

Choral Singing Therapy following stroke or Parkinson's disease: An exploration of participants' experiences.

Laura Fogg-Rogers^{1,2}, Stephen Buetow², Alison Talmage², Clare M McCann^{2,3}, Sylvia H S Leão^{2,3}, Lynette Tippett², Joan Leung^{2,3}, Kathryn M McPherson⁴, and Suzanne C Purdy^{2,3}.

1 Science Communication Unit, University of the West of England, Bristol, UK

2 Centre for Brain Research, The University of Auckland, Auckland, NZ

3 Speech Science, School of Psychology, The University of Auckland, Auckland, NZ

4 Person Centred Research Centre, AUT University, Auckland, NZ

Corresponding author

Laura Fogg-Rogers, Science Communication Unit, University of the West of England, Coldharbour Lane, Frenchay, Bristol, BS16 1QY. Bristol, UK.

Email: laura.foggrogers@uwe.ac.uk

Implications for Rehabilitation

- Choral Singing Therapy (CST) is sought out by people with stroke and PD to help self-manage symptoms of their condition.
- Participation is perceived as an enjoyable activity which improves mood, voice, and language symptoms.
- CST may enable access to specialist music therapy and speech language therapy protocols within community frameworks.

Abstract

Purpose: People with stroke or Parkinson's disease (PD) live with reduced mood, social participation, and quality of life (QOL). Communication difficulties affect 90% of people with PD (dysarthria) and over 33% of people with stroke (aphasia). These consequences are disabling in many ways. However, as singing is typically still possible, its therapeutic use is of increasing interest. This paper explores the experiences of and factors influencing participation in Choral Singing Therapy (CST) by people with stroke or PD and their significant others.

Method: Participants (eight people with stroke, six with PD) were recruited from a community music therapy choir running CST. Significant others (seven for stroke, two for PD) were also recruited. Supported communication methods were used as needed to undertake semi-structured interviews (total $N = 23$).

Results: Thematic analysis indicated participants had many unmet needs associated with their condition, which motivated them to explore self-management options. CST participation was described as an enjoyable social activity, and participation was perceived as improving mood, language, breathing, and voice.

Conclusions: Choral singing was perceived by people with stroke and PD to help them self-manage some of the consequences of their condition, including social isolation, low mood, and communication difficulties.

Keywords

Stroke, Parkinson's disease, aphasia, dysarthria, Choir, self-management.

Introduction

Stroke is a leading cause of adult disability worldwide, with an estimated 33 million stroke survivors [1]. Aphasia is a language disorder limiting the ability of up to one-third of stroke survivors to access, use, and understand words [2]. Co-morbid motor speech problems include apraxia of speech and dysarthria, causing difficulty speaking, poor voice quality, imprecise articulation, and reduced perception/production of speech prosody [3].

Parkinson's Disease (PD) is one of the most common neurological conditions with over 7 million people affected worldwide [4]. Movement symptoms in this progressive, neurodegenerative disorder can be managed with medication [5], however symptoms not controlled by medication, such as low mood and voice problems, may have a more negative effect on quality of life (QOL) with PD [6]. Ninety per cent of people with PD develop hypokinetic dysarthria [7], resulting in weakened respiration, short rushes of speech, reduced loudness, voice tremor, altered voice quality, imprecise articulation, and reduced pitch inflection (dysprosody) [8].

Voice and communication difficulties limit the ability and confidence of people with stroke or PD to participate in conversation and society, potentially isolating them from family, friends, and activities [9,10]. Reduced participation is a risk factor for lower QOL post-stroke and in PD [11–13], and is associated with increased incidence of depression [14–16]. Improvements in communication abilities could slow this reduction in QOL and help people with chronic symptoms of stroke or PD to participate meaningfully in society [17–19]. Speech language therapy programmes exist for people with PD [20] and stroke [21] but access to them is limited by high costs and limited availability of therapists [2,20]. While short-term speech language therapy after acute stroke is generally provided, long-term care

for people with stroke or PD is not routine, resulting in many unmet needs [22–24]. New approaches are needed, which are low-cost, person-centred, and easily accessible, to enhance treatment provision and enable long-term self-management of chronic conditions [25,26].

Choral Singing Therapy as a new approach to enhance living with stroke or PD

Group singing may offer an enjoyable, accessible, therapeutic adjunct to traditional speech language therapies for people living with the chronic effects of stroke or PD [27]. Singing, like speaking, is innate to all human societies [28], with neuroscience imaging studies indicating overlap between singing and speaking brain networks [29]. Singing employs greater neural circuitry [30,31], which may be preserved following a stroke [32]; indeed people with aphasia can often sing despite an inability to speak [33]. Small-scale singing studies with stroke survivors show improved mood [34,35], QOL [36], neuroplasticity [37], and word production [36,38]. Choral singing may also prevent voice decline [39] and improve QOL in PD [18]. Small-scale choral studies with PD have shown improvements in QOL [40], speech intelligibility [41], breath control, and prosody [42]. Large-scale studies of choir participation with healthy older adults indicate improved QOL [43,44], social engagement [45,46], mood [47], immune functioning [48], and overall health [49].

We developed a treatment protocol (Choral Singing Therapy, (CST)) drawing on prior neuroscience research, speech language therapy, therapeutic singing principles, and choral practices [27,50]. We selected a mixed population to enable community group interaction facilitated by therapist support, based on recommendations from Community Music Therapy [51]. In CST, people with different neurological conditions are supported to sing alongside their significant others to facilitate a community focus [52], maximising use of therapist time [53], and possibly enhancing participation, connectedness and creative flow [18,54]. As part of a project investigating the feasibility of CST, we conducted a qualitative evaluation of

factors influencing participation in CST, and experiences of taking part in CST, among people with stroke and PD living in the community.

Method

Ethics

The study was approved by the University of Auckland Human Participants Ethics Committee, reference number 2011/327. Supported communication methods [3] were used to ascertain voluntary, informed consent from people with varied symptoms and communication abilities. While these methods are aimed at people with aphasia, they enhance all aspects of communication, not just language [55], and so also supported people with PD. Spoken interactions were supported by written resources, using short, simple sentences with highly salient vocabulary and indicative pictures [56,57]. Written materials included Participant Information Sheets (PIS), consent forms, questionnaires and interview questions.

Study design

We conducted qualitative descriptive research but also obtained quantitative measures of aphasia, PD, QOL and participation in order to help describe the study participants. A convenience sample was recruited from a regional choir in Auckland, New Zealand in 2011- at that time the only choir offering CST in New Zealand. The choir had about 25 regular members, comprising people with stroke, PD, dementia, and their significant others. A Registered Music Therapist led the choir with volunteers assisting with non-musical aspects. The methodology for establishing the choir [50] and the CST protocol have been discussed elsewhere [27]. The choir and CST had been launched two years previously; choir members varied in prior attendance from six months to two years.

People with stroke or PD (no exclusion criteria) participating in the choir, and their significant others (whether a participant or non-participant in the choir), were invited to take part in the study. As members of the research team, including the choir leader (AT) and organiser (LFR), were known to choir members, information on the study was provided by an unfamiliar research assistant (JL). The information was provided orally (in person at the choir), with supported communication PIS and Consent Forms provided to take home and return in their own time.

Qualitative semi-structured interviews were conducted using a question guide (Table 1). We aimed to elicit participant's experiences of factors influencing the choice to participate in CST and their experiences of participating. Interviews were conducted by the choir organiser and experienced interviewer (LFR) to enhance a supportive, familiar environment for participants. People with PD were interviewed separately from significant others (where nominated by participants) to encourage deep exploration of the topic without reticence expressing emotion [58]. People with stroke/aphasia were interviewed alongside significant others (where nominated) to foster supported conversation. An experienced speech language therapist (CM), trained in supported communication methods, was also present to facilitate the interview and note non-verbal communication and body language. Interviews were audio-recorded and transcribed, then supplemented with the notes from the speech language therapist on vocalisations, gestures and body language [59].

Table 1. Questions and prompts for the semi-structured interviews.

TOPIC	BASELINE PROBE QUESTION	FOLLOW-UP QUESTIONS
Icebreaker or Introduction	Tell me about yourself and your (health condition)?	How do you think your health has been over the past 12 weeks? How does your (health condition) affect you and your life?
Communication abilities	Tell me about your voice and your communication with others	Tell me about your voice and your speech now Tell me about your communication with others now Are there things that help your voice or your communication? What things do you do to help your communication abilities? Has anything changed over the past three months? Is there anything new that you have found in the past three months to help your voice?
Medical care	Tell me about the care you receive from your doctor and other health professionals?	What advice has your health professional given you about your voice or speech? Have you ever asked your doctor about health issues that concern you? Has anything changed with your medical care over the past three months?
General wellbeing	Can you tell me anything else about how your health affects your everyday life?	Do you have any problems in areas such as sleep, relationships, mood? Do you feel you can influence and change your health?
General perceptions of the choir	What do you think of the idea of a choir for people with (your health condition)?	What do your friends or family think about you being in a choir? Have your attitudes towards the choir changed? What do you think makes the choir work? Describe your perfect choir session.
Benefits of being in the choir	Why do you come to the choir?	Tell me about any changes you have seen in your overall health What impact has the choir had on your life? Tell me about any changes you have seen in your mood Tell me about any changes you have seen in your voice or speech
Barriers to being in the choir	What problems do you have from being in the choir? Tell me about any reasons you have heard from friends about why they wouldn't come	What do you think of the location? What do you think of the timing? What do you think of the mixed group of people with different health conditions? What do you think of the songs sung?

Quantitative measures were obtained to provide supporting information about the study participants. Participants were assessed for aphasia severity with the Western Aphasia Battery (WAB-R) [60]. PD motor experiences were assessed with Part II of the Movement Disorder Society Unified Parkinson's Disease Rating Scale (MDS-UPDRS) [61]. Health-related QOL was measured using the World Health Organization Quality of Life brief scale (WHOQOL-BREF) [62] and the add-on module WHOQOL-DIS, designed for adults with physical or intellectual disabilities [63]. Participation was measured using the Subjective Index of Physical and Social Outcomes (SIPSO), a questionnaire designed to measure the level of Fogg-Rogers et al. 2015. Choral Singing Therapy following stroke and Parkinson's disease. Disability and Rehabilitation.

reintegration to a 'normal' lifestyle after stroke [64]. Although not specifically designed for a broad cross-section of patients, Trigg and Wood [65] suggest it has relevance for people with neurological disorders. All assessments were undertaken by a trained and independent research assistant.

Data analysis

Questionnaire and assessment scores were obtained for each participant and analysed according to the appropriate published methods. The interpretation and analysis of qualitative data followed the general inductive approach [66]. The transcribed qualitative data and non-verbal notes were read several times to enable familiarisation with the topics covered [67]. Where interviewed participants were accompanied by a significant other, comments were attributed either to the participant or to the significant other. Familiar gestures and vocal utterances were analysed to interpret the meaning of the conversation [59]. Our use of supported communication techniques meant that during the conversation, the researcher or significant other often interpreted what a participant with aphasia was trying to say, which the participant then confirmed or not. The supported conversation transcripts were analysed as 'frames of communication', whereby meaning was drawn out at a 'meta' level for the participant, rather than the actual semantic meaning attributed to the researcher or significant other [68].

Excerpts of conversation were then analysed inductively for codes in the context of, and in the same way as, the complete verbatim transcripts [66], using QSR International NVivo v.9 software [69]. Rigour was improved with secondary analysis and constant comparison of themes [70]. The themes and original transcripts were then reviewed by two other researchers to check that it represented a credible analysis of the data [22]. Where possible, the language of the participants was used to name the themes and codes [71]. A Manifest content analysis

was performed using a matrix analysis in NVivo, to test for theme frequency and variance according to participant characteristics. Relationships between the codes and themes were explored in a visual format using a temporal model [66]. While patients and significant others may have different perspectives on living with a condition, their experience is still of living with that disease; thus the data refer collectively to people with stroke, or people with PD.

Results

Participant characteristics

Fourteen choir members were recruited (a response rate of 78% from 18 choir members who met the recruitment criteria): eight had a stroke (four male); six had PD (four male); ages ranged from 32 to 77 years with a mean of 62.9 (*SD* 12.5) years. Participants had lived with their condition for a mean time of 5.8 (*SD* 3.8) years, ranging from three months to 12 years. Seven significant others for people with stroke (four female), and two (female) significant others for people with PD were also recruited. Their ages ranged from 55 to 80 years, with a mean age of 66.9 (*SD* 6.3) years. This larger overall sample of 23 people had an average age of 64.4 (*SD* 10.5) years and was almost equal in gender balance (48% male). People with stroke and their significant others numbered 17 and made up 65% of the sample. Table 2 shows participants' demographic and medical characteristics.

People with PD varied in their disease severity from 9 to 36 on the MDS-UPDRS scale, with a mean of 21.0 (*SD* 11.0) out of a possible 72 [61], denoting mild to moderate PD. All the people with stroke had some degree of communication difficulty according to the WAB-R [60] (despite some having a right-sided stroke, and other conditions including apraxia of speech and dysarthria), with Aphasia Quotients (AQ) ranging from 16 (severe) to 95 (mild), and a mean of 59.8 (*SD* 26.9), indicating moderate severity on average.

Table 2. Demographic and medical characteristics of participants.

PARTICIPANT	SEX	AGE IN YEARS	YEARS SINCE DIAGNOSIS	ETHNICITY	PARTICIPANT INFORMATION	MDS-UPDRS (1-72) <i>High score is more severe</i>	WAB AQ (1-100) <i>Low score is more severe</i>	WHOQOL-DIS OVERALL QOL (1-5) <i>High score is positive</i>	SIPSO (1-40) <i>High score is positive</i>
1	M	75	4	NZ European	Left-sided stroke and aphasia	n/a	16	4.0	17
1C	F	71	n/a	NZ European	Stroke significant other (attends choir)	n/a	n/a	n/a	n/a
2	M	65	7	NZ European	Unilateral stroke and dysarthria	n/a	62.3	5.0	25
2C	F	68	n/a	Asian - Filipino	Stroke significant other (attends choir)	n/a	n/a	n/a	n/a
4	M	43	11	NZ European	Left-sided stroke and aphasia	n/a	51.5	3.0	31
5	F	65	12	NZ European & Pacific Peoples	Left-sided stroke, aphasia and apraxia	n/a	57.6	4.0	18
5C	F	62	n/a	NZ European & Pacific Peoples	Stroke significant other (doesn't attend choir)	n/a	n/a	n/a	n/a
6	F	77	1	European	Left-sided stroke	n/a	94.9	3.5	33
6C	M	80	n/a	European	Stroke significant other (attends choir)	n/a	n/a	n/a	n/a
7	M	73	4	NZ European	Right-sided stroke and dysarthria	n/a	90.4	5.0	24
7C	F	66	n/a	NZ European	Stroke significant other (attends choir)	n/a	n/a	n/a	n/a
8	F	32	0.5	Asian - Filipino	Right-sided stroke and cognitive communication disorder	n/a	46.3	4.5	37
8C	M	58	n/a	NZ European	Stroke significant other (attends choir)	n/a	n/a	n/a	n/a
9	F	65	5	NZ European	Left-sided stroke and aphasia	n/a	16	4.5	36
9C	M	67	n/a	NZ European	Stroke significant other (doesn't attend choir)	n/a	n/a	n/a	n/a
10	M	66	4	NZ European	PD	14	n/a	4.0	23
10C	F	62	n/a	NZ European	PD significant other (doesn't attend choir)	n/a	n/a	n/a	n/a
11	F	67	2	NZ European	PD	9	n/a	5.0	17
12	M	68	7	NZ European	PD and dysarthria	36	n/a	2.5	30
12C	F	66	n/a	NZ European	PD significant other (doesn't attend choir)	n/a	n/a	n/a	n/a
13	F	53	12	NZ European	PD	33	n/a	3.0	22
14	M	60	6	NZ European	PD	19	n/a	3.5	12
15	M	71	5	NZ European	PD	15	n/a	4.0	30
Participant Mean (SD)		62.9 (12.5)	5.8 (3.8)			21 (11.0)	59.8 (26.9)	3.96 (0.83)	25.36 (7.71)

Note: Participants were only tested with the communication scale relevant to their condition. Significant others were not tested, hence the n/a results.

The constructs of QOL and participation provide quantitative measures that reflect some aspects of the experience of participation in CST. There was a trend for the mean score of all QOL domains except Social to be higher than the normative data. The WHOQOL-DIS Overall QOL of 3.96 (*SD* 0.83) was higher than the published European data mean of 3.08 for people with disability [63], as seen in Table 3. The SIPSO mean score of 27.58 (*SD* 6.75) was very similar to published scores for stroke survivors (mean 27, interquartile range 17.0-34.5) [64] (Table 3).

Table 3. WHOQOL and SIPSO data for the CST participants and published comparisons.

PARTICIPANTS	MEAN WHOQOL-DIS							SIPSO
	<i>Scores out of 5, a higher score indicates that the QOL domain is scored more highly [62].</i>							<i>Scores out of 40, a higher score indicates participation is scored more highly [63].</i>
	Overall QOL	General health	Physical	Psychological	Social	Environment	Disability	SIPSO
Stroke group mean (<i>SD</i>)	4.14 (0.85)	3.86 (0.38)	3.49 (0.49)	3.87 (0.57)	3.86 (0.67)	3.92 (0.56)	3.71 (0.55)	26.07 (8.65)
PD group mean (<i>SD</i>)	3.75 (0.82)	2.92 (1.16)	3.36 (0.56)	3.49 (0.45)	3.44 (0.44)	3.64 (0.42)	3.77 (0.47)	29.33 (3.54)
Total CST sample mean (<i>SD</i>)	3.96 (0.83)	3.42 (0.93)	3.43 (0.50)	3.69 (0.53)	3.67 (0.60)	3.79 (0.50)	3.74 (0.50)	27.58 (6.75)
Published sample mean	3.08	2.74	2.99	3.17	3.34	3.23	3.28	27

Themes

The four inductive themes and sub-codes indicate the choir members' *experience of their condition*, their subsequent *needs*, their *experience of choir*, and *perceived therapeutic benefits*. The codes referenced by each group (stroke or PD) are shown in Table 4 to indicate themes common to each condition. The themes pertinent to the research aims are summarised, below with participant numbers used to link quotes to their participant characteristics (table 2). Figure 1 depicts a model that suggests relationships between the themes.

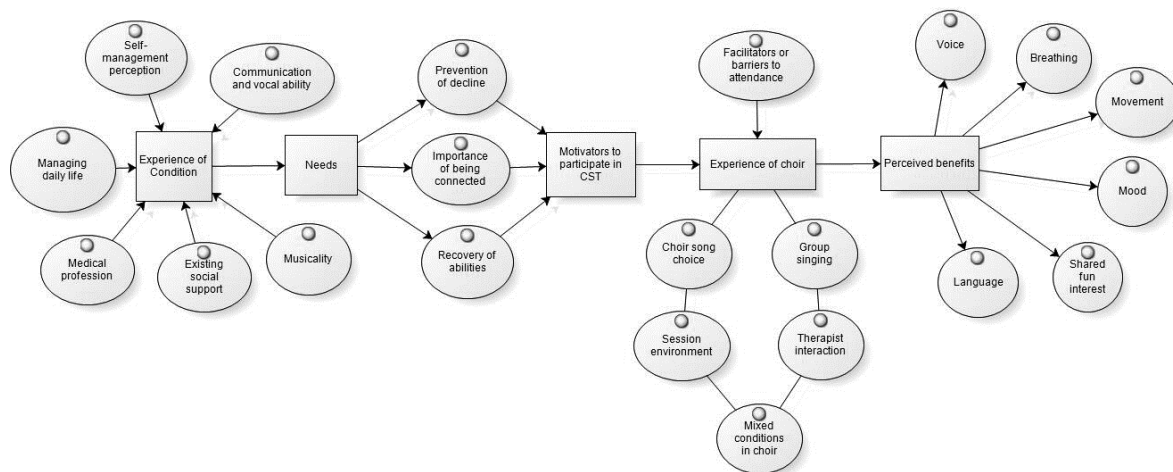


Figure 1. A model depicting the factors influencing participation in CST.

Table 4. Themes describing the motivations for and experience of participation in CST.

THEME	CODE	Referenced by people living with stroke	Referenced by people living with PD
Experience of their condition: Fine, and then, bang, no more	1.1 Managing daily life	90	64
	1.2 Existing social support	48	11
	1.3 Communication and vocal ability	107	41
	1.4 Self-management perception	57	48
	1.5 Medical profession	43	30
Needs: Seeking a therapy	2.1 Importance of being connected	38	35
	2.2 Musicality	39	40
	2.3 Prevention of decline	0	43
	2.4 Recovery of abilities	47	6
Experience of choir: Wonderful, wonderful, wonderful!	3.1 Barriers and facilitators to attendance	38	35
	3.2 Session environment	8	20
	3.3 Mixed neurological conditions in choir	18	33
	3.4 Therapist interaction	6	32
	3.5 Group singing	34	54
	3.6 Song choice	33	30
Perceived therapeutic benefits: New abilities and new connections	4.1 Shared fun interest	32	23
	4.2 Mood	27	47
	4.3 Voice	6	34
	4.4 Breathing	2	7
	4.5 Movement	0	4
	4.6 Language	58	4

Note: Codes with a marked difference between references by condition are in bold

Theme 1: Experience of their condition: Fine, and then, bang, no more

Participants experienced severe functional and social impairments as a result of their condition, consistent with what has been described in the literature [3,6,9,10].

1.1 Managing daily life

Many of the participants had physical difficulties; including hemiparesis, aphasia and epilepsy following stroke; and movement, mood, speaking and sleeping difficulties in PD. All participants took medication to prevent further attacks (stroke) or limit movement and other symptoms (PD).

15 (PD participant, male, age 71): Well it's changed my whole life... With Parkinson's you think ahead [about] what I have to do. It slows you down. It's a damn nuisance (laughter).

5 (Stroke participant, female, age 65): Fine and everything fine and bang. Now, dive, no more, fishing no more, yacht... [swipes hand to indicate that it is over].

1.2 Existing social support

Significant others and participants indicated major life changes to family roles, employment, and socialising. When detailing these symptoms, interviewees appeared to experience sadness at losing activities in which they used to be able to take part.

Researcher (R): So before the stroke?

5 (Stroke participant, female, age 65): Well before, (pause) well I was quite, like is, like is (pause)

R: Like what?

5: (pause) Like you.

R: So like everybody.

5: Yeah.

R: Before? And now?

5: Now? I have got a life, (pause) it's life. Oh... [sighs and looks down]

1C (Stroke significant other, female, age 71): Well you did a lot of other things, do you remember going to the movies, you often went to the movies?

1 (Stroke participant, male, age 75): Mmm.

1C: You'd go to the pub with [a friend] on Friday nights.

1: *Mmm.*

1C: *We'd go to concerts and plays, we'd travel.*

1: *Ohhh.*

1C: *Well maybe this is too tragic. (laughter)*

12C (*Parkinson's significant other, female, age 66*): *I think the main thing is tiredness. Often we'll go out to friends and family and he'll sort of fall asleep (laughter). Not because he's really bored with the company but yeah, just tired sort of thing. So yeah, it's probably limited duties around the house.*

1.3 Communication and vocal ability

The nature of communication difficulties experienced was complex, with both stroke and PD participants experiencing voice and swallowing problems, word-finding language issues, and/or difficulty communicating with others.

14 (*PD participant, male, age 60*): *At times you can almost tell or feel that you're slurring your words or when you're mumbling. I guess you get a bit self-conscious which is understandable I guess.*

Researcher (R): *And describe what it's like when you're trying to tell someone something?*

6 (*Stroke participant, female, age 77*): *Oh, uh...(exasperated sigh)... and, "never mind".*

R: *How does it feel when that's happening?*

6: (*frustrated growling noise*)

R: *Angry?*

6: *Yes.*

R: *Frustrated?*

6: *Yes.*

1.4 Self-management perception and 1.5 Medical profession

While therapies for each condition differed, participants shared similar long-term goals to manage or improve their condition despite limited ongoing help from the medical profession.

Many were connected to other self-help groups such as local charities, and took part in community rehabilitation exercise programmes. Although the term 'self-management' was

not used, the aims expressed by the participants match this body of research [72].

Fogg-Rogers et al. 2015. Choral Singing Therapy following stroke and Parkinson's disease. Disability and Rehabilitation.

10 (PD participant, male, age 66): *I was always going to do something about it, whatever I had. Being, being an incurable brain disease didn't alter that at all.*

7 (Stroke significant other, male, age 77): *Well I'm hoping that things will get better for us rather than worse. You know, I get stronger and more able.*

11 (PD participant, female, age 67): *It's learning to manage it... a personal journey. And that's why I like these alternative, complementary therapies. You know they're like, not crutches, but a couple of walking sticks. One's the gym, one's the choir.*

Theme 2: Needs - Seeking a therapy

Prior experiences left participants with unmet needs and various motivations for attending CST.

2.1 Importance of being connected

Participants described the importance of participating in society for keeping well, both physically and mentally. They sought out opportunities to feel 'normal' and included in society despite their condition, and the choir proved a good fit.

13 (PD participant, female, age 53): *Maybe that's why I enjoy the choir so much because it's such a nice sort of positive, enjoyable thing to be able to do. That I can do, you know. Because there's lots of things that I could or have done but aren't that easy.*

7C (Stroke significant other, female, age 66): *Anything that takes them [people with stroke] out of their comfort zone is a really good thing. Anything, like the choir. I can just think of so many people that should've been going to that choir and they probably wouldn't leave the house.*

2.2 Musicality

Some people with PD had prior choir experience, but had felt that their voice quality prevented them from joining a regular choir. For stroke participants with aphasia, singing was additionally powerful as their only fluent form of communication.

5C (Stroke significant other, female, age 62): *Even though she can't speak, she could sing every song played.*

11 (PD participant, female, age 67): *Well, music suits everybody and language, communication, is such a vital part of life... And especially when it involves music because that's very, almost spiritual. Very meaningful and very satisfying.*

2.3 Prevention of decline

As PD is a degenerative condition, participants discussed their self-management aims for prevention of decline. They believed that vocal exercises and singing were therapeutic for their present and future voice quality.

11 (PD participant, female, age 67): *I know that our voices, people with Parkinson's voices are affected. ... So I come [to choir] to be prepared and to delay that, if it's going to happen, for as long as possible.*

2.4 Recovery of abilities

People with stroke emphasised their self-management aims for recovery of abilities, and discussed regaining language through practice and experience.

Researcher (R): So when you first went to choir, why were you going?

4 (Stroke participant, male, age 43): *Basically I just wanted to, talking [gestures to do more of it]*

R: So you thought it would be like a therapy?

4: *Yeah.*

R: Therapy or just opportunity to talk?

4: *No, no therapy. Because you guys [interpreted as therapists] are here so you know what to talk.*

R: So you thought the singing would help your talking?

4: *Yeah. And I didn't worry if my singing was crap [sic] or good.*

Theme 3: Therapeutic process of choir - wonderful, wonderful, wonderful!

This theme described how CST works as a beneficial therapeutic modality, and encompassed *group singing, song choice, music therapist interaction, session environment*, and the nature

of *mixed neurological conditions in choir*. The resulting protocol for CST, along with ideas to reduce *barriers and facilitate attendance*, are discussed elsewhere [27].

Theme 4: Therapeutic benefits of choir - new abilities and new connections

Participants described their perceptions of how CST had improved their symptoms and met their needs, and therefore why they continued to attend the group.

4.1 Shared fun interest

The choir appeared to provide opportunities to meet people in a purposeful environment, where everyone, regardless of diagnosis or role, enjoyed making music. Participants and significant others reported a sense of achievement at developing a skill and helping others, in comparison with other failures.

12C (PD significant other, female, age 66): I think not only the singing and the exercises. I think it's the companionship too. I think it's a very social thing and he can see how it's helping other people as well as himself.

7C (Stroke significant other, female, age 66): It's lovely just to sit in there singing away too, and just to look around and watch everybody participating at their own level, in their own way, with no pressure. They don't have to do 10 of those or eight of those. And it's such a level playing field. It's a joy to behold, honestly.

4.2 Mood

Most participants asserted that CST boosted their mood, but this was expanded on particularly by women and people living with PD. The potential mechanisms were explored through the codes of a *shared fun interest*, indulging their *musicality*, taking part in *group singing*, and certain *song choices*; with participants asserting they felt happy while anticipating and attending choir.

15 (PD participant, male, age 71): There's a feel-good quality to singing. Keeping me in a better frame of mind so that I don't, less likely to get depressed or less depressed.

Researcher(R): So what do you enjoy?

5 (Stroke participant, female, age 65): Singing, and, "Hi, how are you?" and everything.

R: So meeting people?

5: Yes. And singing and laugh sometimes.

13 (PD participant, female, age 53): Singing does, it's good for your mood and you know if you can do something you enjoy it's good to be able to have that opportunity to do it.

4.3 Voice

People with dysarthria, whether from stroke or PD, indicated that attending choir had improved their swallowing, voice quality, loudness, inflection (prosody), and confidence. While the extent varied, all agreed that focusing on their voice was beneficial for their confidence in communicating with others.

12C (PD significant other, female, age 66): [His voice] was sort of on the borderline of being almost a monotone but now it's got the, you know, the... ups and downs.... For a long time we never went out or did anything, but now he's happy to socialize.

10 (PD participant, male, age 66): It's probably quite good if I come more or less regularly to singing because I'm exercising my voice and being aware of it which is good.

7 (Stroke participant, male, age 73): I think it's helped me lift my voice a bit... As opposed to, as [significant other] will tell you, you know, my voice used to sound quite different before I had the stroke. So, you know, I think it does help me just a little bit.

4.4 Breathing and 4.5 Movement

Participants all positively mentioned the skills needed to sing in a group, including focusing on posture, watching the therapist for cues, and increasing volume and phonation through breathing control. Some people with PD described how they entrained their movements to the musical beat. Rhythm was also useful for people with aphasia to learn and produce new songs.

Fogg-Rogers et al. 2015. Choral Singing Therapy following stroke and Parkinson's disease. Disability and Rehabilitation.

15 (PD participant, male, age 71): *Well I'm more aware of when they say take a deep breath and you do sort of warm up exercises and things like that; because I was an asthmatic I used to run short of breath.*

5 (Stroke participant, female, age 65): *And sometimes... [participant uses gaze, alternating between two people, to convey the importance of watching the music therapist]*

R: *If you watch her?*

5: *Yes, and sometimes... [indicates words or song coming out of her mouth]*

4.6 Language

All people with stroke agreed they could produce words in song almost fluently, even though it was difficult for them to produce words in speech. While participants sometimes got lost while singing, as they could not read new words quickly enough, they indicated they could join in again when they picked up the words or chorus. People with stroke also stated that as well as singing familiar songs, they could learn new songs.

Researcher (R): *Can you learn it?*

4 (Stroke participant, male, age 43): *Yeah, but it just takes...[indicates hand turning over for time]*

R: *Takes long?*

4: *Yeah. That's I think with everyone, if you heard it, no problems. Like [other stroke choir member], she knows everyone [interpreted as all the songs]. (laughter)*

However, while this word production did not always generalise to everyday speech, some people indicated that their language skills had improved since participating in CST. This included improved word finding, conversational fluency, and confidence.

4 (Stroke participant, male, age 43): *Definitely, because I've found that my speaking has definitely [become] better, you know... Like I've had, you know, [gestures for more - interpreted as 'other therapies'] and the only thing, I had just different was this one, so they sort of like, if, must be that one.*

5C (Stroke significant other, female, age 62): *Yes, we've definitely noticed that [stroke participant's] speech is improved, hasn't it?*

5 (Stroke participant, female, age 65): *Yes.*

5C: *All of a sudden she's saying words that I honestly didn't know she could say. And so, we really think it's made a big difference.*

Discussion

This is the first study to explore the factors influencing participation and the resulting experiences of CST by people with stroke or PD. Qualitative interviews indicated that participants had many unmet needs, and were looking for long-term self-management options. They selected CST with the hope of preventing decline (PD) or recovering their abilities (stroke). Participation was perceived to improve social isolation, mood, breathing, swallowing, language, and voice.

Communication difficulties and personal recovery

Participants described physical and communication impairments typical of stroke and PD [7,73], which medication did not fully control [24,74]. Quantitative measures of communication abilities indicated the sample had moderate aphasia and mild to moderate PD. As identified in previous research, participants experienced reduced ability to participate in all spheres of life as a result of their condition [75–77]. Previous studies also show the potential impact of this reduced participation on lowered QOL [78] and mood [79,80].

The CST programme appeared to enable each individual to work through their own model of personal recovery [81] and self-management of their condition [53]; people with PD aimed for ‘prevention of decline’ while people with stroke aimed for ‘recovery of abilities’. People with PD wanted to maintain their optimum function for as long as possible, manage symptoms, and slow further decline; these being recognised goals of neurorehabilitation [26,82]. People with stroke, in common with other studies [25,83,84], hoped to regain lost communication function to allow meaningful social participation.

All these different motivations co-existed within one mixed group. This supports the argument, within the Community Music Therapy literature, for communities of interest

brought together by their aims, rather than their condition [52]. Self-management literature [53,85] reinforces the notion that within these communities the patient is the expert on their chronic condition, and should share responsibility with their medical provider to self-tailor interventions to their own needs. Access to a specialist therapist is critical to enact this self-management [86], and so combining therapy for people with similar symptoms is more cost-effective for the community as a whole [53]. Previous studies investigating the impact of choral singing for people with PD or stroke have not mixed people with different neurological conditions [34,42]. Rather than undermining therapeutic intentions, people found the mixed community setting helpful. Indeed, people with stroke or PD discussed helping others within the group with different conditions to themselves [27]. Helping others and contributing to society are proposed as higher levels of participation, and are therefore also therapeutic activities [54].

QOL in group singing

Singing is accessible to people with PD and stroke. Choir members recognised the special qualities of music enabling group participation [87], which their disability might otherwise prevent. This encouraged less able singers to participate through listening and imitation, and thus the group as a whole acted as a therapeutic stimulus. Similar meaningful, creative, and collaborative endeavours [88] have been shown to improve a sense of life control and self-esteem [89]. Recent research has also indicated that people with PD taking dopaminergic drugs may demonstrate enhanced visual and verbal creativity [90], so choral singing may offer an outlet for this.

Quantitative measures indicated that participants had similar SIPSO scores to normative data [64], but tended to have higher QOL in most domains of the WHOQOL-DIS compared to published data [63]. As people with stroke and PD experiencing communication difficulties

and mood problems tend to have reduced QOL [91], it is perhaps surprising that CST participants have higher self-rated QOL than a large international sample of other people with disabilities. This is consistent with large-scale studies involving healthy adult members of international choirs, who also reported higher scores on the WHOQOL-BREF than the norm [43].

Therapeutic benefits of CST

Improved mood was highlighted as a key benefit of CST participation, particularly by women and people with PD. It was experienced while listening to music and singing [92] but also following choir participation, which may be generated by hormonal and related immune changes [18,48]. This is consistent with literature on music therapy for stroke [35,37], along with a similar study involving choral singing solely for people with aphasia [34]. However, only one study to date has indicated that music therapy showed improved mood in PD [93].

Improvements in voice were noted by people with dysarthria (stroke and PD), including loudness, tone, inflection (prosody), and confidence; they also felt more understood in conversation, consistent with other small-scale choral studies [41,42,93,94]. Improved breathing appeared to be another benefit, consistent with earlier small-scale choral studies for people with PD [42,93].

People with severe aphasia described near fluent word finding while singing, consistent with other literature [33]. Participants described how they watched the choir leader for cues, and used group flow and rhythm to entrain to melody and words; similar to other therapies suggested for Broca's aphasia and dysarthria [95,96]. This lends support for rhythm as a therapeutic agent in music [18,97], rhythmic cueing for word production in song [36], and the benefits of singing in synchrony with an auditory model (provided by the choir and choir leader) [98].

Fogg-Rogers et al. 2015. Choral Singing Therapy following stroke and Parkinson's disease. Disability and Rehabilitation.

While the descriptions varied, some people with aphasia described how confidence, fluency, and vocabulary in conversation had improved since participating in CST. Theoretically, singing may encourage neural functional reorganisation to recover language following aphasia [84]. However, evidence for this effect is limited [99], and has not yet been demonstrated with choral singing. While this is subjective evidence, it would be interesting to investigate further whether choral singing can improve language abilities for people with aphasia.

Limitations

While the interviews strongly suggest that participation in CST can support self-management of the symptoms of chronic conditions like stroke and PD, this finding is based on subjective accounts from people living with stroke or PD rather than objective scientific evidence. However, the strength of the evidence provided by qualitative research compared with quantitative research cannot be easily compared because the methodologies each address fundamentally different questions and there is no agreement on the standard against which to make comparisons [100]. Our personal interviews provide powerful information on the perceived impact and meaning of creative therapies to participants themselves [88].

These interviews were collected in different styles to facilitate communication with people with different needs. However, this meant analysis varied, as comments in the stroke interviews were subject to interpretation as frames of conversation by the researcher. While this means the interview data were not treated the same throughout the analysis, it was a pragmatic decision to enable people with aphasia to participate in the interviews. In reporting the frequency of codes we recognize that frequency is not equivalent to importance, since for

example infrequent codes can still be important. We have taken this into account in our analysis.

We used the SIPSO questionnaire developed for stroke rather than PD as we could not find a generic, easily understood participation measure at the time the study was developed. Future studies could consider the use of alternative assessments of activities and participation such as the Impact on Participation and Autonomy (IPA) [101]. Also, this was an exploratory study and participants were already receiving CST before recruitment limiting the ability to interpret how their QOL, participation, and opinions had changed since initial attendance.

Conclusions

CST was found to be an enjoyable music therapy intervention that was considered inclusive by people with stroke, PD, and their significant others. It was sought by participants as a way to self-manage some symptoms of the effects of chronic stroke and PD in the community. It was perceived by choir members and their significant others to help improve or maintain communication abilities, thus impacting on mood and QOL for people who might otherwise be socially isolated. CST may therefore enable access to specialist music therapy and speech language therapy protocols within community frameworks. This qualitative study could inform quantitative research to evaluate benefits and costs of CST for people with stroke and PD.

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Declaration of Interest

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