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RESEARCH REPORT

It's quite good fun: A qualitative study of a singing/songwriting programme for people with Parkinson's disease and their spouses

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Abstract

Background: : Group singing for people with Parkinson's disease (PD) is an established intervention not only to improve voice and speech difficulties but also for emotional and social benefit. Less is known about the experiences of group singing on the couple—the person with PD and their spouse or partner together—and studies have not specifically tracked impact through time or in combination with songwriting.

Aims: : To understand the impact of group singing/songwriting on couples (participants with PD and their spouses) to unpack whether this broader view might help explain why such interventions are reported as beneficial. Using a trajectory approach, a form of longitudinal research and focused ethnography, the research sought a deeper appreciation of participation through time for the couple in a singing/songwriting group.

Methods & Procedures: : Four couples attending a singing/songwriting programme were observed for 10 weeks, and interviewed formally and informally weekly. Data were analysed thematically across-case through framework analysis but also within-case to explore the couples' experiences and narratives over time.

Outcomes & Results: : The theme of 'improved relationships' between the couples was new and extended previous studies' findings of positivity, physical benefit, sense of self and social opportunity. The stories of each couple highlighted the importance of musical reminiscence and emotional respite, and demonstrated changes with time through the singing and songwriting group.

Conclusions & Implications: : The benefits of offering singing/songwriting groups may be felt not only by participants with PD but also by their spouses/partners even if they choose not to attend themselves. Such benefits may include improved relationships related to the shared joy of music, musi-

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cal reminiscence and emotional respite. The addition of songwriting encourages creativity and agency. A longitudinal trajectory approach is one way to appreciate how these benefits may unfold over time for participants.

KEYWORDS
focused ethnography, group singing, longitudinal trajectory research, Parkinson's disease, songwriting

WHAT THIS PAPER ADDS

What is already known on the subject

- Group singing for people with PD has been shown to have physical, emotional and social benefits as measured on mainly pre-post-assessments of vocal, speech, respiratory function and quality of life questionnaires.

What this study adds to the existing knowledge

- This study adds three new aspects: studying the benefits for the couple (both people with PD and their spouse/partner); taking an in-depth focused ethnographic approach over time to collect couples' narratives and experiences; and exploring the potential for adding songwriting to the intervention.

What are the potential or actual clinical implications of this work?

- A qualitative trajectory approach may help clinicians understand why such interventions are experienced as beneficial. Clinicians running singing groups for people with PD should offer attendance to spouses/partners because of the potential for such groups to improve relationships and build new points of connection for the couple, as well as provide peer support for spouses. Songwriting is a useful addition for creativity, cognitive flexibility and self-expression.

INTRODUCTION

Parkinson's disease (PD) is one of the most common degenerative neurological conditions, rising in prevalence with age (Dorsey et al., 2018). It is due to deficient production of dopamine, a neurotransmitter produced in a region of the midbrain called the substantia nigra, part of the basal ganglia. Dopamine has an important role in controlling and coordinating movement. Reduced levels of dopamine associated with PD cause classic symptoms of resting tremor, muscle rigidity and bradykinesia (slowed execution of movement). Clinically, signs include loss of postural reflexes, a shuffling gait, loss of facial expression and dysarthrophonia—changes to speech intelligibility and voice which negatively impact on communication. As the disease progresses there may also be changes to cognition, particularly executive functioning (Kudlicka et al., 2018) characterized by loss of attentional control for planning, reasoning and decision-making and behaviour changes such as increased apathy. These physical, cognitive and behavioural changes may negatively influence relationships between people with PD and their spouses/partners due to changes in role and increased physical burden, emotional stress and fatigue (Kudlicka et al., 2018; Mach et al., 2019). Speech and voice difficulties can result in communication breakdown, increased social isolation and decreased quality of life (QoL) (Ramig et al., 2008; Walshe & Miller, 2011).

Studies exploring the impact of PD on spouses/caregivers have found it to affect physical health, mental health and social relationships (Den Oudsten et al., 2011; Lageman, et al., 2015; Theed et al., 2017). Corallo et al. (2017) reported a correlation between spouse QoL and that of the person with PD. Barken's (2014) ethnographic study of eight spouses caring for partners with PD used interviews and participant observation at a PD support group over 8 months to gain an in-depth understanding of their experiences. Barken discusses how spouses managed biographical disruption, negotiated uncertainty and sought a sense of control through coping strategies such as staying engaged with recreational activities, gaining support from other spouses and trying to preserve aspects of their relationship before PD onset.

In recent years, there has been growing recognition of the benefits of collaboration between the arts and health (Davies et al., 2014). A systematic review of 56 studies published between 1989 and 2020 (Barnish & Barran, 2020) explored the benefits of four key performing arts modalities for people with PD: dance (38 studies), singing (12 studies), music therapy (four studies) and theatre (two studies). The review found evidence of benefits in all areas across a range of outcome domains.

Researchers and clinicians in both speech–language pathology and music therapy have been interested in singing with people with PD. Music therapy, the profession which uses music to promote health and wellbeing (e.g., https://www.austmta.org.au/) has a developing evidence base of research on interventions for PD (Raglio, 2015). Rhythm has been found to be particularly useful for motor symptoms, while relational aspects and promotion of emotional expression through music have psychosocial benefits (Raglio, 2015). Group singing has been found to be useful with its holistic and person-centred approach and is increasingly popular (García-Casares et al., 2018; Pakdeesatitwara & Tamplin, 2018). A rationale for using group singing is that it not only addresses the physical impairments of PD, but also emotional and social aspects, promoting social interactions among participants (García-Casares et al., 2018; Pakdeesatitwara & Tamplin, 2018). Regarding communication benefits, Haneishi (2001) found that vocal and singing exercises were effective in improving the speech intelligibility and vocal intensity (volume) of people with PD and suggested that singing engages the respiratory musculature, promotes good posture and increases respiration efficiency. Speech intelligibility in people with PD has been found to improve with an 11-week choral singing intervention (Higgins & Richardson, 2019). Vocal improvements have also been noted by Di Benedetto et al. (2009) who found that choral singing as voice therapy can improve patients' maximum phonation time, loudness, prosody and breath support. In addition, Tanner et al. (2016) reported significant improvements in maximum vocal intensity, range and pitch after completing a 12-week singing therapy treatment block. Singing has been found to not only improve vocal quality but also slow down the speech and voice deterioration associated with PD over time (Elefant et al., 2012; Evans et al., 2012). Group singing has been reported to promote health related QoL, social interaction and emotional support for both people with PD and their caregivers (Abell et al., 2017; Di Benedetto et al., 2009; Fogg-Rogers et al., 2016).

Abell et al. (2017) summarized the range of approaches taken to explore group singing in PD and reported that most studies used quantitative measures to demonstrate the effects. For example, Evans et al. (2012) administered the Frenchay Dysarthria Assessment (Enderby & Palmer, 2008) with their 17 participants at the start of the study and then every 6 months for 2 years. They also found small improvements in QoL as measured on the Parkinson's Disease Questionnaire (PDQ-39) (Peto et al., 1995) thought to be related to the group nature of the therapy rather than relating to the improvements in vocal quality (Evans et al., 2012). Fogg-Rogers et al. (2016) assessed PD motor experiences to show that music therapy improved the health-related QoL of their six participants with PD. More recently, Tamplin et al. (2019) ran a controlled trial with 75 people with PD comparing their intervention (ParkinSong) with an active control condition at two dosage levels over 3 months using vocal, respiratory and voice-related QoL measures.

In contrast, two studies have adopted a qualitative research approach using one-off in-depth interviews to explore participants' experiences of group singing. Abell et al. (2017) used interpretative phenomenological analysis to capture six main categories of positive effects (physical, mood, cognitive functioning, social connectedness, flow-on effects and enhanced sense of self). Fogg-Rogers et al. (2016) used thematic analysis of their semi-structured interviews to show that their choral singing therapy allowed people with PD to self-manage the social consequences, low mood and vocal symptoms of their condition.

The current study sought to extend research on group singing in PD to date in three ways. First, we wanted more focus on its effects on both the participant and their spouse, particularly in view of the links found between QoL for people with PD and their spouses (Corallo et al., 2017) and the reported improvements in social connectedness and communication through attending group singing in PD. This focus on the effects of group singing on the couple has not been specifically addressed previously. Second, through a qualitative trajectory approach (Grossoehme & Lipstein, 2016; Neale, 2021) and focused ethnography, we sought to examine the experiences of a small number of participants in depth through time, using repeated formal and informal interviews and participant observation, to understand in a more personal way about *why* participants reported benefits of group singing. Several studies have used ethnography to better understand the experience of living with PD (for a review, see Soundy et al., 2014), and of caring for a spouse with PD (Barken, 2014). However, this ethnographic approach has not yet been used to examine participation in group singing. Our interest was not simply to gain before and after perceptions of participation in the group, as seen in previous studies, but to explore it *through* time with the couples. Thirdly, while there is a literature on therapeutic songwriting (Mantie-Kozlowski et al., 2021), this approach has not been reported within this type of programme and therefore this study extends further previous work in this area. In summary our research questions were: how do couples (people with PD and their spouses) perceive the group singing programme; what are their experiences *through* the time of the group; and what is the role of songwriting within the group singing programme?

METHODS

This study took place at a hospital in Western Australia where a singing/songwriting group programme (SSWP) was a regular offering for outpatients with PD. The SSWP had been running for several years, in 10-week blocks, and was flexible enough to include spouses as and when they wished to accompany their partner with PD. People often elected to attend more than one block. There was no charge to attend. The SSWP was run weekly by a professional musician (who was in the process of training to be a music therapist), speech–language pathologist and/or allied health assistant in a group room at the hospital. The programme involved physical and vocal warm-ups, singing and learning songs often selected by the participants, and songwriting where, guided by the musician, the group worked together to write the lyrics to a newly created melody. The musician sang with the group, and accompanied them at different times on a keyboard, guitar and ukelele. Lyrics were available on a PowerPoint screen at the front of the room, and the musician transposed songs into keys that were comfortable for people to sing. Speech–language pathology voice facilitating techniques (e.g. shoulder and neck relaxation, vocal projection, abdominal breathing, and sustained phonation) were incorporated throughout the programme. Each session ran for 90 min with a short morning tea break. Ethics approval for this current study was gained both by the hospital human research ethics committee (HREC), and the local University HREC.

This study used a trajectory approach, a type of longitudinal research (Grossoehme & Lipstein, 2016), useful for learning about individuals or small groups and how their experiences change in time. It is difficult to define the exact extent of *longitudinal*, and Saldaña (2003) writes that notions of change and time are highly contextual and vary with different studies. Neale (2021) suggests longitudinal work may be conducted over relatively modest periods (in this case, over the 10 weeks of the group, with more interviews in the following 2 weeks), and is useful in health contexts to explore the impact of an intervention on service users over time:

> Instead of making bald comparisons between two snapshots in time, a more intensive approach generates a cyclical, reflexive, and processual understanding, 'a description through time'….(103)

Our research also used focused ethnography based on *naturalism*, where the social world is studied as it occurs, observed by the researcher (Hammersley & Atkinson, 2007). Focused ethnography (Knoblauch, 2005) describes small-scale observational and qualitative interview-based research conducted in authentic settings to explore cultural meanings and practices. It is often used in applied research and is characterized by field visits to part-time settings over a constrained time, but with data intensity. As such, the study aimed to describe the setting, activities, and people in the programme recognizing that: 'human actions are based upon, or infused by, social or cultural meanings' (7). This approach required immersion in the group (albeit *etic*, considering the researcher was a health professional and not a person with or caring for someone with PD), weekly participant observation, and data collection using field notes, formal and informal focus group and individual interviews. The ethnographic approach in this study, with multiple opportunities to talk with participants and observe them, sought to add to existing findings from other previous studies which collected data about participant experiences through questionnaires and single, one-off interviews (Abell et al., 2017; Fogg-Rogers et al., 2016).

While 12 people with PD as well as their partners attended the SSWP overall, purposive sampling was used to recruit a smaller sample of eight people (four couples) for this study. The overall group, run by the third author, was aimed at improving vocal volume and quality through group singing and promoting social interaction. We sought participants with PD of different gender, time since diagnosis and disease severity, from the pool of attendees of the SSWP and their spouses. All people with PD invited to participate in this study had been assessed by their managing hospital geriatrician to confirm that there were no cognitive deficits that might impact on the ability to understand the research project or to give informed signed consent. Throughout the SSWP, including during the morning tea break, the second author attended and joined in sessions, and collected field notes of observations, recording physical setting, participants' appearance and engagement, verbal and non-verbal interactions and informal conversations with participants. She was also provided with a summary of information from the participants' medical file by a hospital staff member to note any relevant changes relating to their physical health over the course of the programme such as hospital admissions/appointments, change of medication and recent assessment reports.

In addition to the data collected as described, a 20-min informal focus group, run by the second author, was held in a side-room along the corridor from the group room, at the start and end of each weekly session to gain understanding about the evolving experience and perspective of participants (both people with PD and spouses) attending the SSWP. Focus groups have been shown to be a useful and reliable way to collect the views of people with PD and their spouses (Den Oudsten et al., 2011). In these informal discussions, participants were asked about their week, how they felt after the previous session and then, post-singing, about the current session. One week after the final session of the SSWP, two formal semi-structured group interviews were conducted, each lasting between 45 and 60 min, one for the participants with PD and one for their spouses. A third interview was run after a further week for one couple together who were unable to attend the previous sessions. Unlike the weekly informal focus group interviews captured through field notes, the final formal focus group interviews were audio-recorded and transcribed verbatim, later removing identifying information. A summary of the transcripts was given to the participants for member-checking in line with the Consolidated Criteria for Reporting Qualitative Studies (COREQ) recommendations, but no changes were requested (Tong et al., 2007).

A recommended approach for managing and analysing the different sources (here, field notes and interviews) of text-based data gathered within ethnographic research is framework analysis (Gale et al., 2013; Jones & Smith, 2017). Framework analysis offers a rigorous, structured and systematic way to present and work with data to develop themes. Neale (2021) notes that 'case analysis (the production of case histories and case studies) and framework grid analysis are useful combinations' in qualitative longitudinal research, particularly in having a 'temporal, case-led mode of thematic analysis, which ties themes, cases and processes more closely together' (308). The second author transcribed the interview data, and did initial coding, and the first and third author each reviewed these codes. Material from the different sources was organized into an Excel-based matrix to visualize patterns and developing themes within and between cases (individuals and couples). Analysis was inductive and involved considerable discussion and reflection over multiple meetings by all three authors to develop and deepen the interpretations of the data. The reporting of results included detailed observations of even seemingly mundane aspects of setting or interactions, rich and plentiful quotes, and within-couple narratives to retain a sense of each individual or couple as well as themes across all participants (Gale et al., 2013).

RESULTS

Four people with PD (two women and two men, age ranged from 65 to 78 years [$M = 69.25$, SD = 5.31] and diagnosed 5–16 years before the study [$M = 11.13$, SD = 3.94]) and their spouses (ages not collected) agreed to participate in the study (Table 1). All participant names (including the musician facilitator's name) are pseudonyms to protect confidentiality.

Field notes

The second author kept notes from her observations over the nine sessions. A photograph, typical session agenda and example of the field notes are provided in Figure 1. Field notes sought to describe the setting, atmosphere, activity and detail of the group with notes like 'light-hearted, with regular laughter'. Comments included observations over time: 'Over the weeks, people got to know each other and enjoyed making each other laugh,' and 'Kathy (musician) used friendly banter to engage people, which became more individualized over the SSWP as she got to know participants better.' Certain moments seemed important, such as when a song was familiar or a favourite of the participants: 'the room became more animated: participants sang louder, tapped their feet, clapped their hands, or nodded their heads to the rhythm of the song. Kathy was physically, vocally, and facially animated'. Notes also recorded incidents such as the well-intentioned decision by staff to rearrange the room from rows of tables and chairs, considered too formal, to chairs arranged in a circle to gain space and reduce the formality. However, participants with PD requested return to the original layout because of their physical difficulty holding a cup or plate and needing a surface for items to be put down.

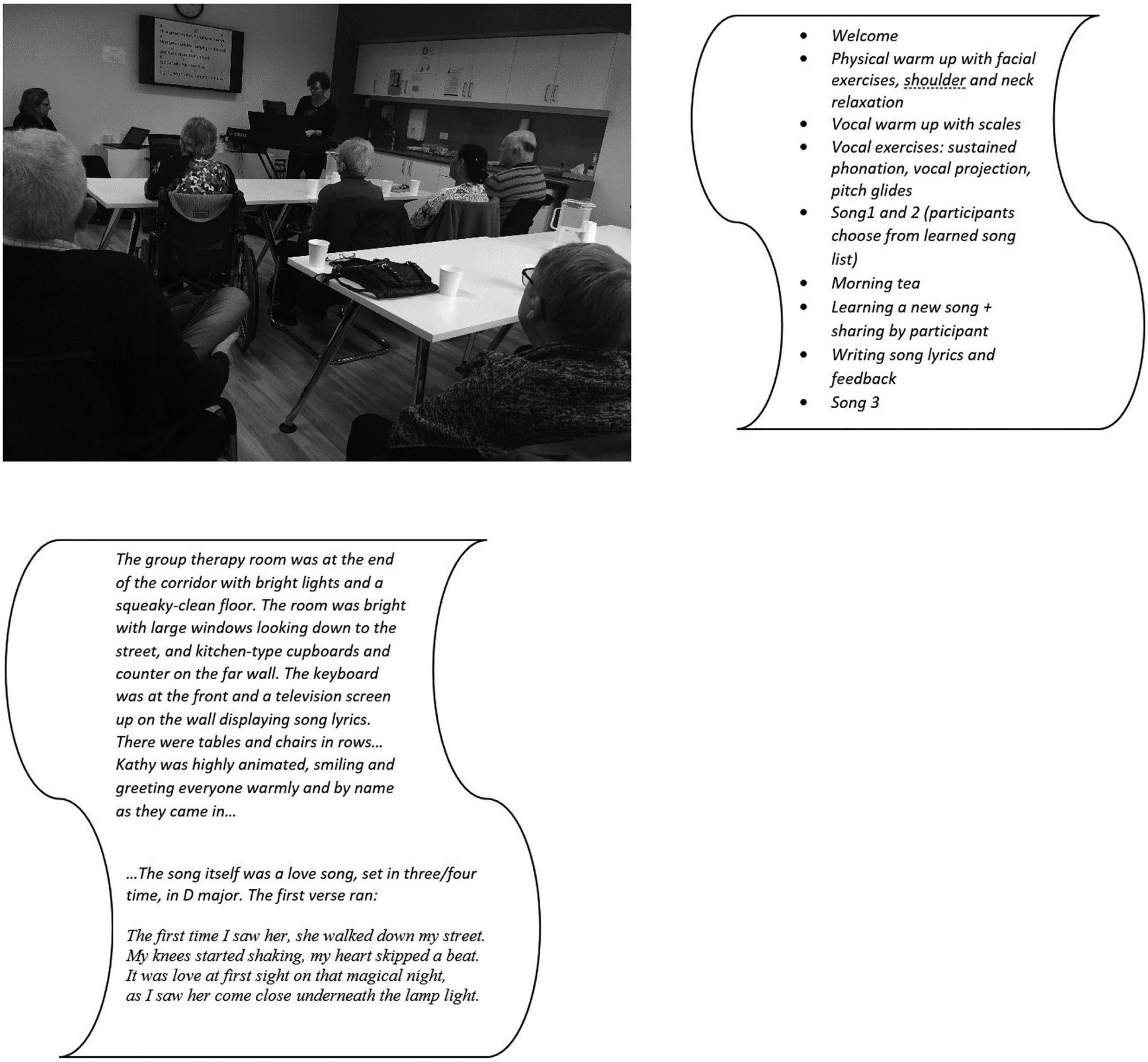
Narratives

Each couple's story is summarized below to contextualize the changes for the couples throughout the group, and also the themes which follow.

TABLE 1 Participant demographic data

Pseudonym of the person with PD	Gender	Age (years)	Years since diagnosis	Severity scale (Hoehn & Yahr, 1967)	SSWP attendance (%)	Spouse pseudonym
Michael	Male	69	12	2.5	89	Michelle
Simon	Male	65	11.5	4	89	Simone
Robyn	Female	65	16	5	78	Robert
Lucy	Female	78	5	2	89	Luke
Mean (SD)	69.24 (5.31)		11.13 (3.94)		86.25	

Note: SSWP, singing/songwriting group programme.



- *Welcome*
- *Physical warm up with facial exercises, shoulder and neck relaxation*
- *Vocal warm up with scales*
- *Vocal exercises: sustained phonation, vocal projection, pitch glides*
- *Song1 and 2 (participants choose from learned song list)*
- *Morning tea*
- *Learning a new song + sharing by participant*
- *Writing song lyrics and feedback*
- *Song 3*

The group therapy room was at the end of the corridor with bright lights and a squeaky-clean floor. The room was bright with large windows looking down to the street, and kitchen-type cupboards and counter on the far wall. The keyboard was at the front and a television screen up on the wall displaying song lyrics. There were tables and chairs in rows… Kathy was highly animated, smiling and greeting everyone warmly and by name as they came in…

…The song itself was a love song, set in three/four time, in D major. The first verse ran:

The first time I saw her, she walked down my street.
My knees started shaking, my heart skipped a beat.
It was love at first sight on that magical night,
as I saw her come close underneath the lamp light.

FIGURE 1 The singing/songwriting group programme (SSWP) group therapy room, and three excerpts of field notes: typical session agenda, describing the setting and a section about the final song written by the group

Couple 1: Michael and Michelle

Michael was a retired computer technician and his wife, Michelle, a retired primary school teacher. Michael described his initial experience with the SSWP as *awkward* because he was self-conscious about *pulling silly faces* and making *funny sounds* during vocal warm-ups. Michelle was aware of his embarrassment about participating and was concerned that her presence would make this worse. Therefore, she attended the informal pre-post-discussions each week, but when Michael was in the session itself, she would either chat with other spouses in the larger group in the reception area or would run errands. As the weeks went by, Michael became more comfortable in the group and fully participated in the session (even the *ridiculous* vocal warm-ups) and reported enjoying singing familiar songs each week. At the start of the SSWP, Michael's PD medication was changed. Michelle felt this may have altered his behaviour (she reported issues with short term memory, confusion, hallucinations, and difficulty sleeping with nightmares) and pre-empted one hospital admission secondary to a fall. These problems appeared to be resolved once Michael's medications were reviewed. Despite not participating in the singing sessions, Michelle said that her relationship with Michael had improved since coming to the programme as they talked about the weekly events in the group and spent time between sessions listening to and searching for songs while reminiscing about the songs together.

Couple 2: Simon and Simone

Simon had worked in a managerial position prior to retirement. His wife, Simone, was a retired secretary. In addition to his PD, Simon also had chronic back pain and had undergone recent back surgery which impacted on his mobility and resulted in him needing a walking frame. He described getting out the house as a *chore at the best of times*, however, on a Tuesday, the day of the SSWP, he said he found it much easier to get ready in the morning, invigorated by the anticipation of going to the group. Simon and Simone participated in the singing sessions together and reported that attending the programme as a couple allowed them to spend quality time with one another. Attending the sessions with Simon was Simone's way of showing her support for him in an already busy schedule where Simone cared not only for Simon but also her elderly parents, adult children and grandchildren. In addition to finding the programme beneficial to their relationship, Simon and Simone also reported that their emotional well-being improved as they found singing uplifting and a way to relax. Simone explained that unlike other medical appointments, she was able to enjoy the sessions: 'I don't have to worry about him. I can come here and relax and clear my head. Unlike when he had the deep brain stimulation, I was very panicky and stressed out about the whole thing!'

Couple 3: Robyn and Robert

Robyn, a primary school teacher, was diagnosed with PD at 49 years. She had since retired, and her husband, Robert, also now retired, was her primary caregiver. At the time of the SSWP, Robyn had just transitioned to using a wheelchair from a walking frame as her motor symptoms had recently deteriorated. In week 9 of the programme, Robyn received the initial surgery for deep brain stimulation which caused her to miss the last two sessions. Robyn initially attended the SSWP alone while Robert went to a nearby café to take *time for himself*. However, in week 7 and 8 of the SSWP, Robert attended after Robyn convinced him of the benefits of the singing. At that time, he was experiencing health related stress and had difficulty sleeping. In the two weeks that he attended the session, he described his experience to be positive reporting that the singing was an opportunity for him to put his problems aside and enjoy the company of others for a couple of hours. After Robert's first session, he commented that: 'It was definitely worthwhile, singing was a good distraction that made me stop thinking about my own issues and I left the session feeling lighter.'

Couple 4: Lucy and Luke

Lucy had always loved singing and used to sing in a local choir, so when she heard about the SSWP, she signed up immediately. Every week, Luke, Lucy's husband, drove Lucy to the SSWP and picked her up after the session. While Lucy attended, Luke used the time to read, catch up with his friends over the phone or do grocery shopping. Sometimes Luke waited at the reception area and chatted with other spouses. Lucy reported the SSWP allowed her to practice her breathing and maintain her vocal quality. At the start of the programme, Lucy appeared to be quietly spoken and reserved. However, by the end of the 10 weeks, she was chattier and more open to sharing her personal stories to the group. She started referring to the other participants as her friends: 'Seeing my group of friends here makes it a good week.' Luke was socially confident from the start and enjoyed the weekly informal focus groups as they gave him the opportunity to interact and exchange stories with the other participants and spouses.

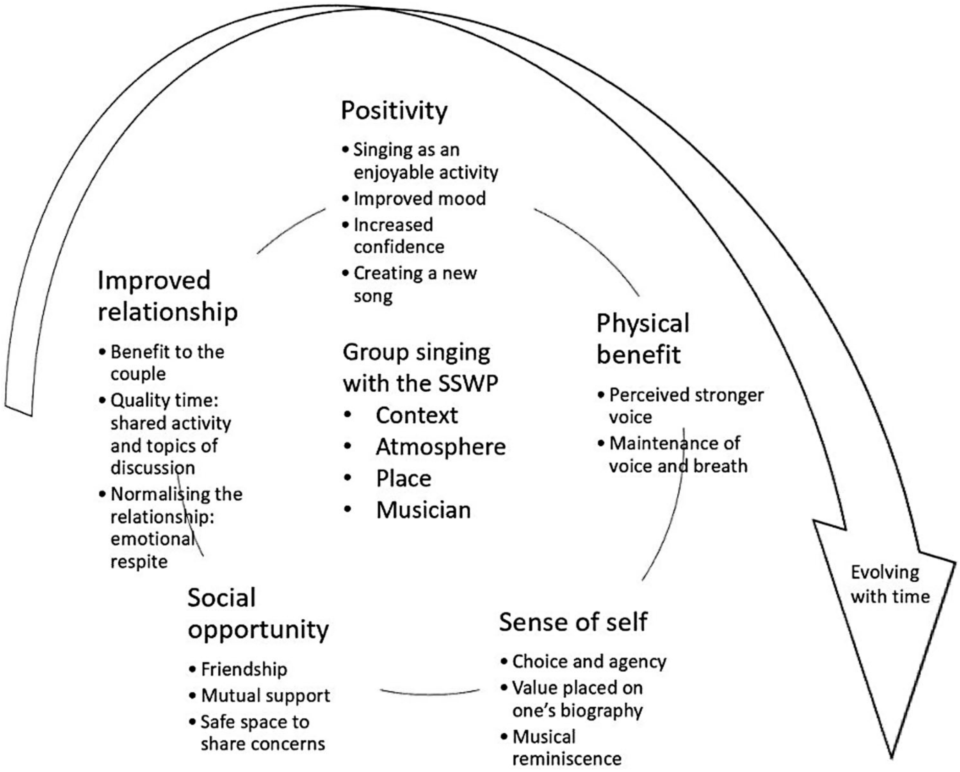


FIGURE 2 Summary of themes for the singing/songwriting group programme (SSWP)

Thematic analysis

Five main themes were developed through analysing the data across all participants: positivity; physical benefit; sense of self; social opportunity; and improved relationships. These are illustrated in Figure 2.

Positivity: 'It makes everything more positive'

The participants with PD reported that the SSWP improved their mood and emotional well-being as they found the singing in the group to be an enjoyable activity:

> Every Tuesday I look forward to coming because I feel positive. Because I know it's going to be a good day with the singing and the group. It's a positive experience for that period' (Simon).

Robyn, who usually had the typical mask-like expression of PD, nevertheless often smiled broadly after the singing sessions. She said: 'I think that it has helped me to be more positive. Certainly, on a Tuesday I feel bright all day.' For Lucy, it was both the singing and interacting with people that made it a positive experience. Lucy said: 'I could so easily stay at home, but I come because I enjoy it. And I know that coming here will make me feel better.' Some reported a carryover effect of *feeling happy* into the rest of the week particularly when engaged in music related activities at home. Michael reported: 'I sing at home and in the car more. So, the positive feelings from coming to the singing group would last through the week. But by the weekend it's running low. And we look forward to Tuesday again' (Michael).

In addition to singing more at home, Michael said that he spoke more about music to his friends and family: 'All my friends and family know about choir now. Even the grandkids. They always ask: "How's your choir going grandpa?" and "Are you doing a concert?" So, it makes everything more positive.'

Participants with PD consistently reported that coming to the SSWP reduced the low mood common with PD:

> You can get quite down and depressed which can be part of the symptoms of PD or part of PD because it's like 'Why have I got this? And this is going to get worse' that sort of thing which can lead to depression. And singing would get you out of that. Enjoying something and having a laugh instead of thinking poor me.' (Lucy)

Coming to the programme improved confidence when interacting with other people, to share opinions and participate in conversations beyond the SSWP:

> Coming to singing group helps me with gaining confidence in talking in groups and practice my conversational skills. Because I need time to process and sometimes, I have trouble with finding the word or I forget what I want to say. So, it's nice talking to like-minded people and go out feeling good about yourself. (Simon)

Simon shared that since he had PD, he perceived his cognitive skills had started deteriorating and he found it difficult to participate in conversations. Attending the programme was a confidence booster for him. Robyn reported: 'I could just be myself.' This notion was explained further by Michael:

> It doesn't matter what you do because we all are singing the same tune and are on the same page and if someone's out of tune or if someone forgets the words, there's someone down in the row that's doing exactly the same. So, you can just be yourself. (Michael)

Michael was always careful how he presented himself; he was well-dressed and had tried not show that he had PD. A key shift for him over the course of the SSWP was being comfortable about telling people about his medical condition: 'It's made me feel better within myself. Even though I've got PD. I'm not ashamed or worried to tell someone I've got PD. Yeah, it's definitely made things happier.' For Michael to say that he was not ashamed to tell people that he had PD was a personal achievement and an effect of the SSWP that was only highlighted through understanding his personal journey over time.

Physical benefit: 'It helps my voice from getting worse.'

Participants with PD reported the SSWP maintained their volume and vocal quality and helped with breathing.

> Whether your voice is strong or weak, at the end of the day when you sing, it's always strong. (Robyn)

< Setter note the line space here >

> Two things, the voice and breathing. Because singing helps with your breathing, I don't get out of breath as easily when I talk and coming here helps my voice from getting worse. (Lucy)

Michael enjoyed coming to the programme because it helped with his volume, prosody and breathing: 'My voice does go monotone and they do teach you how to raise your voice and all of that sort of stuff. How to breathe and all.' The observations in SSWP also included notes about physical engagement in the music, sitting alert, moving to the rhythm, and increased facial expression.

Sense of self: 'You are also somebody'

As part of the SSWP, all attendees were requested to nominate two songs that reminded them of their childhood and their life-story respectively to generate the group's song list. For the participants, this aspect of the programme made them feel that their experiences and history were valued:

> It was very nice that you get to choose a song and tell your story—the reason for choosing it. It puts a value on you. To say you are also somebody. You also got your choices. And Kathy made you feel that way. Because if you didn't give it to her that day, she'll come back to you the next week and say where's my music? (Michael)

Simon loved sharing the story behind his selected songs: 'One song was for Simone, the song of our wedding march and one song for myself, to tell my life story.' Field notes were important in recording how participants reacted to their selected songs. Robyn would sit alert in her wheelchair, shifting her posture to lean forward, while Lucy would beam with joy when songs important to her and Luke were selected to be sung. Michael closed his eyes to appreciate the music of his song as he sang louder than usual.

Social Opportunity: 'It's a social event, not a medical event'

The SSWP was time where participants could meet other people and socialize rather than simply attend as a way of receiving treatment to manage their PD speech and voice symptoms: 'I think this has done a world of good for her because she gets to go out among other people. Like coming here is just like a social event not a medical event' (Luke).

Based on observation and self-reports during discussion sessions, participants had created new friendships by coming to the programme and were eager to catch up each week. In week 8, both Simone and Lucy commented: 'We're all 15 minutes early today so we can get extra time to chat.' As time went by each week, the participants got to know each other on a deeper level and were more open to sharing the positive highlights and/or struggles they had encountered during the week rather than just having small talk or superficial conversations. At the end of the 10-week programme, all the participants spontaneously exchanged phone numbers to stay in touch with one another.

Participants also reported that the discussion sessions before and after the SSWP felt like a 'safe space' to unload any emotional burden or to seek advice from one another:

> We all have different issues in our lives and with our spouses. And you think you are the only one going through certain things. But when you hear that someone else … what they are going through, that's really good. To know that you are not alone, you don't feel alone. Especially when you don't want to burden your family with what you are going through because they've got all their stuff. (Simone)

Each week, when the informal focus group discussion was finished, the conversation topic would often go to talking about their daily struggles of living with PD. For example, some weeks the participants would discuss their PD medications while the following week they lamented together about the struggles of travelling. Michelle explained why the programme was valuable to her:

> It was support and I loved that because I don't have that. I was in that good space at choir and we all say things that we would have never said to anyone else. And we know that no one is going to judge you and that's how I feel at our group. So, it has been amazing for me. (Michelle)

Improved relationship: 'We as a couple are happier'

The spouses reported having improved relationships with their partners. Simone said that coming to the programme with Simon allowed her to have quality time with him considering she was often busy with other family caring responsibilities:

> It most definitely had helped with our relationship. Just for one day of the week we share that together, as for him and for me. It's his thing and our thing. And I can show that I support him by coming. We get a lot out of it. (Simone)

Michelle found that she was spending more quality time with Michael since participating in the programme:

> He's all excited about choir so we will chat about that, and we will talk about music. We're more chatty. So, we as a couple are happier after choir. And as the days of the week go past, we are still looking at music and getting out old records and playing old songs and going on Google and reminiscing about the songs. (Michelle)

Furthermore, since Michelle did not attend the sessions with Michael, it was a time that she could 'let go' and give Michael the opportunity to do something without her: 'It's his independence. Because I usually don't like leaving him for 5 minutes or anything like that. So, he likes it when he used to drive to the sessions himself.' This helped balance Michelle's role as a spouse and as a caregiver and provide a sense of normality to the relationship.

All the spouses felt that that coming to the programme provided them with time to take a break from the responsibilities of being a caregiver. During the SSWP, each spouse used the time differently. For Luke, it was being able to spend time alone doing things that he loved, such as reading or catching up with a friend over the phone. As for Robert, he spent the time alone at the hospital café and he described that time as 'my time':

> One of the things for me is this ongoing thing—respite. That carers need respite as well. And coming to the singing allows me to have 'my time'. I like to sit at the café downstairs and enjoy my coffee while reading a book. (Robert)

However, from week 7, Robert started attending the sessions with Robyn: 'I enjoyed the singing, it is like a distraction for me to stop thinking about my own issues.' Therefore, unlike Luke, it showed Robert was not referring to 'respite' as a period of physical separation to be refreshed from his caregiver role, but rather the opportunity to 'take a break' from being a caregiver whether with

Robyn or not, and to be free to choose what he wanted to do. The idea of 'taking a break' was also raised by Michelle: 'It was an opportunity to not worry about Michael.' Therefore, Michelle looked forward to the sessions: 'When he goes to choir, I used to say, 'oh yay he's gone!' [laughs] I've got two hours just to do what I need to do, and I know that he is safe.' Lastly, even though Simone attended the session together with Simon, she did so as an equal with Simon rather than as a caregiver. This allowed her to 'take a break' and to care for her own emotional well-being: 'I let go a bit. Last week, I have been quite stressed, so I come to relax myself.'

Songwriting

For the first 6 weeks of the SSWP block, participants worked together to create their song. The musician led the writing of the melody of the song (verse and chorus), with participants providing feedback, and they then developed lyrics to the song based on the melody. Once the song was complete, participants then learned to sing the song over the next four weeks. The song was a source of great pride in the group, and an example of creating something that countered perceived cognitive slowness and word-finding difficulties: 'I went the hours trying to make up a song with words and rhyming words and phrases and it helped with my thinking of words and getting words out' (Simon).

Not only was the song an exercise to use language and music creatively, but the group chose to write about new, young love. This focus, and the choice of a dance rhythm and major key, were all about joy, about discovery, and living life to the full, and noteworthy for a group of older people brought together because of PD: 'I'm swept off my feet. Your love takes me to a higher place' (Figure 1).

DISCUSSION

This small but novel study used focused ethnography to explore, in-depth and over time, the experiences of the SSWP for four people with PD and their four spouses. Through analysis of field notes of observations over 10 weeks, and of multiple informal and formal group interviews, this research has contributed personal insights, and stories about the couples over time, to show how programmes like the SSWP are perceived, and why they may be seen as beneficial. The framework analysis yielded five main themes: positivity; physical benefit; sense of self; social opportunity; and improved relationships. The first four themes reflect findings from Abell et al. (2017) who reported six categories of benefit: physical, mood, cognitive functioning, social connectedness, flow-on effects, and sense of self. Our results are also consistent with other previous research that has demonstrated increased health related QoL in people with PD after group singing, increased social confidence (Evans et al., 2012) and perceived improvements in voice quality, respiration, and breath support (Di Benedetto et al., 2009; Elefant et al., 2012; Fogg-Rogers et al., 2016; Haneishi, 2001; Stegemöller et al., 2017; Tanner et al, 2016). The SSWP benefits were also reported to have a carryover effect of maintaining vocal quality throughout the week. This finding is similar to the flow-on effects reported by Abell et al. (2017) and the lack of deterioration in vocal quality over two years for participants in the group singing programme described by Evans et al. (2012).

The context of the SSWP, in the hospital setting, was a little different from the group singing in previous studies. The CeleBRation choir (Fogg-Rogers et al., 2016) included people with other neurological conditions, and the 'Shake, Rattle and Roll Choir' (Abell et al., 2017) met at a community centre, sang à cappella, and participated in public performances. Another difference with our study was that, as part of the SSWP, participants engaged in songwriting, a novel component reported to have a positive impact on cognitive functioning (such as memory and word retrieval). The creation of a new song was very important to the group and it was a positive experience developing the lyrics to a newly created tune. This creativity is supported by neuroscience research which suggests that music related activities do have a positive impact on cognitive functions because they activate areas of the brain involved in higher level cognitive functions such as attention, working memory and episodic memory (Särkämö & Sihvonen, 2018). In addition, people generally experience pleasure when engaging in music related activities (Särkämö & Sihvonen, 2018). Not only did music contribute to the emotional well-being of participants, but the atmosphere of the room, culture of the group, role of the musician and choice of songs were also important factors. The longitudinal nature of this study highlighted that some people needed time to experience a benefit or changed in their level of commitment as time went on. Participants described carryover effects of improved mood, and increased engagement with music-related activities at home, findings also consistent previous studies (Abell et al., 2017; Fogg-Rogers et al., 2016).

This study is novel through including the perspective and experience of spouses of those with PD participating in group singing. The study by Fogg-Rogers et al. (2016) included two female spouses of participants with PD who attended the choral singing therapy, but these spouses did not attend the group itself. A finding of the current study is that participants reported having improved relationships with their partners since attending the programme. The strength of the relationship between people with PD and their spouses is known to impact QoL (Karlstedt et al., 2017) which can reduce as the disease progresses and as social isolation increases (Kudlicka et al., 2018; Mach et al., 2019). The spouses were given the option to attend the SSWP and, while only two of the four chose to participate in the group itself, all noted a positive difference for them resulting from either their partner with PD attending or both attending. All noted the importance of respite, putting aside their responsibilities as a caregiver, and to either take time away or to enjoy the singing as a participant. While the notion of respite, a temporary physical separation from the patient, for caregivers is widely discussed in the literature as an intervention to support them in their role, respite in this study did not necessarily imply a physical separation (Schwartz et al., 2018). Simone and Robert reported being able to have time for respite 'to stop thinking about issues, relax and not worry', despite still being physically present with their partner and participating in the singing session. This study introduces a notion of *emotional respite* rather than the usual assumption of respite requiring distance between caregiver and person. It normalizes the relationship, allowing the couple to be together in their previous roles rather than as patient and carer, and it arises because of the nature of the intervention in the SSWP as an essentially enjoyable activity that can be shared by the couple equally. Moreover, just as being together in the SSWP was important for two of the couples, so was the act of choosing meaningful songs together at home and the joy of singing old songs that appeared to reconnect people to their younger, healthier selves. This has been noted in Figure 2 as *musical reminiscence* reinforcing people's sense of self and history as a couple. The normalizing of the relationship within the programme, the sharing of meaningful music and singing, and having the time to look back at positive shared experiences all help to explain why couples felt their relationship was stronger after attending the SSWP. Michael's comments about the SSWP being a source of conversation with his grandchildren is another example of the programme enriching conversation, enabling shared points of interest, and promoting a sense of self beyond simply being a person with PD. Together with the other previously reported physical, mood, cognitive and social benefits of group singing, this study deepens our understanding of the powerful value of music and singing as an intervention in PD, but also demonstrates how the impact is felt beyond the person with PD to their spouse and potentially other family members.

The sample size of four couples was appropriate and deliberately chosen to enable a personalized view of the experiences for the couples over the course of the SSWP. While our results are in line with previous research, data collected from participants is clearly not generalizable to everyone with PD, but rather about is deepening our understanding of the group singing/songwriting experience and the meaning it held for each of the couples. The use of weekly pre- and post-session discussions with all participants present (rather than talking to people individually) could have hindered participants from sharing personal information related to their spouse, or any negative information about each other. However, for these four couples, there was an openness to all the talk and no sense that things could not be said in front of the partner. Additionally, the final formal interviews were separate for the people with PD and their spouses.

CONCLUSIONS

This study took a focused ethnographic view of a singing/songwriting intervention for PD, particularly how it was experienced by both the person with PD and their spouse through the 10 weeks of the programme. Our findings extend previous research on group singing in PD by looking in more depth at the perceptions over time for each couple, highlighting a benefit to their relationship through the intervention. This research has enabled a deeper appreciation of the role of the context and culture of the group itself, including the enthusiasm and skill of the musician who facilitated the group and the importance of embedding choice and agency by inviting participants to choose songs which are personally meaningful. The songwriting component demonstrated the value of novel creativity through lyrics and music as a way for people to reclaim the joy of their younger days. This study has also noted musical reminiscence in strengthening the relationship of the couples, and the idea of *emotional respite* for spouses in a caring role, not simply a physical respite. The in-depth nature of this study has both theoretical and clinical value and adds to other research on the value of arts–health interventions such as the singing/songwriting programme.

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CONFLICT OF INTEREST STATEMENT

There are no real or potential conflicts of interest related to the manuscript.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author.

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