research, Quality of Life

## **Background**

Parkinson's disease (PD) is a progressive neurodegenerative disorder resulting from the loss of dopaminergic neurons within the basal ganglia, leading to altered neural control of movement, contributing to classic motor symptoms of rigidity, tremor, bradykinesia, akinesia, postural instability, and gait disturbances (Albin, Young, & Penney, 1989; Kish, Shannak, & Hornykiewicz, 1988). However, additional symptoms of PD, including impairments in voice, respiratory control, and swallowing are also affected by altered neural control of movement (Chaudhuri, Healy, & Schapira, 2006; Darley, Aronson, & Brown, 1969; Duffy, 1995). Some studies point to music therapy as an effective nonpharmacological treatment for improving both motor and non-motor symptoms of PD (Bloem, de Vries, & Ebersbach, 2015; Ashoori, Eagleman, & Jankovic, 2015; Spina, Barone, Mosca, et al., 2016). Group-based music therapy also provides an interpersonal context that can be more fully explored by employing qualitative methods (Wheeler, 2016). Yet, the perspectives of persons with PD regarding the impact of therapeutic interventions has not received sufficient scholarly attention. Little information has been systematically collected to document this interpersonal context and explore participants' perspectives about how patients with PD engage with music therapy programming. The purpose of this descriptive study was thus to gather perspectives of participants with PD who took part in a group singing intervention (GSI) program.

The use of qualitative methods has been used in health research to understand viewpoints of the healthcare recipient, and better evaluate program effectiveness (Harris, 2010; Morse, 2011). In the music therapy literature, qualitative research has been increasingly utilized to better understand the experiences of study participants (e.g., Bradt, Norris, Shim, Gracely, & Gerrity, 2016; Carr, d'Ardenne, Sloboda, Scott, Wany, & Priebe, 2012; Docherty, Robb, Phillips-Salimi, Cherven, Stegenga, Hendricks-Ferguson, et al., 2013; McDermott, Orrell, & Ridder, 2014). In the PD literature, investigators have used qualitative inquiry to explore participants' reflections about quality of life (QOL), couple relationship quality, caregiver support, mental health, and treatment adherence (e.g., Greer, Hermanns, & Cooper, 2015; Hodgson, Garcia, & Tyndall, 2004; Lenderking, Mannix, Petrillo, Kenney, Landrian, & Schrag, 2015; Wressle, Engstrand, & Granérus, 2007). However, scholars have not fully attended to the underlying

aspects of music therapy (Aigen, 2014; Amir, 1999; Bruscia, 2005; Wheeler, 2016). For example, Amir (1999) advocated looking more deeply at how music affects participants' mental and physical well-being as well as exploring the meanings that participants attach to music. In another instance, Wheeler (2014, 2016) offered similar support for examining latent influences and encouraged approaches to music therapy studies that would attend to participants' subjective experiences and look at the nature of interpersonal relationships in research settings. Aigen (2014) also underscored the importance of attending to social networks and personal experiences in community-based music therapy programs, because such contextual factors can influence QOL, health, and well-being. To date, the literature is replete with published work in which scholars have taken a quantitative approach, utilizing objective assessments and focusing on observable and measurable changes with music among persons with PD (Raglio, 2015; Bloem et al., 2015). More attention given to participants' subjective experiences of music therapy will fill a gap in the literature.

Research examining singing in PD is one such example of an area in which the understanding of participants' subjective experiences is lacking. There is as much as a 90% prevalence of voice and swallowing impairment in persons with PD, and neither medication nor deep brain stimulation surgery effectively treat such impairments (Bloem et al., 2015; Mahler, Ramig, & Fox, 2015; Sato, et al., 2006). Previous quantitative studies have demonstrated that singing has been effective in treating voice and respiratory impairments in individuals with neurological disorders (Tamplin, Baker, Grocke, et al., 2013; Wan, Rüber, Hohmann, & Schlaug, 2010), suggesting that this treatment strategy may be effective in PD. Preliminary quantitative studies investigating singing in persons with PD have produced equivocal results (Di Benedetto, et al., 2009; Elefant, Baker, Lotan, Laesen, & Skeie, 2012; Fogg-Rogers, Buetow, Talmage, et al., 2016; Haneishi, 2001; Shih, Piel, Warren, et al., 2012). However, more recent quantitative research conducted by our study team has revealed that group singing, as led by music therapists, significantly improves respiratory control, swallowing, and QOL in persons with PD (Stegemöller, Hibbing, Radig, & Wingate, 2017; Stegemöller, Radig, Hibbing, Wingate, & Sapienza, 2017). Yet, to our knowledge, only one study has adopted a qualitative approach to determine the

perceived benefits of singing on persons with PD, and this study was conducted in a different country, i.e., New Zealand (Fogg-Rogers, Buetow, Talmage, et al., 2016). An understanding of participants' subjective experiences of the singing intervention may help in understanding the equivocal findings of previous quantitative research investigating singing in persons with PD.

Therefore, we conducted this small study based on previous empirical work about the importance of attending to latent aspects of music therapy interventions as well as our observation of participants' engagement as they took part in our original quantitative GSI study (e.g., Stegemöller et al., 2017a, 2017b). The purpose of this descriptive study was to gather the perspectives of 20 adult participants with PD who had previously taken part in a GSI led by credentialed music therapists. This study's specific goals were: (1) to understand why participants chose to take part in the singing intervention, (2) to learn what the participants believed were the beneficial (or non-beneficial) aspects of participating in the intervention, and (3) to improve the overall design and delivery of future singing interventions. We adopted a qualitative research design and a descriptive approach and employed semi-structured interviewing techniques to document 20 participants' viewpoints.

## **Method**

### **Participants**

The Iowa State University Institutional Review Board (IRB) approved this research project and ethical guidelines for recruitment were followed. Thirty non-smoking participants diagnosed with idiopathic PD and on a stable anti-parkinsonian medication regimen from the original quantitative study were invited to participate. Exclusion criteria from the original quantitative study were applied to this study, including untreated hypertension, history of head or neck cancer, significant cognitive impairment (Mini Mental State Exam score <24), or major psychiatric disorder (Beck Depression Inventory score <18). Ten participants declined due to scheduling conflicts or difficulty in traveling to the research office. The first author recruited, enrolled, and scheduled 20 participants for one in-person interview conducted four to six months after the completion of the GSI. Interviews were

delayed due to the need for an extension to the ethics clearance. See Table 1 for demographic and clinical descriptions of the participants. Due to speech impairments in persons with PD sometimes making interpretation over the telephone difficult, only face-to-face interviews were carried out.

### **Group Singing Intervention**

An abbreviated description of the intervention is included below. More detailed descriptions of the GSI and quantitative results have been previously published elsewhere (Stegemöller et al., 2017a, 2017b). Participants with PD completed eight weeks of group singing at four intervention sites led by board-certified music therapists. One group participated in sessions once a week while a second group completed sessions two times a week. While there were significant improvements in the quantitative outcome measures over eight weeks of GSI, there were no significant differences between the groups that completed session once or twice a week. Thus, the cohort for the interviews were treated as one group. All music therapists were trained prior to the beginning of the intervention and their activities monitored to ensure that they followed the intervention protocol. All exercises used in the GSI were selected to target non-musical behaviors that are needed areas for persons with PD. Specifically, exercises targeted vocal loudness, range, and elements of respiratory control. This differs from traditional choral singing in that the goal of the exercises in the GSI was not to produce a better choral sound but rather to address specific therapeutic needs of persons with PD.

Each session began with a series of vocal exercises followed by group singing. The vocal exercises completed during each session were similar to vocal exercises used during singing and choral rehearsals, but were modified to meet the participants' levels of vocal ability and to target specific therapeutic needs of the PD population. Participants also received a CD of the vocal exercises and songs and were instructed to complete the same exercises and singing at home twice per week. The vocal exercises included:

1. *Lip buzzing*. Participants began by lip buzzing with no pitch. Once this task was successfully accomplished, they continued to lip buzz with high, medium, and low pitches. Finally, they moved on

to lip buzzing while changing pitch. This exercise was designed to target respiratory control, because a certain level of air pressure must be maintained to effectively vibrate the lips in this way.

2. *Glissandos*, sliding between pitches. This exercise was designed to target frequency range. The interval between pitches was increased over each session, starting with an interval of a third and systematically increased at each session until reaching an interval of one octave (eight pitches of the Western major scale).
3. *Mezze de Voce*. This exercise was designed to target vocal intensity. Participants began by holding a pitch as softly as possible. After approximately two seconds, participants were instructed to increase the intensity (i.e., loudness) of the pitch to a preset decibel level, as measured individually with a decibel meter. The target level of intensity, based on pretest values obtained from the intensity measurement, was systematically increased during each session.
4. *Articulation exercises*. These exercises were designed to challenge the articulation muscles of the lips, tongue, and jaw. Participants sang a five-step scale using the syllables ‘mee, meh, my, moh, moo’. The starting consonant then was replaced with the consonants ‘t’, ‘d’, ‘s’, and ‘k’, and sung once again.
5. *Group singing*. Participants were asked to complete group singing of the familiar songs “You Are My Sunshine” and “Mairzy Doats.” For “You Are My Sunshine,” participants were asked over the course of the eight sessions to increase the length of each phrase from two measures to eight measures before taking a breath; this exercise was designed to target breath control. The song “Mairzy Doats,” required clear articulation and spanned a large frequency range.

### **Interview Procedures**

Here we outline the interview protocol used in this descriptive study. The second and third authors conducted the interviews; they are a middle-aged female faculty member and a female doctoral student in early adulthood, respectively, who drew upon their training and expertise in qualitative methods and personal understanding of the disorder gained through observing family and friends cope

with PD, and knowledge of the the original quantitative study. The faculty member has an earned doctorate in Human Development and Family Studies and Demography, has more than 15 years of experience in qualitative and mixed methods, and teaches graduate courses on advanced qualitative and mixed methods. She is a middle-class Black woman. The doctoral student earned a Bachelor's degree in Psychology and a Master's degree in Human Development and Family Studies. The doctoral student studied for four years with the aforementioned faculty member and participated in qualitative interviews in other projects. She identifies as bi-racial, of Latino and White heritage. These background characteristics and experiences are described because they hold the potential to shape the authors' angles (e.g., insider versus outsider perspective), lenses (e.g., gender, age, race, economic class, occupation, disciplinary approach, qualitative methodology), and filters (e.g., personal experiences with PD) and impact how they interacted with the participants as well as how the participants' responses were collected, perceived, and interpreted (Saldaña, 2016).

The faculty member led the doctoral student through two training sessions and described ways of asking questions, strategies for using probes to obtain full responses from participants, and tactics for handling sensitive issues. The faculty member also reviewed the original quantitative study purpose with the doctoral student and shared the approved IRB materials and funded grant proposal with her. The faculty member was not involved in the earlier quantitative study of the GSI and thus had no prior relationship with the participants; the doctoral student had observed a singing group session while she was conducting interviews for the current study to learn more about the process. Neither of the interviewers were involved with leading the GSI nor quantitative data collection and analysis for the original quantitative study. Both interviewers reviewed the project documentation to become familiar with the GSI activities and the overall project. This positioned them well to probe for further information if participants mentioned specific group activities.

Participants were interviewed in a semi-private office at a research laboratory. All questions were open-ended to maximize the depth and range of information provided by participants. Interviewers introduced themselves to the participants and described their relationship to the first author and their

personal connections to PD. Interviewers read the Informed Consent document to participants. The risks and benefits of taking part in the project were explained and participants were reminded that their involvement was voluntary and assured them that they could leave the study at any time without penalty. Interviewers responded to questions participants had about the study before their consent was secured.

We used qualitative interviews to advance the study goals, to understand why participants enrolled in the study, and to discover what participants believed were the beneficial (or non-beneficial) aspects of the GSI in order to improve the overall design and delivery of future GSI. The interviewers asked participants about the meaning of their involvement in the study. Interview questions explored three main topics—program enrollment, program engagement and participation, and program evaluation. Table 2 provides sample questions for each topic. Interview questions were drawn from another program evaluation study that the second author previously conducted, and the questions had thus been pilot-tested with another sample (Hurt, Brody, Murry, Nerke, & Chen, 2013). Each interview lasted approximately 20 minutes and was digitally recorded. The interviewers, where needed, probed participants for additional clarification of answers (Harris, 2010). A professional transcriber with whom the second author has had a 12-year working relationship downloaded the digital audiorecordings from a secure, password-protected, university-controlled, web-based computer server. She transcribed the recordings and uploaded the completed transcripts to the same server. Transcripts were used to document the spoken word in the digital recordings (Miles, Huberman, & Saldaña, 2014), and participants were not provided with copies of the transcripts.

Confirmability and dependability were addressed through regular, often daily, communication between the interviewers about their comfort with administering the interview protocol. To ensure confirmability and dependability, interviews were digitally recorded and the interviewers conducted intermittent checks by listening to the digital recordings to ensure quality control. Interviewers evaluated the study method and discussed their interpretations with one another through regularly-scheduled meetings.

## **Analyses**

Over a three-month period, six qualitative analysts—all authors except the first author—met for two retreats. The backgrounds for two of the authors has already been described in the section entitled Interview Procedures. The backgrounds for the four additional analysts/authors will be described next. All were outsiders, none had any personal experience with PD and were thus not particularly attuned to the ways in which the participants coped with their PD symptoms and program experiences. Three analysts identify as Black women; one analyst identifies as a White woman. All are in early adulthood or middle adulthood and live working class or middle class lifestyles. All are females pursuing graduate degrees in human development and family studies, student affairs, or social work. Their research promotes advocacy, support, and equity among marginalized groups. All have two or more years of training in qualitative research.

The qualitative analysts reviewed digital recordings and transcripts. The third through seventh authors listened to the digital recordings and compared them to the written transcript to ensure accuracy. Any errors or inconsistencies were noted with red font and discussed at retreats. Content analysis procedures were next employed to achieve better understanding of participants' perspectives, identify similarities and differences in their responses, and draw conclusions about patterns or themes in the participants' responses (Merriam, 2009; Miles, Huberman, & Saldaña, 2014). Saldaña (2011) defined content analysis as “the systematic examination of texts...to analyze their prominent manifest and latent meanings” (p. 10). This analytic approach is appropriate given our goal of learning about the content of the participant interviews and the nature of their responses with respect to why they enrolled in the study and what they believed were beneficial or non-beneficial parts to the intervention as a means for improving future GSI.

Because the qualitative analysts worked to analyze the content of the participant interviews, they adopted a within-case analysis approach to “describe, understand, and explain” what each participant shared (Miles, Huberman, & Saldaña, 2014, p. 100). The qualitative analysts carefully reviewed the digital recordings and transcripts to understand the participants' responses, and then practiced data

reduction to focus on the most important aspects of the participants' experiences relative to program enrollment, program engagement and participation, and program evaluation (Miles, Huberman, & Saldaña, 2014). In doing so, all analysts used Microsoft Word or Excel to develop content-analytic summary tables to lay out the interview content for each participant (i.e., rows) pertaining to program enrollment (i.e., column 1), program engagement and participation (i.e., columns 2 and 3), and program evaluation (i.e., column 4). Miles, Huberman, and Saldaña (2014) define a content-analytic summary table as "a matrix display that batches or brings together all related or pertinent responses from multiple cases into a single form for initial or exploratory analysis. Each cell of the matrix specifies the dimensions you are interested in" (p. 148). This process reflects data selection and condensation. Each qualitative analyst independently evaluated, compared, and contrasted interview content for each participant and summarized the responses using tables.

After focusing on individual participant experiences, qualitative analysts compared responses across cases to explore similarities and differences in their program experiences. This is consistent with a cross-case analytic approach (Miles, Huberman, & Saldaña, 2014). With a goal of identifying variability among participants, the qualitative analysts explored participants' reflections about program enrollment, program engagement and participation, and program evaluation (Saldaña, 2016). Qualitative analysts compared and contrasted participants' reflections and focused on recurrent themes, frequency of participants' experiences, and how participants' communicated their program experiences (Merriam, 2009).

Interviewers discussed emergent themes with the analysts to obtain feedback about the information collected. Analysts developed lists of participant experiences, derived solely from the participants' responses, and thus reflecting a deductive process guided by key topics covered in the interview (i.e., program enrollment, program engagement and participation, and program evaluation). In summary, the analytical procedures involved iterative sequences of reviewing, categorizing, verifying, and drawing conclusions from participants' responses (Miles, Huberman, & Saldaña, 2014).

At the retreats, qualitative analysts compared findings from their independent analyses and discussed themes in a collaborative way (Saldaña, 2016). Each qualitative analyst also recorded her own self-reflections and wrote independent audit trails to establish credibility. Each audit trail included reflections about the transcripts and digital recordings, as well as notes related to themes and analytic memos to record the process (Carlson, 2010; Miles, Huberman, & Saldaña, 2014). It was important for each qualitative analyst to record her work to minimize the challenges associated with different authors analyzing the participants' responses in dissimilar ways (Saldaña, 2016). They analyzed the interview content, drew conclusions about similarities and differences in participants' responses, grouped findings together, and highlighted key points with narrative statements (Miles, Huberman, & Saldaña, 2014). The authors reconciled any differences in coding to create a consensus; there were no unresolved analytic differences (Saldaña, 2016). Overall, this analytic process established dependability in coding, analogous to reliability in the quantitative paradigm (Anfara, Brown, & Mangione, 2002).

In the spirit of member-checking, the first author was asked to validate the themes that the six qualitative analysts identified and, based on her experience with the sample, she served as a valuable key informant by reviewing a manuscript draft in which the findings were detailed. Previous work has highlighted that member checking is best conducted when a finished product can be reviewed and interpretations are offered for themes (Carlson, 2010). The first author reflected on her project experiences and interactions with the participants and agreed with the identification of themes presented in the next section (Creswell, 2013). She was familiar with the community of participants and offered insight, knowledge, and understanding about the context of the participants' comments (e.g., singing sessions, group t-shirts). These practices, related to confirmability and dependability, are well-supported in the literature (Carlson, 2010).

## **Findings**

In this section, we outline patterns in participant responses pertaining to program enrollment, program engagement and participation, and program evaluation, using pseudonyms for the participants to

preserve their confidentiality (Table 1). We present the range of participants' responses using quotes and exemplars.

### **Program Enrollment**

Participants recalled hearing about the GSI through presentations at different venues (e.g., state fair, annual PD symposium or conference, forum at a university union, support group) and by way of referrals (e.g., doctor's office, friend, neighbor, PD resource center). Participants stated that they either signed up at the presentations or called the research office to learn more about the project and eligibility requirements. They overwhelmingly stressed the importance of advancing PD research to find ways to improve QOL through learning skills and strategies to improve speech, swallowing, voice projection, diet, and lifestyle. Betty expressed this concern: "One of the very important things I think is most of the people that have Parkinson's have trouble swallowing at the later stages and a lot of them choke to death. That's a hard fact, I guess. That's what they say. So why wouldn't you want to do whatever you could to keep from choking?" Their overall goal was to help others, including patients with PD and PD researchers, while also helping themselves. Charles reflected, "I agreed to participate. I know I want to do what I can to help us learn what we can to improve our lives. I don't expect to find a cure for Parkinson's in my lifetime but I hope I can make my own life better and maybe other persons' lives better... I understand that if the [first author] doesn't get participants, she can't do her study and if she can't do her study, there's no benefit to the Parkinson's community."

Most wanted to learn everything they could about PD, and several characterized their involvement in the project as mutually beneficial. They expected the study to afford them an opportunity to practice singing and have fun while also furthering PD research. A few participants were anxious about their singing abilities, but still agreed to take part in the project despite these reservations, recognizing that their singing talents (or lack thereof) would most likely be masked by group participation.

### **Program Engagement and Participation**

All participants described being enthusiastic about the study and motivated to take part in all sessions, and while only a few missed any GSI sessions, they did have two opportunities to make up for

missed sessions. They were allowed to bring family members along if they so desired. Attendance was more consistent, particularly during the summer months, when family members (e.g., adult children, grandchildren) were sometimes already visiting participants, resulting in increased program engagement and participation.

Participants viewed the sessions as fun and engaging and appreciated the opportunity for fellowship with other persons with PD, many of whom became friends. One participant characterized the singing groups as more like a social event or a support group and less like a research study. Through the GSI meetings, participants built a community of support and friendship. Group membership had a particularly positive impact on the few participants who coped with loneliness and sadness. They appreciated being socially-connected to their community and decided to design a t-shirt including the lyrics from “Mairzy Doats” and “Jumbled and Jivey” to celebrate their group identity and spirit of togetherness. Helen shared, “It was fun... it was good camaraderie and a good support system... You don’t change any medicine. It’s not going to change your medicine habits, which is huge for Parkinson’s people. It’s good friendship-building, good camaraderie, and I mean just something fun, something different to do.” Deb said: “I noticed that when we finish our studies on Wednesday, when Dr. S said, ‘Well, we’re through,’ nobody wanted to leave. Nobody stood up. We all sat there just chatting, so I think we all were kind of in the same boat. I think we’re all retired and, you know, it’s kind of nice to have a little gathering every now and then like that.”

Participants benefitted from having an outlet independent of their family members and close friends; it gave them an ability to expand their networks of supportive friends who understood PD intimately and learned tips about how to manage the physical and psychological changes associated with PD. Ella said, “We all looked forward to our Wednesday afternoons. Oftentimes somebody came with a question right off the bat and somebody was there to say, ‘Yeah, I had that same problem too’ or ‘here’s how I tackled it’.” Participants understood that PD affected each person uniquely. Ann said, “It’s called the designer disease is what I’ve heard because it affects everybody differently.” Consequently, participants attended the GSI sessions both on good days (e.g., good mood, few physical challenges) and

bad days (e.g., balance problems, memory issues, inability to get up from a sitting position) without embarrassment. Charles noted: “A guy in the group wears support hose. He’s got the courage to wear them with shorts...I [also] have to wear support hose to help with swelling in my lower legs. I have the courage to wear those out in public now, because it looks kind of dorky. It really does but I get strength from other people.” Deb also confided, “Another thing that was big for me was that it was also a safe place where you did not have to worry about your tremor. You know, ‘cause everybody else was doing the same thing.” Participants had a shared understanding about limitations associated with a PD diagnosis, and they were thus able to help support one another with arriving and departing tasks. In another interview, an interviewer recalled observing the GSI sessions and said, “I remember you guys were talking about how you don’t have to ask to help each other put your coats on.” Irene responded, “You don’t have to ask ‘cause everybody knows you need help.” Further, through this type of sharing, participants’ awareness of the challenges that persons with PD can face (e.g., inability to buzz, say “psst;” difficulty breathing, standing, and maintaining balance) was enhanced.

Overall, participants were less burdened by their PD diagnosis when in the company of other participants. The GSI shifted the focus from self to others. Jane asserted, “[I would recommend the singing to a friend.] Because it’s a wonderful thing for people with Parkinson’s. We’re not too fond of having it. We don’t know what’s coming next and stuff and so it’s just good. You don’t think about yourself quite as much.” Claire continued, “I put it in my Christmas letter that [being in the choir] was how to have fun with Parkinson’s disease. I’m just going to have fun with Parkinson’s disease.” Ella concurred: “We have got to have fun when we’ve got Parkinson’s. We can’t just dwell on it, ‘Oh dear! Ain’t it awful?!’”

### **Program Evaluation**

In rating the overall quality of the GSI sessions and the group facilitators, only a few participants offered constructive feedback related to the program’s meeting schedule and location (e.g., sessions held twice per week for eight weeks, needing to travel away from home) and intervention activities (e.g., not having lyrics printed on paper, not having all songs included in the practice CD, eating pudding for the

swallow study). Only one participant critiqued a facilitator for closely following an intervention session script, recommending that the facilitator be more dynamic and engaging in presentation of the material. Adam recommended that the facilitator disclose more about her background, education, and motivation for conducting the study: “If she would have told us in the first part of the [project] that it’s a musical study and the practice that we did, and [more about] her degree or background, I’d probably had been more excited about it.”

Participants overwhelmingly evaluated the facilitators highly. They described the GSI facilitators as helpful and committed to meeting participants’ needs. Bob said, “They were excellent. Just because they made it fun and then it makes you want to make sure not to miss a session because it was so much fun.” Participants observed that facilitators had a heart for people and as a result, it was easy to trust them. Participants reflected that they did not always understand why they were being asked to learn and practice various skills and strategies. However, because they were confident in their facilitators’ abilities and expertise and established good rapport with them, they willingly followed instructions and asked follow-up questions. For example, Deb said, “She was good at clarifying why we were doing some things. She didn’t want us to read music [on paper] because of the work in the memory skills. At first, I didn’t realize that was why but it makes sense.” In another case, Fran offered, “I was blowing through a straw and after a while, it started to make sense.”

Participants also evaluated the program location and sessions highly. Deb viewed the fellowship facility at the church as “almost like somebody’s living room type of setting.” Participants viewed vocal training as the most helpful aspect of the GSI sessions and recalled working on range and pitch through warm-ups and songs. Irene recalled, “Because she had us do different scales and different volumes and measure it with this thing. She would tell us, you know, whether higher, lower, whatever, and so she would have us comparing it to realize yes, it did make a difference.” Participants who could not sing well grew more confident by singing in a group setting. Gail said, “Everybody is always friendly. Nobody complained when I tried to sing. I’m not the singer type, usually every once in a while... but I’ll sing for the group.” Ann corroborated this point saying, “I know I don’t have much musical talent but we could

sing ‘You Are My Sunshine’ and nobody really cared if you were on pitch or on key. I think that’s what made it fun. I [couldn’t do that] in some church choir. We could make a joyful noise and nobody really cared about the quality of the noise.” Others noticed how healthy competition emerged among participants, particularly among those previously involved in church and community choirs. This is not surprising given the exercises they were asked to practice.

Participants learned about the significance of exercise for promoting QOL and delaying the limitations associated with PD. The group facilitators encouraged participants to use their voices and to strengthen their muscles and coordination. They recalled learning about how PD affects the body’s physiology and how to counteract limitations associated with PD, using methods that could trigger brain pathways through laughing, singing, and developing skills. Irene said, “You [learn how] to breathe correctly for the best benefit to make these muscles being used and gradually being stronger so that down the road... It’s a fact, Parkinson’s patients have problems with swallowing, so the theory is if you can make those muscles stronger you would be able to lessen the bad effects of poor swallowing or choking. Choking is frightening.” Helen also said: “I think people with Parkinson’s should exercise because we have to keep our arms and our legs strong or we aren’t going to function. We’re going to go downhill quicker. This is an exercise. When you’re singing, you’re exercising.”

Participants identified specific ways in which the program was physically helpful to them, including talking better and louder, sitting up with better posture, and having more stamina to stand longer and walk further. Betty noticed her improvement while actively involved in the GSI sessions: “I had forgotten how many—it was three or four people—told me that I was talking louder. They could understand me better and two of them did not ever know I was doing the study. They just noticed and told me. So that was real encouraging. I was quite surprised.” Other participants expressed how speaking loudly improved their communication with their spouses who had complained about their inability to hear them; participants reported resulting stress and frustration in their marriages. In addition to speaking louder and enunciating better, other participants recalled breathing better and more deeply, helping promote relaxation, reduce back pain, and minimize stress. Deb said, “I’ve learned how to use deep

breathing to kind of calm myself if I'm in a stressful situation. Then sometimes, even at night, if I just practice that slow deep breathing, it helps me fall asleep more easily.”

When asked how soon they started using the skills they practiced, participants' responses varied widely from not at all to daily. Fran recalled this: “I still listen to the CD. Mine doesn't have certain songs on it. A couple of my grandkids came to the study group 'cause they were with me in the summertime. They learned some of the songs 'cause I'd sing them in the car too. I can't remember the one very well. But they'll say, 'Grandma, sing the one about the tortilla' and I'm like 'I don't remember it at all.' Only the way it is on the tape and my CD. So, I wish I had all the songs we sang.”

Overall, the GSI program exceeded expectations. Participants indicated that they would share their experiences with others if asked. It appeared that the depth of participants' responses reflected individual differences with respect to talkativeness or speech limitations associated with a PD diagnosis (e.g., slurring, rambling) rather than a level of discomfort with the interviewer or interview context. All noted that they would recommend the program to their friends, citing the importance of giving back to PD research, the opportunity to learn about PD and meet new people, and to practice useful skills and strategies. Charles summed up his involvement this way: “This is what it did for me. It puts you in a situation where you're aware of the impact that an illness has on your life and you discover your own ways of dealing with it. It helps you learn the questions and gives you an opportunity to answer the question in your own way... It provided proof to me that if you leave yourself open, you may discover things about yourself or things about your illness that you'd never suspected before. So yes I would recommend it and that's the reason.”

### **Discussion**

The findings of the qualitative interviews revealed that participants were specifically motivated to enroll in the program because of their commitment to furthering PD research and improve QOL for themselves and others. Participants regarded their involvement in the study as mutually beneficial. They appreciated the opportunity to receive more education about PD and learn different skills to strengthen their voices, breathing, and swallowing through music therapy, and they enjoyed singing in a group

format. Participants regarded the groups as fun and engaging and appreciated the fellowship with other adults with PD that encouraged retention and engagement. The opportunity to connect with others with similar experiences led many to feel that the GSI was more like a social event or a support group; this was particularly helpful for a few participants who struggled with PD changes, loneliness, and sadness. Participants evaluated the GSI sessions highly and offered little constructive feedback about the program format or facilitators. They trusted the facilitators and completed the skills practice as recommended, even though they were unsure of the purpose of some of the activities. In keeping with the results from the original quantitative study, many experienced improvements in their abilities to breathe better, thereby promoting relaxation, minimization of back pain, and encouragement of restful sleep. Participants also noticed an ability to speak louder, thereby improving communication with spouses, family members, and close friends. The findings highlighted the study's positive impact on intended program outcomes as well as cascaded effects into other areas of physical health, marital quality, and well-being.

Qualitative research involving group singing has been conducted with samples of healthy young and older adults and in persons with dementia (Camic, Williams, & Meeten, 2013; Clift & Hancox, 2001; Skingley & Bungay, 2010; Skingley, Martin & Clift, 2016). Camic and colleagues (2013) found that, among persons with dementia, engagement and attendance was very high and, although the disease continued to progress, QOL remained stable for both patients and caregivers, suggesting that group singing promotes well-being. Likewise, engagement and attendance was very high for participants in this study, one of the first to examine participant perspectives of group therapeutic singing in persons with PD. Only one previous study has included persons with PD (Fogg-Rogers, Buetow, Talmage, et al., 2016), which also support the notion that group singing is enjoyable and increases social support in persons with PD. While the study by Fogg-Rogers and colleagues (2016) evaluated choral singing therapy among a combined group, including persons with stroke and PD in a New Zealand sample, they noted that participants described the singing as an enjoyable social activity and perceived singing to improve mood, language, breathing, and voice. This is in keeping with the findings of the current study. Taken

together, therapeutic singing may be a valuable treatment strategy to combat these symptoms in persons with PD through increased social support and engagement in an enjoyable activity.

In the original quantitative study, all participants completed eight weeks of the group therapeutic singing for a 100% compliance rate and were actively engaged throughout the sessions (Stegemöller et al., 2017a). Adherence to treatment is very important in PD because it is a progressive condition. Irregularities and forgetting to complete therapy exercises is further confounded by cognitive impairment that occurs in between 25% and 80% of persons with PD (Aarsland, et al., 2003; Cummings, 1988; Pirozzolo, et al., 1982). There thus remains a need to develop treatment strategies to enhance adherence to treatment and therapy in persons with PD. The findings of the current study suggest that enjoyment and social support afforded through group therapeutic singing may be unique features of this type of therapy, possibly enhancing compliance. There are many additional complimentary therapies that are suggested for persons with PD, from yoga to boxing. Given the more challenging nature of these exercises for a population with movement impairment, including music therapy with other therapy exercises to increase enjoyment and social support may aid in adherence.

Research in healthy young adults participating in choral singing groups has revealed four common themes, including meeting new people, feeling more positive, increased control over breathing, and feeling more alert and spiritually lifted (Clift & Hancox, 2001). Similar findings have been found for healthy older adults, with study conclusions demonstrating that singing groups promoted physical, psychological, social, and community well-being (Skingley, et al., 2015; Skingley & Bungay, 2010). The most common sentiment expressed was one of enjoyment (Skingley, et al., 2015). Participants also commented on the social aspects of group singing, reporting benefits from peer support and getting to know the local community (Skingley, et al., 2015). These same generalities from healthy adults apply to the participant perspectives in this study. However, enjoyment and peer support may have a greater impact on the PD population. Sadness, anxiety, and apathy are common non-motor symptoms in PD (Gallagher & Schrag, 2012). Moreover, reduced social support has been identified as a psychological predictor of these symptoms (Garlovsky, Overton, & Simpson, 2016). Engaging in enjoyable activities

and opportunities for social support has been recommended as an important part of the treatment for neurological disorders (Garlovsky, et al., 2016).

These findings underscore how secondary and tertiary prevention efforts can improve QOL for adults diagnosed with PD. In research studies, the perspective of the participant often remains unknown. Recent research has suggested that having access to expertise in PD, increasing knowledge and understanding of PD, and taking the person and environment into account will facilitate participation in person-centered interventions (Nilsson, Iwarsson, Thordardottir, & Haak, 2015). The findings of this study indeed suggest that each of these elements was present as part of the singing intervention. While these elements were not specifically planned as parts of the original research study, they are unique aspects of GSI sessions, at times in contrast to choral singing. Taking into consideration the view of the participant may explain some previous equivocal results relating to the quantitative effects of singing on voice, respiratory control, and QOL in persons with PD. The focus of the GSI was on non-music behaviors, such as appropriate posture for breathing and not on producing a nice choral sound. Participants collaborated this focus and reported that even though they did not have much musical talent, they still felt comfortable singing in the group. Perhaps administering group singing for persons with PD under the guidance of music therapists facilitates participation that may directly affect quantitative results and QOL for persons with PD.

When applying the findings of this study to clinical music therapy practice, perhaps the most important implication is that GSI has the potential to target many symptoms of PD, particularly the non-motor symptoms (i.e., depression and anxiety) that do not readily respond to current pharmacological treatment. As clinicians, it is important for us to understand what PD symptoms are well managed with medication, such as tremor and rigidity. This allows for the focus of treatment to be on symptoms of need for the patient with PD. The findings of this qualitative study combined with our previous quantitative studies demonstrate that GSI improves voice, respiratory control, swallowing, and quality of life in one enjoyable type of intervention and represent key speaking points for music therapists when engaging neurologists and other medical professionals to secure employment working with this population.

Additional clinical applications that were obtained from the participants' responses include the need for music therapists to be less scripted yet clearly articulate the purpose for the intervention. Participants reported that this helped to build trust with the music therapist. Participants also noted the need for the music on the practice CD to be identical to the music used in the GSI. The original intent of the CD was to offer a variety to the music used in the sessions for at-home practice. The songs were the same, but arranged differently. As clinicians, it is important to remember that consistency, even though it may be redundant to the clinician, is important for the client. Finally, participants indicated that measuring their performance and disclosing the outcome of their performance in each session was beneficial and encouraging. Including numerical values and/or tangible representation of improvement to compliment verbal praise during a music therapy session can facilitate motivation and continued participation.

### *Limitations*

Several limitations of the current study are notable. The findings may not be transferable to adults who do not have PD or adults with PD who reside in other geographic locales. Furthermore, the participants' responses were obtained from retrospective reports and are subject to accuracy of participants' recall and interpretation of their experiences. Collection of participants' responses across cases was also uneven. Although we did not delete any cases from our analyses, some respondents did not offer full accounts of their experiences. Depth of participants' responses appeared to show individual differences as previously noted rather than a concern with the interviewer or interview context, social desirability bias, or lack of honesty. To counteract speech limitations, interviewers practiced active listening and frequently paraphrased participants' responses to ensure they heard them correctly. Participants' openness did not seem to be influenced by their involvement in the original quantitative study or knowledge of other efforts to collect participants' responses. In addition, a more inductive approach *may* have yielded different findings and insights. The interviews were completed 4-6 months after the original study due to the time needed to assemble a study team and obtain IRB approval. Given that PD is a progressive disease, continued decline in cognitive function may have impacted our findings.

Nonetheless, our findings remain positive. Finally, though the sample offered new understandings about participants' experiences in a GSI, the sample size was small (Harris, 2010).

### *Conclusion*

The purpose of the original quantitative study was to test whether a GSI was an effective treatment for voice, respiratory, and swallowing impairment and a means for promoting long-term compliance for persons with PD by engaging them in an interactive program. From this qualitative study, we learned about participants' reasons for enrolling as well as the beneficial and non-beneficial aspects of program outcomes. Findings revealed that participants regarded their involvement in the study as mutually beneficial, fun, and engaging. They were thankful for the fellowship with other adults with PD and observed noted improvements in their abilities to breathe and speak better. As Charles shared, "It puts you in a situation where you're aware of the impact that an illness has on your life and you discover your own ways of dealing with it." Our hope is that this information can be used to help improve the design and delivery of future GSI for a larger more diverse population of persons with PD.

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