

Parkinson's spouse caregivers and group singing

“We’re pushing back”: Group singing, social identity and caring for a spouse with Parkinson’s

Abstract

This article explores spouse caregivers’ experiences of a community singing group for people with Parkinson’s disease and their carers. Previous studies have demonstrated the health and wellbeing benefits of group singing for a range of populations including people with Parkinson’s disease, however, caregivers’ experiences of these same groups remain under-researched. Semi-structured interviews were conducted with six spouse caregivers who regularly attended a joint caregiver/care recipient Parkinson’s singing group for a minimum period of 18 months. Interpretative Phenomenological Analysis was used to explore and interpret caregivers’ experiences of group singing. Using the “social cure approach” as a theoretical lens in the later stages of analysis, findings demonstrated that group singing created a social identity which helped fulfil caregivers’ basic psychological needs for belonging, meaning and purpose, social support and agency within the marital relationship. Caregivers’ new and valued social identity helped counteract the diminishing effects of life impacted by Parkinson’s. These findings support the recognition and further understanding of group singing as an accessible and cost-effective community-based psychosocial intervention for Parkinson’s spouse caregivers.

Keywords

spouse caregivers, social cure approach, singing experiences, group singing, IPA

Parkinson’s disease is an incurable, progressive, debilitating neurological disorder. Motor symptoms include tremor, Bradykinesia (slow movement), muscle rigidity, and later in the disease, postural instability (Parkinson’s Australia, 2020a). Non-motor symptoms include pain, sensory changes, gastrointestinal issues, depression, anxiety, apathy, cognitive difficulties, and sleep disturbance (Parkinson’s Australia, 2020a). Whilst the incidence of Parkinson’s increases significantly with age (Van Den Eeden et al., 2003), 20% of diagnoses are in fact working-aged people, including many in their 30s and 40s (Parkinson’s Australia, 2020b).

Parkinson’s is the fastest growing neurological disease globally. The past generation has seen a doubling in the prevalence of Parkinson’s worldwide, and with ageing populations,

the future burden of the disease is predicted to increase substantially (Dorsey et al., 2018). This increasing prevalence is accompanied by growing numbers of people caring for people with Parkinson's. Care is most commonly undertaken informally by either a spouse or an adult child of the person with Parkinson's (Parrish et al., 2003; Schrag et al., 2006). Caring can adversely affect caregivers' health, social relationships and depression levels (Schrag et al., 2006; McLaughlin et al., 2011). The incidence of depression for Parkinson's caregivers is comparable to that found in caregivers for people with Alzheimer's disease (around 50%) (Schrag et al., 2006). Spouse caregivers can also experience stress on the marital relationship (Lyons et al., 2009). Commonly reported problems for spouse caregivers include disorganized domestic routines, diminished social life, challenges with taking holidays and disturbed sleep (Thommessen et al., 2002). Compounding these effects, the level of care required for a person living with Parkinson's PD—and caregiver strain—increases as the disease progresses with age (Carter et al., 1998; D'Amelio et al., 2009; Hand et al., 2019).

Understanding caregivers' experiences has “clinical and community relevance to support services that may improve [quality of life]” (Roland & Chappell, 2019, p. 257). For researchers, this means demonstrating how and why certain interventions work for particular participant groups in order to advocate for structural and policy support, so that funding can be strategically allocated for maximum impact (Fancourt, 2017).

Group singing for caregivers

Support for caregivers can take multiple forms, such as provision of respite care, education, training and psychological interventions. For a meta-review of the evidence relating to psychosocial interventions for caregivers see Parker et al. (2010). Increasingly, arts-based interventions are also being used to support caregivers' wellbeing. A growing body of research demonstrates that group singing can improve health and wellbeing for a range of adult populations (see Clift et al., 2010 for a systematic review; also Daykin et al., 2018). Active participation in social musical activities can confer health and wellbeing benefits on older people (Creech et al., 2013). Whilst research on the health and wellbeing benefits of group singing for people with Parkinson's is progressing apace (see Barnish et al., 2016 for a systematic review; e.g., Abell et al., 2017; Baird, 2018; Tamplin et al., 2019), less is known about the ways in which Parkinson's caregivers experience joint caregiver/care recipient singing groups.

Studies of caregivers for people with diseases other than Parkinson's provide a useful guide for the ways in which group singing and other arts-based interventions can support family caregivers' wellbeing (see Fancourt & Finn, 2019 for a summary). These studies have focused on caregivers for people with Alzheimer's disease and dementias (e.g. Rio, 2018; Clark et al., 2018), caregivers for people with cancer (e.g. Fancourt et al., 2019; Warran et al., 2019) and aphasia (e.g. Mantie-Kozlowski et al., 2018). Taking Alzheimer's disease and dementias as an example, research has demonstrated that group singing can:

- relieve caregiver strain and provide social support (Rio, 2018—music therapy support group which incorporated some group singing);
- create empathic friendships, enhance the relationship between caregiver and recipient and engender feelings of wellbeing in both parties (Clark et al., 2018—singing group run by credentialed music therapists);
- improve caregivers' mood, focus, relaxation and energy levels (Davidson & Almeida, 2014);
- facilitate better communication between caregiver and care recipient (Davidson & Fedele, 2011).

Clark et al. (2018) reported that participants identified with the group via shared understanding of circumstances and lack of judgment or stigma, and for some dyads, singing brought a new dimension to their relationship, or enabled them to continue a lifelong enjoyment of singing. Unadkat et al. (2017) found that effectively facilitated group singing promoted a sense of belonging and group identity, and conferred benefits on caregivers and people with dementia, both individually and as a couple (see also Osman et al., 2016 and an earlier pilot study by Camic et al., 2013). Given the benefits for caregivers demonstrated in these studies, exploring Parkinson's spouse caregivers' experiences of group singing provides an additional and important dimension to this body of research.

The social cure approach

Established theoretical frameworks can assist in explaining the processes by which group singing might support caregivers' wellbeing. For example, the social cure approach proposes that social identity is of vital importance to good (and poor) health, hypothesising that benefits flow to members of social groups to the extent that individuals identify with a particular group (Haslam et al., 2018). The approach draws on psychological theories of social identity (Tajfel & Turner, 1979) and self-categorisation (Turner et al., 1987). These

theories, viewed together as the “social identity perspective”, “recognise that people’s individual characteristics and their group memberships play a significant role in shaping attitudes, values, beliefs, and behaviour” (Reynolds et al., p. 279). Social identity—as distinct from *personal* identity or a person’s sense of their own individuality—is theorised as “*internalised group membership* that serves to define a person’s sense of ‘who they are’ in a given context” (Haslam et al., 2018, p. 15, emphasis in original). Within the social cure approach, social identification is important to health because it is the necessary pre-condition to group-based interactions and behaviours which are experienced as “*purposeful and meaningful*” (Haslam et al., 2018, p. 17, emphasis in original). Social identity engenders:

- connection or belonging through feeling “psychologically close” to other people;
- a sense of meaning which helps people to act with passion and purpose;
- motivation to help and support those who share the identity;
- the ability to transcend hopelessness or powerlessness, and to build a stronger sense of personal control or agency.

Thus, social identity is a psychological resource in the form of belonging, meaning, social support and personal agency (Greenaway et al., 2016; Haslam et al., 2018). Ultimately, social identity is important to health and wellbeing because a strong sense of identification with the collective builds a stronger sense of self (Haslam et al., 2018).

Social identification can “cut both ways”—the nature and basis of social identities must be considered, as some social identities carry stigma (Cruwys et al., 2014a). For example, people with depression who identify with others suffering from mental illness may be prone to negative social influences (Cruwys & Gunaseelan, 2016). People with Parkinson’s and their caregivers can experience stigma associated with diagnosis as a “subjective symptom” of the disease (Maffoni et al., 2017) which impacts quality of life (Ma et al., 2016). However, others who are members of a group perceived to be stigmatised (e.g. drug “abusers”) may actively use this negative social identity to frame their own identity positively in opposition to it (Rødner, 2005—drug “users” cf. drug “abusers”). Thus, any social identification derived from a Parkinson’s-related group activity (such as a singing group) must be interrogated to understand the precise nature and basis of the identification.

The social cure approach has been used as a lens in recent research on arts, health and wellbeing. Williams, Dingle, Calligeros, et al. (2019) explored the ways in which group

participation in creative writing and singing groups fulfilled the psychological needs of participants with chronic mental health conditions. Group identification created a sense of belonging, support, self-efficacy purpose and positive emotions for participants (see earlier Dingle et al., 2012). A study by Williams, Dingle, Jetten, et al. (2019) found that for adults with chronic mental health conditions, there was a significant relationship between an individual's strength of group identification (with either a creative writing or singing group) and improvement in their mental wellbeing (see also Tarrant et al., 2016 and Tarrant et al., 2018 re designing interventions which "actively nurture" and develop social identity in aphasia singing groups). Williams, Dingle, Jetten, et al. (2019) review other studies which have also shown that mere participation in arts-based groups is not enough to confer benefits on members—participants must strongly identify with the group and view group identity as an aspect of the self (e.g. Cruwys et al., 2014b; see also Davidson & Faulkner, 2016 for case studies on the different ways singers identify with a choir or singing group).

This study aims to contribute further to this line of inquiry by exploring spouse caregivers' experiences of group singing for Parkinson's through the theoretical lens of the social cure approach: "How do participants experience group singing? Does group participation create a social identity which is a psychological resource for spouse caregivers?"

Study context

A local community-based Parkinson's singing group—"Park 'n Songs" (established in April 2017)—provided the opportunity to explore caregivers' experiences and whether group singing created a new social identity for caregivers. Group sessions are facilitated by two community musicians (either together or individually) and supported by a piano accompanist. Sessions begin with stretching, breathing and vocal exercises with movements (10-15 minutes) and incorporate activities such as tongue-twisters, rhythmic activities, fun and humour. Singing popular songs forms the bulk of the session (45-60 minutes). Lyrics are projected onto a screen enabling singers to look up (rather than down at song books), to engage with facilitator/s, and to perform movements. Some singers play simple percussion parts, if they wish. Singing is usually in unison with the exception of rounds, as harmony singing tends to make members feel anxious. Accompaniment varies from piano, to guitar and ukulele, depending on facilitators' availability. Afterwards, members enjoy afternoon tea

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and socialising (approx. 30 minutes). Sessions usually run between one and a half to two hours, total.

Method

Research design

Interpretative Phenomenological Analysis (IPA) (Smith, Flowers, & Larkin, 2009) is concerned with meaning-making for both researcher and participants (Smith, 2019). IPA employs a double hermeneutic in that the researcher interprets the participants' interpretations of experience (Smith et al., 2009). For participants, this meaning-making involves reflection upon either discrete or ongoing life events or experiences (Smith, 2019). For researchers, meaning-making requires an interpretation of what is happening to participants (Smith, 2019). Recently, Smith (2019) has provided a "theoretically informed and empirically grounded extension to IPA" (p. 166). Drawing on the theoretical writing of Taylor (1985), Smith argues that meaning occurs "within a field" and not in a vacuum; therefore when we make meaning, we do so as individuals in relation to the phenomenon itself and within a specific context. These theoretical ideas are then linked to previous IPA studies on pain to gain a "close to personal experience" of pain (Smith, 2019, p. 180). IPA is first and foremost concerned with an individual's (reflective) experiences of a particular phenomenon and the meaning derived from those experiences; these experiences are interpreted by the researcher, and this interpretation can be informed by existing theory in the later stages of analysis (Larkin et al., 2006; Smith, et al., 2009; see e.g., Oakland et al., 2012; Smith, 2019). In this study, the researcher used the social cure approach as a theoretical frame in the later stages of analysis to explore whether singing group participation created a new social identity for Parkinson's spouse caregivers.

Participants

Whilst one member attends the group with various formal caregivers, all other caregivers in the group are the spouse of a person with Parkinson's. The formal caregivers for this group member were not included in the study, as the nature of the formal caring relationship was considered too dissimilar to a spousal relationship for inclusion in an IPA study, which requires a certain level of homogeneity in the participant group (Smith et al., 2009). The term "spouse" (rather than the broader "partner") has been used as all participants were in cisgender married relationships. Participants were purposively sampled according to criteria: participation since commencement of the singing group, and a willingness to speak

in detail about their experiences (participants were known to the researcher in her capacity as university liaison for the group). All caregivers approached by the researcher to participate agreed to an interview. Signed consent forms were provided to the researcher before interviews commenced. Pseudonyms were chosen by each participant for the reporting of findings.

Five out of the six participants have attended the group weekly (with holiday breaks) for two and a half years (from April 2017 to November 2019). There have been approximately 30 sessions annually during that time. According to group rolls, sessions attract on average 20 to 30 attendees. One participant (Ann) attended regularly from the group's inception for 18 months before leaving the group due to increasing care burdens, and another (Alex2) continues to attend the group after the passing of his wife in May 2019. Details of each participant and their interviews are summarised in Table 1.

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Pseudonym	Gender	Age	Relationship to person with Parkinson's	Approx. time since Parkinson's diagnosis	Primary carer	Respite	Date of interview	Approx. time with group	Notes	Interview length
Lily	F	69	Wife	11	Y	N	8 August	2.5 years		40:38
Island Girl	F	78	Wife	17 years	Y	N	25 October	2.5 years		25:04
Dave	M	78	Husband	7 years	Y	N	1 November	2.5 years	Wife has dementia	24:01
Edward	M	72	Husband	13 years	Y	N	1 November	2.5 years		25:14
Ann	F	67	Wife	12 years	Y	Y	1 November	1.5 years	Left group due to caring responsibilities	25:20
Alex2	M	71	Husband	5 years	Y	N	6 November	2.5 years	Wife passed away May 2019; continues to attend group	22:41

Table 1: Participant and interview details

Data collection

Semi-structured interviews were conducted, recorded and transcribed by the researcher. Interviews took place either at the caregiver's home or at the researcher's office. Due to high care needs related to dementia (in addition to Parkinson's), in one case (Dave), the caregiver's wife was necessarily present for the interview. Table 2 outlines sample questions from the interview protocol. Interview questions were designed "to come at the research questions 'sideways'" using guidelines outlined by Smith et al. (2009) (p. 58)—questions were formulated to be "open and expansive" (p. 59) and to encourage fulsome responses. The questions moved from eliciting descriptive or narrative responses early in the interview towards encouraging more analytical responses later (Smith et al., 2009). Transcribed interviews were provided to participants for review with one participant (Edward) electing to make minor changes to expression.

What drew you to the singing group?
 At that time, were you thinking of the group as something for you as well as the person you cared for?
 How long have you been involved? How regularly?
 How do you experience the sessions? The afternoon tea? The singing itself?
 How much do you focus on yourself during the sessions? On your spouse?
 Do you see the group as something for you, your spouse, or both of you?
 How do you feel before, during, after the sessions?
 What role do the other people in the group play?
 What has it meant to you to be involved in the group?

Table 2: Example interview questions

Data-analytic strategies

IPA proceeded in accordance with the procedure outlined by Smith et al. (2009). All interviews were read twice for familiarisation. Each interview was then read again with initial noting in the margins regarding linguistic, conceptual or exploratory points of interest. The interview was then analysed to interpret and construct (from the noting commentary) emergent themes which closely reflected both the participant's experiences and the researcher's emerging interpretation of those experiences (Smith et al., 2009). Emergent themes were compiled into a Microsoft Word document. Using abstraction to cluster "like" themes together, the analysis then identified connections across emergent themes. These steps were repeated for each case. Convergent themes were then identified across cases and superordinate and subordinate themes constructed for the data set. The earlier stages of analysis for each case were inductive and focused on remaining as close as possible to participants' experiences without recourse to existing theory (see also Oakland et al., 2012).

During the later stages of analysis, the social cure approach was used as a theoretical lens to explore whether participants' had experienced a shift in identity through group participation. Whilst other themes were constructed from the data (including themes related to personal identity, enjoyment/positive emotions, and mood regulation), findings reported here are confined to one superordinate theme relevant to the research questions and theoretical frame. It is acknowledged that the analysis is limited by the sole author/researcher's subjective interpretation of the data, however, analysis and interpretation were undertaken with reference to IPA quality criteria (Smith, 2011). This is discussed further below as a limitation of the study. Subordinate themes are supported by extracts from at least three participants (Smith, 2011; see Table 3).

Findings

Superordinate theme: The singing group creates a new social identity

Viewing participants' experiences through the lens of the social cure approach in the later stages of IPA revealed that singing group participation created a new social identity for participants, which was a psychological resource in the form of connection, meaning, support and agency (each of these is discussed as a subordinate theme below).

Social identity was interpreted by the researcher as something "created" or "given" to participants by group membership and participation. There was an overarching sense from participants' metaphorical language that the group was experienced as "giving", whereas Parkinson's was experienced as "taking". The singing group counteracted the "diminishing" effects of Parkinson's. According to Ann, Lily and Edward, caring for someone with Parkinson's can feel like life is "closing in", that life's opportunities are narrowing and fading from view. Ann describes the impact of Parkinson's on her life: "my life has gone from large to this very small life now." Lily identifies the group as one opportunity that *hasn't* been taken away from her and her husband:

we just can't go and just walk in the park anymore, or do some of the things that we may well have done... So as some of those things, close their doors, even though I might still be able to go to them, to go together, I mean, you know, the choir will become even more important.

Where Parkinson's has stolen many of the simple pleasures in life, Lily perceives the group as giving something back to her relationship with her husband—it is something they continue to enjoy *together*. For Edward, participation in the group has meant that the "gravity or drift" into loneliness and isolation has not been as strong as it would have been without the group:

Life can be fairly empty. I think the problem is that, whether it's deafness or any illness, you can get sidelined and you can become insular. It's meant that the gravity or drift into that has not been as strong. And that we're pushing back against those things, and re-engaging with people, and relationships and in a situation which was otherwise just closing in, diminishing. So, [the group means] a lot because, I don't, nobody likes what happens to you. And it's very hard to reverse that trend when you're by yourself.

Edward's choice of metaphor is revealing. Edward experiences the consequences of Parkinson's as inevitable as gravity—Parkinson's is an incurable disease, a force which ultimately cannot be resisted. However, the group is a way to at least in part, and for a time, to counteract that force. Edward and his wife are “pushing back against those things”—the group has given the couple a sense of power, agency and strength to resist the inevitable consequences of Parkinson's. Figure 1 provides a visual representation of the singing group creating a new social identity for spouse caregivers. The following discussion of subordinate themes demonstrates how social identification with the singing group enabled this “expansion” of identity by providing a new psychological resource for caregivers.

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Superordinate theme	Subordinate themes	Examples
The singing group creates a new social identity		The group creates a new social identity to compensate for some of what Parkinson's takes away: life with Parkinson's is a "very small life" (Ann); Parkinson's means things in life "close their doors" to you as a couple (Lily); "the gravity or drift" of Parkinson's is inevitable but not as strong because of the singing group (Edward)
	Belonging in the form of shared caring identity	we were all in the same boat (Island Girl); instant acceptance (Edward); automatic understanding (Lily); you can't get this in "normal society" (Dave); camaraderie among carers (Alex2); you know you're not alone (Ann)
	Social support	I can talk to them and they understand where I'm coming from (Island Girl); they're my friends (Alex2); they are extended family (Dave); more of a friendship group (Lily)
	A sense of purpose	Contributing a healthy voice to improve the singing group sound (Alex2); taking on additional caring role during sessions (Ann, Lily); starting the group (Lily); lending a practical hand (Edward)
	Agency within the marital relationship	We're pushing back [against Parkinson's] (Edward); the group is something for both of us (Alex2, Island Girl, Lily); seeing and enjoying spouse as someone <i>beyond</i> the disease (Dave, Alex2)

Table 3: Overview of themes with supporting examples

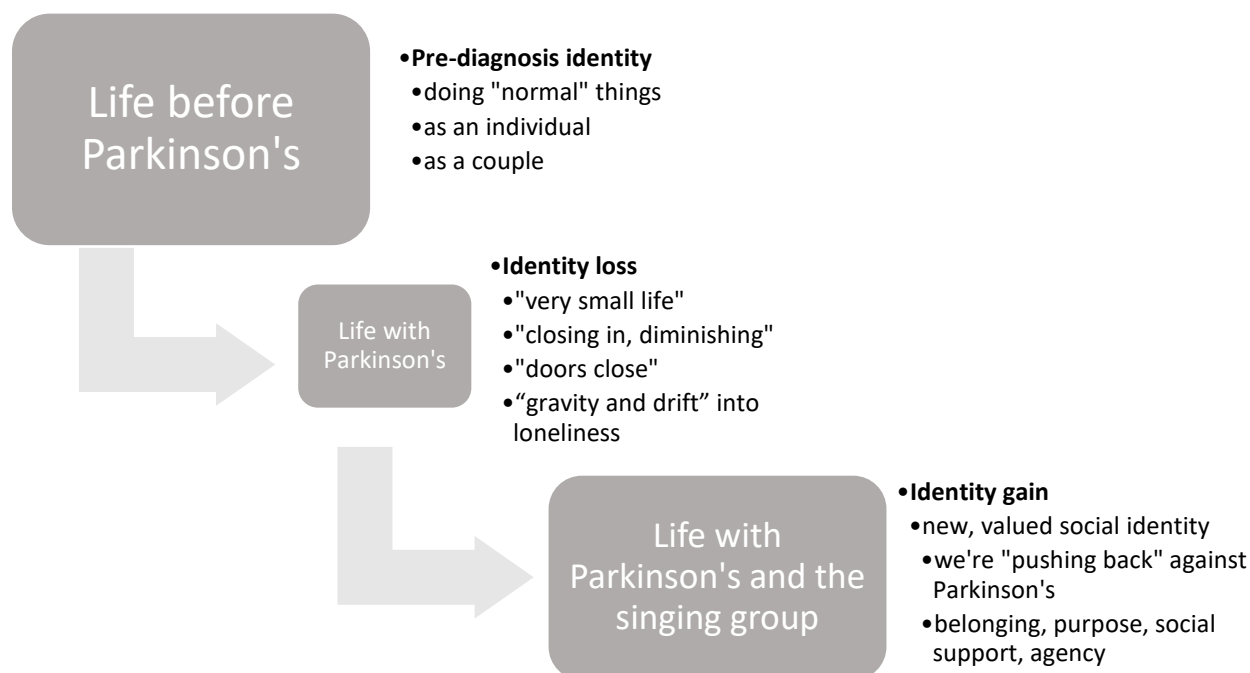


Figure 1: Singing group creates a new social identity for spouse caregivers of people with Parkinson's

Belonging. All caregivers experienced a strong sense of belonging to the group because they shared the identity of “caregiver” for someone with Parkinson's. For Lily there was an “automatic understanding”; for Edward, it was “instant acceptance”—“we just *know* what everyone's going through”; Ann said “you know you're not alone”; and for Alex2 there was a “sort of a camaraderie with other carers. You know that they're going through the same things...” Island Girl too felt a strong sense of belonging with the other caregivers:

we were all in the same boat... every carer understood the other carers' issues; we felt at home, and not out of place; you're okay amongst these people; nobody's going to look down at you because you, because of what's happening because they all have been there or understand what you're talking about.

Island Girl feels a sense of belonging because there is a lack of judgment or stigma around Parkinson's in the group: “nobody's going to look down at you”. Dave felt similarly: “...you got [something] which you wouldn't have in normal society.” Given the isolation that caregivers can feel, this sense of belonging is an important benefit of participation. Dave's observation that the group provides him with a place of belonging which would not be available in “normal society” evidences the power of the group to *give* something more to caregivers than would otherwise be available to them. This sense of belonging for caregivers appears to be most strongly derived from the shared caring identity rather than from any other identity as “singing group” or “choir” members. There was therefore a strong sense amongst

participants that they were “psychologically close to, and yoked with” the other caregivers in the group (Haslam, et al., 2018, p. 27).

Support. Caregivers experienced giving and receiving support via the group overtly and tacitly. Island Girl enjoyed being able to talk with others for support:

I feel comfortable with the people, some of the people I've mentioned I know I can talk to them and they understand where I'm coming from.

It was important to Island Girl that there were people in the group looking out for *her* health interests. In one instance, Island Girl was urged by another caregiver to seek medical advice which uncovered a serious health issue. Both Island Girl and Dave acknowledged there were specific people they could call on for help, should they need it. For Edward, support was important, but took a more subtle form:

So, we appreciate seeing each other. If somebody is not there you wonder and you might make the phone call, but just seeing somebody there you know I might even say to somebody, You made it! You know, that's all they need. That's all I need sometimes, just to be there. But I think everyone, I can't speak for everyone else [laughs], must be fortified by the, the power of the group.

The fortifying nature of the “power of the group” can be experienced merely by being present and by having members look out for each other. Both Ann and Lily were happy to adopt a caring role during group sessions to help others in the group, especially those who were attending on their own. Edward mentioned that he felt he already had enough on his plate and preferred to keep his group relationships as friendships (which he saw as a form of respite), rather than as additional means of support for caring.

For some caregivers, the group provided support because it created genuine friendships and deep relationships. Lily notes that the group “has developed into more of a friendship group.” The group became an important way for Alex² to stay connected to his deceased wife: “they’re my friends who are still going to the choir so I’d like to go and see them from week to week.” For Dave, the relationship is more akin to an extended family: he sees one member with Parkinson’s as an “older sister”; the accompanist as a “grand-daughter”; he has “special feelings in his heart” for one of the facilitators and for Ann. Caregivers experienced the group as a means of social support either as directly or simply as respite from caring duties, as well as a place where strong bonds were formed. Caregivers were motivated to help each other in both subtle and overt ways, and viewed the welfare of other caregivers not as an added burden, but as an important responsibility of group membership.

A sense of purpose. All caregivers derived a sense of purpose from singing group participation. Alex2 found his sense of purpose through contributing to the vocal sound of the group. His previous choral experience gave him the confidence to “boost the ranks” and lend an able voice to the singing:

You have to have the numbers there, and it gets a bit thin and streaky when there's only a few people you know it's sort of, not really a choir, also the failing voice is one of the big problems with Parkinson's, you see. So if they were only Parkinson's sufferers there, it will be a very small quiet choir to be honest. (Alex2)

Lily acknowledges that starting the singing group has given her a strong sense of purpose, whereas upon her husband being diagnosed with Parkinson's, she “was at an absolute loss as to what to do to try to make, you know life [pauses] keep life together, worthwhile.” She derives great satisfaction from seeing people enjoy the group which she established. Despite their existing heavy caregiving burdens, several caregivers found a sense of purpose in being able to support people with Parkinson's other than their spouse at group sessions. For Ann, the group was a way for her to contribute to something bigger than herself:

...you've got to do something with your life, you know! “Why are we here?” and all that stuff. So, you know, I've probably never thought about that, yeah, but you have to contribute, like, you've got to contribute to society.

Ann talked about the way her caregiver role has precluded her from doing many of the things which formerly made her life meaningful (volunteering roles, school teaching). Ann saw a place for herself in the group where she could be *useful* and of service to others, as did Lily and Dave. Edward was grateful for the opportunity as a “practical giver” to assist others in tangible, practical ways during group sessions by “serving coffee or doing tidying up”. The group therefore gave caregivers a new sense of purpose, meaning, and personal control, which helped counteract the sense of powerlessness which so often accompanies caring for someone with an incurable disease.

Agency within the marital relationship. Spouse caregivers experienced the singing group as a valuable activity for their identity as someone married to a person with Parkinson's (note that Ann's husband did not attend the group and she did not discuss any impact of the group on her relationship). Island Girl and her husband have always seen themselves as highly social people—they are people who “do things together”—and the group has enabled them to maintain this identity. For Alex2, the group “was something for both of us”. Lily too felt the group has had a positive impact on her relationship with her husband because it has given them something they can do together: it is a way for them to *be*

in public, where they maintain and strengthen their identity as a married couple. As Parkinson's takes its hold on her husband, Lily said "the choir will become even more important" as other opportunities to be social as a couple "close their doors". For Dave, the thought of going to the group for both him and his wife means "we're happy in the morning on a Friday."

Singing and socialising can assist couples to view each other as people capable of enjoyment, or simply as people in their own right (beyond the Parkinson's identity). Singing together reminds caregivers of the positive feelings they have for their partners. Alex2 very much enjoyed his wife enjoying singing: "I felt good that she enjoyed doing that". Dave too enjoys his wife singing: "You can hear her sing along with it and that and I'll have a little giggle to myself". It was also an opportunity for Dave's wife to socialise independently of him: "I saw it as an opportunity for her to talk to someone different". For Dave, the music is a way of reconnecting with their younger selves, as a couple: "the older tunes bring back memories of when we were young." These positive experiences allowed spouse caregivers to retain a sense of control or agency within the marital relationship—witnessing their spouse enjoy singing and socialising reminded caregivers of the person they married, beyond the identity of a spouse who has Parkinson's.

Beyond this reclamation of self for the people with Parkinson's, the singing group dignified couples. Edward enjoyed the fact that group provides an excuse to get dressed up and go out in public: "it's nice to get dress and [put on] good clobber [laughs]". Dave said the group gives his wife "pleasure and enjoyment and self-respect, dignity." Moreover, the group allows his wife, as a person with Parkinson's and dementia, to gain a sense of agency: "she's given that opportunity to say, you come or you go or what are we doing tomorrow, sort of stuff. And she always says, I wanna go." Both Alex2 and Dave noticed that the weekly group "appointment" motivated them to do other things as a couple (Alex2, Dave). Again, for both Alex2 and Dave, the group has a way of "defusing" tensions themselves and their spouses. Dave noted: "[it] helps relieve any stressful...certainly does. I don't seem to be aggressive or anything like that driving home, that sort of thing." Some caregivers noticed that the singing group gives couples something positive to talk about after the sessions. Witnessing the humanising and dignifying effects of singing for people with Parkinson's—and maintaining positive regard for each other as a couple—was an important aspect of spouse caregivers' experiences.

Discussion and limitations

This aim of this study was to explore spouse caregivers' experiences of group singing for people with Parkinson's, and to interpret these findings through the lens of the social cure approach. This approach frames social identity as having important consequences for health and wellbeing—strong social identification fulfils psychological needs in the form of belonging, meaning, support, efficacy and agency. Caregivers' experiences were interpreted as supporting the overall contention that social identification with the singing group “allowed psychological resources...to flow to group members” (Williams, Dingle, Calligeros, et al., 2019, p. 9). Similar to findings by Clark et al. (2018), caregivers experienced meaningful belonging to the group via their shared caring identity which was free of stigma or judgment (see also Unadkat et al., 2017). Caregivers gave and received social support (see also Rio, 2018), and felt a sense of purpose and worth. Caregivers also experienced feelings of positive regard within the marital relationship and increased agency as a married couple (see also Camic et al., 2013; Tamplin et al., 2018; Unadkat et al., 2017).

Beyond merely confirming various aspects of previous studies, however, findings here use the social cure approach to demonstrate that psychological resources flow from caregivers' social identity, thus illuminating the processes by which group singing can effect caregivers' wellbeing. The singing group was an expansive, generative presence in the lives of spouse caregivers, creating a new social identity which allowed them to reclaim some of what Parkinson's had taken away— group identification was both a psychological resource and a means of resisting, for as long as possible, the diminishing effects of Parkinson's on caregivers' existence.

Within the context of disease, social identification can take both positive and negative forms (e.g. Cruwys & Gunaseelan, 2016; Rødner, 2005). As noted earlier, stigma associated with Parkinson's is an experiential symptom for both diagnosed and caregiver. In this study, caregivers' social identification with a Parkinson's-related activity reinvigorated their identity as part of a married couple *beyond* the Parkinson's diagnosis. Caregivers derived enjoyment and satisfaction from seeing their spouse enjoy themselves singing and socialising independently. Singing had a humanising effect, enabling caregivers to see their spouse not just as someone with Parkinson's, but as the person they married (see also Unadkat et al., 2017). The group was a source of motivation in their lives as couples: they reported getting dressed up to go out and doing other activities around the singing group outing. It was very

important to a number of caregivers that the group provided them with something to do “as a couple”. This helped them reclaim their previous marital identity as “social people”. Social identification with the Parkinson's singing group, perhaps somewhat paradoxically, helped caregivers to reclaim their spousal identity in a way which was *not* tied to the Parkinson's diagnosis. This new identity was free of the stigma attached to the diagnosis, indicating that caregivers experienced group singing with their spouses as a more positive representation of married life impacted by Parkinson's.

Whilst other themes were interpreted from the data—relating to personal identity, positive emotions, enjoyment of singing, and using singing to regulate mood outside the group—these fell beyond the scope of the social cure lens adopted here (see also Williams, Dingle, Calligeros, et al., 2019). There is scope for further group singing research to explore the ways in which these and other effects might meet caregivers' psychological needs and support their wellbeing.

It is not the intention of this article to suggest that group singing for spouse caregivers is feasible through all stages of the progression of Parkinson's as it is not possible to generalize across the lifespan of such a disease (Carter et al., 1998). However, early identification of caregiver stress is important to manage its ongoing impacts (D'Amelio et al., 2009), so singing group participation early in the diagnosis is encouraged. Care burden increases significantly with progression of Parkinson's (Hand et al., 2019), therefore singing group participation will not usually be possible for spouse caregivers once their spouse's symptoms have reached a certain level of severity (as evidenced by Ann, who had to give up the group after 18 months once her caring role prevented group participation).

There are several limitations to this study. As the interviews, transcription and analysis were conducted by the sole author/researcher, the potential for bias is acknowledged. However, analysis and interpretation were undertaken with reference to IPA quality criteria to demonstrate transparent processes and to present a “plausible and persuasive” evidence base (Smith, 2011, p. 23). The participant pool was limited in size and constitution, in that the six caregivers (and their spouses) in this study were all middle-class, cisgender, Caucasian and Australian citizens. Therefore, the ways in which groups beyond WEIRD populations (western, educated, industrialized, rich, and democratic) might experience group singing in this context is yet unknown. Further, the role of the facilitators in nurturing social identity has been noted elsewhere (e.g. Tarrant et al., 2016, Tarrant et al., 2018; Unadkat et al., 2017), but

this study did not explore the roles of facilitators. Outcomes may well be different with other facilitators taking the lead in group activities.

Conclusion

Spouse caregivers are critical to the provision of care for people with Parkinson's—they are “the most valuable and also the most vulnerable resource we have” (Carter et al., 1998, p. 20; see also Parker et al., 2010). With ageing populations and the growing prevalence of Parkinson's, this will increasingly be the case into the future. It is therefore vital that researchers and health practitioners can identify accessible, cost-effective ways to support Parkinson's spouse caregivers' wellbeing. Whilst further research with larger and broader populations is needed, this study provides preliminary support for the benefits of finding a new social identity through group singing for spouse caregivers of people with Parkinson's. It is hoped these findings motivate further research which can, in turn, garner structural and policy support for joint caregiver/care recipient Parkinson's group singing interventions.

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Human ethics

All procedures relating to the conduct of this research were undertaken in accordance with the human ethics approval provided by the host institution. Participants provided written, informed consent to participate.

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Conflict of interest

The Author declares that there is no conflict of interest.

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