

**Music-making in the community with people living with dementia and care-partners - 'I'm leaving feeling on top of the world'.**

SMITH, Sarah K <<http://orcid.org/0000-0002-7356-2042>>, INNES, Anthea and BUSHELL, Sophie

Available from Sheffield Hallam University Research Archive (SHURA) at:

<http://shura.shu.ac.uk/29019/>

---

This document is the author deposited version. You are advised to consult the publisher's version if you wish to cite from it.

**Published version**

SMITH, Sarah K, INNES, Anthea and BUSHELL, Sophie (2021). Music-making in the community with people living with dementia and care-partners - 'I'm leaving feeling on top of the world'. Health and Social Care in the Community.

---

**Copyright and re-use policy**

See <http://shura.shu.ac.uk/information.html>

# Music-making in the community with people living with dementia and care-partners – ‘I’m leaving feeling on top of the world’

Sarah K. Smith  | Anthea Innes  | Sophie Bushell

Salford Institute for Dementia and Ageing,  
School of Health & Society, University of  
Salford, Manchester, UK

## Correspondence

Sarah K. Smith, Salford Institute for  
Dementia and Ageing, School of Health &  
Society, University of Salford, Manchester  
M6 6PU, UK.  
Email: s.k.smith1@salford.ac.uk

## Funding information

This project was supported by the Dowager  
Countess Eleanor Peel Trust and the Booth  
Charities.

## Abstract

Evidence exists relating to music-based initiatives and positive health outcomes for people living with dementia who can access them. Yet, knowledge about the impact of ‘music-making’ on the well-being of community-dwelling people with dementia is limited. Much of the existing evidence about the benefits of music is focused on care home settings where initiatives can be readily applied as part of a weekly schedule of activities. Therefore, this initiative aimed to provide opportunities to participate in music-making, to increase social interaction and ultimately well-being in a community environment. Ten music-making sessions were scheduled for community-dwelling people living with dementia and care-partners, once a month between September 2019 and March 2020. Three sessions did not take place due to Covid19. Eighteen participants consented to take part including seven people living with dementia, five care-partners and six former care-partners. Baseline semi-structured interviews explored the lived experience of music and expectations of the upcoming music-making cafes. Self-report questionnaires captured ‘in the moment’ experiences of each music-making cafe. Follow-up semi-structured interviews explored the impact of music-making on participants’ self-reported well-being. Interviews were transcribed verbatim and analysed thematically. The findings demonstrate that participating in the music-making café benefitted the self-reported well-being of participants in three ways: first, a sense of camaraderie that enabled the facilitation of connections with others; second, creating opportunities to ‘level the playing field’ by always assuming a person’s strengths and abilities; and third, group participation in music-making meets a need for meaningful musical experiences. We conclude that participating in music-making is a powerful medium to promote well-being for community-dwelling people living with dementia and care-partners.

## KEYWORDS

community dwelling, dementia, music-making, participation, well-being

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2021 The Authors. *Health and Social Care in the Community* published by John Wiley & Sons Ltd.

**What is known about the topic?**

- There is evidence that music-based initiatives enhance the well-being of people living with dementia and care-partners.
- Much of the existing evidence is focused on care home settings where initiatives are readily applied as part of a weekly schedule of activities.
- Opportunities for people living with dementia in the community to participate in 'music-making' are less well understood.

**What this paper adds**

- Supportive environments and settings can enhance participation of people living with dementia in music-making cafés.
- Music-making and social interaction together are a powerful combination for the promotion of well-being.
- Self-report perspectives of people living with dementia and care-partners are essential if we are to understand what works and why.

**1 | INTRODUCTION**

There is increasing acknowledgement of the possibility of music to engage and increase well-being for people with dementia in various settings (Bamford & Bowell, 2018). An examination of music-based initiatives concluded that 'Music can promote a range of hugely beneficial outcomes for people with dementia' (Bamford & Bowell, 2018, p.7). This may be because music is accessible for people with dementia, compared to non-musical forms of activity; enabling opportunities for reminiscence and positive expressions of well-being (McDermott et al., 2014). Although it should be acknowledged that opportunities may not always be positive, the possible negative effects of music-based initiatives need to be further examined and communicated.

Recent reviews on psychosocial interventions in dementia concluded that there was evidence for enhanced well-being via music-based approaches (Abraha et al., 2017). In addition, sharing music within a group can have a beneficial psychosocial impact for the person with dementia and their care-partners (Rio, 2018), and a review of the participative arts in dementia (Zeilig et al., 2014) indicates the significance of music-based interventions when compared with alternate art practices. Tapson et al. (2018) found increased happiness in residents and staff exposed to music while live music performances have been shown to have a positive effect on human contact, care relationships, positive emotions and negative emotions in persons living with dementia in nursing homes (van der Vleuten et al., 2012). The positive impact of concert performances on the well-being of people with mild to mid-stage dementia have been explored, showing increased levels of cooperation, interaction and conversation (Shibazaki & Marshall, 2017).

Research on music and dementia has been primarily undertaken in care home settings (Elliott & Gardner, 2018) and there is a gap in knowledge about the impact of music for community-dwelling people living with dementia (Wittenberg et al., 2019). There is a further gap in the evidence base in relation to music-making or participatory approaches to enjoying music. A thematic synthesis of the personal benefits of

'musicking' for people living with dementia focusing on active musical participation was undertaken by Dowlen et al. (2018). They concluded that engaging with music was seen to have a number of psychological, social, and emotional benefits for people with dementia.

Two examples of participatory music-making were found with people living with dementia in residential care (Pyykonen, 2013) and in acute hospital settings (Daykin et al., 2018). Daykin et al. (2018) found that music is useful for enhancing patient and staff experiences and improving care in acute dementia care environments (Daykin et al., 2018). Also, intensive participation with music can have positive effects on people's creativity, expression, social interaction and self-esteem, by enriching their everyday lives also impacts positively on well-being (Pyykonen, 2013).

Despite there being a plethora of evidence regarding music therapy (McDermott et al., 2014), music in care homes (Tapson et al., 2018), singing (Särkämö et al., 2014) and other music initiatives, our understandings relating to the potential of a 'music-making café' with people living with dementia in the community are limited, with a couple of notable exceptions. Music in Mind was a creative music therapy initiative run by the Manchester Camerata chamber orchestra, which sought to improve quality of life for people with dementia by enhancing communication and relationships through music-making (Campbell et al., 2017). Their findings showed the potential of improvised music-making to harmonise group dynamics by co-creating "in-the-moment" experiences (Campbell et al., 2017). McCabe et al. (2015) explored the development of a creative opera involving people living with dementia and their care-partners finding that the positive outcomes included improved confidence and being seen in a new light.

The findings of our research demonstrate that the effects of the music-making café can illustrate a shift in thinking from music as a 'therapy' to address symptoms of dementia, towards music to enhance well-being and quality of life of people with dementia (Sixsmith & Gibson, 2007). This shift in thinking relates to the social and emotional benefits of music-making and the main aim of this

research was to provide opportunities to enable people living with dementia and care-partners to participate in music-making, to increase their social interactions and ultimately their well-being in a community environment. Our research contributes to knowledge of the benefits of a music-making café and responds to contemporary policy recommendations of enhancing well-being post-dementia diagnosis (Department of Health, 2012, 2015).

## 2 | MATERIALS AND METHODS

The research was a collaboration between the authors and an International Orchestra to deliver a monthly participatory activity, referred to as 'the music-making café', involving people living with dementia and care-partners. The music-making café took place at the authors Institution in a purpose built re-fit facility designed with the input of people living with dementia and care-partners. Each music-making café session was developed by the musician delivering the sessions. Ten music-making sessions were scheduled (three were cancelled due to Covid-19) occurring once a month between September 2019 and March 2020. Sessions lasted for 1 hr with time before and after for attendees to socialise and enjoy refreshments. Eighteen participants were recruited by attending outreach activities at locally run groups and events for those living with dementia and care-partners. Free parking was provided for those with their own transport and taxis were provided for those who did not drive. Most participants were familiar to each other as they attended other groups at the authors Institution or elsewhere locally.

The music-making cafés evolved through a process of involvement and the initiative was novel as participants were actively engaged in creating the music with the musician. People living with dementia and their care-partners attended a rehearsal of the Orchestra followed by a workshop in October 2018. Potential participants were then asked for their feedback and the consensus was that people wished for opportunities to be involved in creative music-making, using simple instruments. A taster session at the authors' institution was held in April 2019. This process ensured that the musician could take into account the abilities of all participants. Each music-making café had a theme that was communicated to attendees 1 week before the session, although much of the content was improvised on the day. Each participant chose a percussion instrument supplied by the musician. The musician created an accessible way for all participants to create music by conducting the group through the piece of music, practicing in segments, and brought together as one piece at the end of the session. There was much singing, humming, laughter and noise throughout. The musician led each session, supported by staff at the authors' Institution. The musician was experienced in engaging people living with dementia and care-partners with activities and had previously worked with residential care homes.

All participants gave informed consent following Dewing's (2008) process consent method. The 'process consent model' provides direction offering five key elements for effectively gaining and maintaining meaningful consent (Dewing, 2008). Seven participants

were living with dementia (five men and two women), five were care-partners (four women and one man) and six were former care-partners (all women). Of the seven participants living with dementia, five took part as a dyad with either their spouse (three) or family member (two). The participant's ages ranged from 50 to 87 years.

### 2.1 | Ethics

Ethical approval was given by the University of Salford Ethics committee in July 2019. A further amendment to the ethics application to include video conferencing or telephone interviews was approved in April 2020 to accommodate COVID-19 pandemic restrictions.

### 2.2 | Data collection

Qualitative semi-structured interviews of 1 hr were conducted as baseline using an interview guide to explore how people living with dementia and care-partners define well-being, what motivated participants to attend the music-making café and what expectations participants had for the group. All interviews were digitally recorded and transcribed verbatim. Participants were given a choice of where the baseline interviews took place, either at their own home or at the music-making café venue. It is acknowledged that bias may occur when people living with dementia are interviewed alongside their care-partners. However, all participants were given the choice to be interviewed independently or as part of dyad and those who were part of a dyad all chose to be interviewed alongside their care-partner. The lead author conducted all interviews.

Each participant completed self-reported questionnaires to capture satisfaction and well-being 'in the moment' before and after each session. The questionnaires were developed in consultation with people living with dementia and care-partners via iterative drafts to ensure the wording was accessible and understandable. The pre-questionnaires consisted of two multiple-choice questions that participants were required to complete on arrival for the session. The post-session questionnaire consisted of a further seven questions (three multiple choice and four open ended).

Follow-up semi-structured interviews were conducted with 12 participants via telephone or video conference. Interviews explored if and how being involved with the music-making sessions had contributed to their well-being and if their expectations had been met. For example, participants were asked 'do you think there have been benefits of being a member of the music-making café?' and 'has your sense of well-being been influenced by being a member of the music-making café?' Seven participants who had baseline interviews did not participate in follow-up interviews for the following reasons: four had withdrawn, one participant had sadly passed away and two participants declined to be interviewed at follow-up. All follow-up interviews were conducted by the lead author and all participants who were involved in the sessions as a dyad also opted to be interviewed with their care-partner.

## 2.3 | Data analysis

The baseline and follow-up interview transcripts were coded and analysed drawing on the principles of thematic analysis (Braun & Clarke, 2006). The next phase involved combining the codes and initial themes into a framework of main themes and subthemes. This was an iterative process to ensure the refinement of codes and themes. One researcher generated the codes, and these were checked and verified by another, with any modifications agreed.

A total of 82 pre-questionnaires and 82 post-questionnaires in total were completed by participants who attended sessions over the 7-month period. The questionnaire data were descriptively analysed by calculating averages across all questions and responses over the 7-month period.

## 2.4 | Findings

The three key findings from the analysis of the baseline qualitative interviews were *maintaining participation in a shrinking world; feelings of belonging* and *where words fail, music speaks*.

### 2.4.1 | Maintaining participation in a shrinking world

Many participants spoke about the ways their worlds had shrunk since they or their loved one received a diagnosis of dementia. Their well-being had been negatively impacted as they experienced increasing isolation and decreasing confidence. Yet, participants created strategies to encourage and cajole themselves to continue participating within their communities.

as somebody gets diagnosed with this you start not doing what you did as normal way of life, how that (your world) shrinks.....

(CP04).

Our worlds have shrunk considerably..... it's got harder because he finds it harder to cope with the pack of people

(CP05).

My wellbeing took a dip (after diagnosis), but I was very lucky to have Chris who was sort of filling in the cracks

(PLWD05).

Two participants living with dementia spoke about opportunities to maintain capacity and get involved with activities that had

a focus on strengths and abilities as a way of increasing feelings of well-being.

I'm still an active member of society, I can still contribute. The thing about that is, that sense of purpose and the joy and enthusiasm that remains

(PLWD06).

I do lack motivation. It's making the effort but once you make it, it's worth it, and you realise you do feel better physically and mentally

(PLWD07).

Both participants living with dementia spoke about pushing themselves to make the effort to participate and when they did, this was always rewarded with feelings of purpose and well-being.

### 2.4.2 | Feelings of belonging

Participants spoke about the importance of finding opportunities to learn that provided purpose and kept them socially connected. They sought out friendships with like-minded people to offer and receive peer support.

We were looking for people in the same position as us and sharing their experiences, because I felt that we could learn off them

(CP04).

peer support was critical, without a shadow of a doubt, sometimes I feel so disconnected

(FCP03).

Care-partners spoke of their motivations to encourage their loved ones to continue participating in everyday life as part of their own desire for peer support and social contact. Opportunities to share knowledge and experience between people supporting someone living with dementia was an important aspect of peer support.

I could be this person who's lost confidence, who's lost that being of self, who's lost my identity, because all I'm doing is caring. And one thing I have found, is that when dementia comes into your life, you actually do lose all your friends

(CP03).

The feelings of inclusion and belonging in a setting was also reported as important in many ways. People wanted to feel safe and

secure in a setting that was non-judgemental, inclusive and sensitive to their needs.

Places like this that I can come to are essential, where nobody is judged

(CP03).

In a safe space, no one's going to judge and think, you're rubbish. It's not like academics and people with dementia and their carers, we're all like one

(PLWD07).

The theme **feelings of belonging** illustrates the ways participants sought out opportunities to connect with others experiencing life in similar ways. Participants reported the importance of safe environments that were inclusive and non-judgemental enabling peer support in a reciprocal manner.

### 2.4.3 | Where words fail, music speaks

Music remained a meaningful activity to engage with that is evocative, stimulating and uplifting for all participants.

But it also shows how basic sound and rhythm is to us as living beings that it's a bit like smell, it's very evocative and it gets into a part of us that other things don't access

(CP05).

I need to...to keep my mind active and keep busy. A lot of it is uplifting and you can join in. And just enjoy it and it takes you...you're in the present, you're here and now, you're not thinking about the past or the future, you're thinking about now

(PLWD07).

.....where words fail music speaks. I mean, you can feel a bit down and music always lifts you one way or another, it always has an emotional effect

(FCP05).

It was clear that all participants had agreed to be involved with the music-making café due to their love of music and their perceptions that music could evoke emotions, memories and well-being.

At baseline, participants spoke about the need to participate in meaningful activities in a non-judgemental environment that was inclusive and friendly. All participants spoke about their expectations for the music-making café and were excited at the prospect, although some did admit to being apprehensive about what it may involve.

## 2.5 | Findings from the pre-and post-self-report questionnaires

Overall, 82 pre-questionnaires and 82 post-questionnaires were completed over the seven music-making cafes. The questionnaires were administered to capture how participants were feeling on arrival and if any changes in mood and well-being could be attributed to the music session by capturing how participants were feeling as the session finished. The pre-questionnaires consisted of two questions and participants were asked to complete this on their arrival at each session. The first question asked, 'How are you feeling before today's music-making café?'

Figure 1 illustrates the responses to the pre-questions across all seven sessions. Sixty-three per cent of participants arrived for the sessions feeling happy with a further 18% feeling very happy. Fifteen per cent of participants arrived at the sessions with feelings of neutrality and 4% feeling unhappy across all seven sessions. The second question on the pre-questionnaires asked, 'Have you been looking forward to today's music-making café?' Fifty-two per cent indicated that they had been looking forward to the session very much, with a further 39% indicating that 'yes' they had been looking forward to the session.

Once each session had finished, participants were asked to complete a post-session questionnaire with seven further questions. The post-questionnaire aimed to capture participants' mood and well-being through their responses after taking part in the music-making session. The first question on the post-questionnaire asked, 'How are you feeling AFTER today's music-making café?'

Figure 2 illustrates that 87% of participants felt very happy after the music session had finished. A further 11% felt happy. Seventy-eight per cent arrived already feeling happy/very happy enabling us to conclude that 20% experienced an increase in mood and well-being after each session and accumulatively across the seven sessions. An indication of why 87% of responses were 'very happy' can be illustrated by the responses to the next question which was 'How much did you enjoy today's music-making session?' Eighty-seven per cent of participants' responses illustrate that they enjoyed the music-making café with a further 12% opting that they highly enjoyed it. In the pre-questionnaire, although the majority of responses show that participants were looking forward to the music café (52% very much, 39% yes), the post-questionnaire illustrates a majority

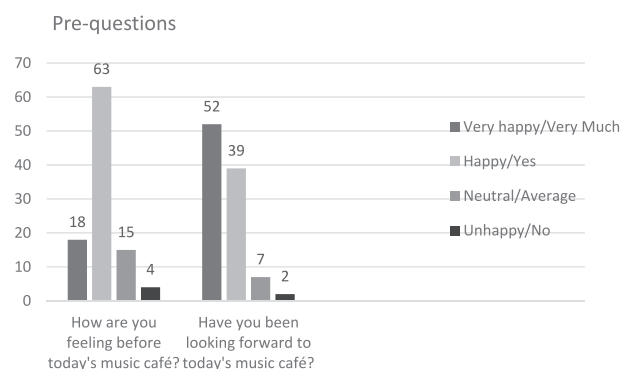


FIGURE 1 Pre-questionnaire

## Post-questions

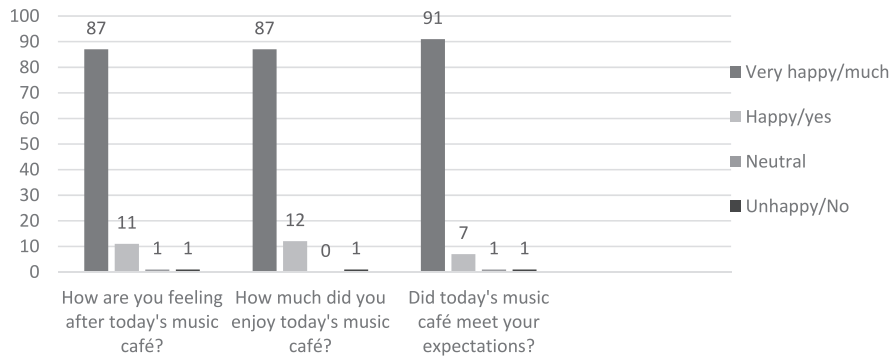


FIGURE 2 Post-questionnaire

shift to enjoying the session 'very much' overall. The final multiple-choice question on the post-questionnaire asked, 'Did today's music-making café meet your overall expectations?' Ninety-one per cent of responses said that the music-making café 'very much' met expectations, with a further 7% agreeing, 1% neutral and 1% responding 'not really' demonstrating that participants had strong positive experiences of the music-making café.

The remaining four questions required participants to elaborate further on their experiences of the music-making café in their own words. The most answered question was 'What did you enjoy most about today's music-making café?' with 72 responses of the 82 completed questionnaires. Responses included 'being involved', 'everyone having a chance to join in', 'being inventive', 'being creative', 'the participation and involvement' and the 'camaraderie'. For some participants, the opportunity to learn more about classical music was the most enjoyable aspect. When asked if participants had any further comments, the responses included 'Very enjoyable, I'm leaving feeling on top of the world'. Others described how the music-making sessions involved laughter and enjoyment and was a clear mood enhancer, 'Working together with laughter is a tonic' and 'I feel very happy after the session'. Some felt that they were lucky to be involved. 'A fabulous concept which will grow into something unique' and 'I feel very lucky to be part of it'.

## 2.6 | Findings from the follow-up qualitative interviews

Participants were asked if and how being involved with the music-making sessions had contributed to their well-being and if their expectations had been met. The findings that emerged from the analysis of the follow-up qualitative interview data were *camaraderie and creating music; laughter and learning* and *exceeding expectations*.

### 2.6.1 | Camaraderie and creating music

Participants reported that the way of engaging with music that had been introduced to them was a new experience. Opportunities

to create music with a musician from a prestigious Orchestra was something that most had never foreseen. Participants found that actively participating and creating music was more meaningful than passively sitting back and listening to music.

...and because it was something we'd created together, it was more meaningful,  
(CP03).

It's the being together and the ability to produce a lot of really good music, most of the time  
(PLWD05).

The experience of music-making was found to be meaningful and uplifting because participants felt that they accomplished something together. When opportunities to participate in meaningful activities are presented to the person living with dementia, personhood (Kitwood, 1997) is upheld, promoting increased sense of self-worth, a key part of well-being.

Participants spoke about their apprehension in the beginning, even though the majority of participants were already familiar with one other. Participants reported not wanting to make a mistake and let the group down. Belonging to the music-making group was reported as bringing them together.

We were really all in it together and it didn't matter who we were, what we were, how we were. You could walk in feeling, oh god, and walk out feeling a million dollars. We've got to know each other differently and deeper  
(CP05).

So it's the fact that it's the (anonymised) Orchestra that is the big thing, and I come out after a session and think, oh bloody hell this is wonderful. It's the being together  
(PLWD05).

Creating group music was novel to all participants and they reported that the experience had brought them closer as a group. This could be due to overcoming initial nerves as the sessions progressed but also because participant's felt a sense of 'we're all in this together'. It was clear that this led to genuine feelings of social inclusion and belonging and acted as a leveller in terms of group participation rather than one's own identity as a carer or person living with dementia.

## 2.6.2 | Laughter and learning

Participants spoke about the fun and the laughter that they enjoyed while being a member of the music-making café. In addition, participants felt that they had accomplished something, growing in confidence and learning a new skill.

We were learning how to put music together and for it to actually mean something. There was a sense of accomplishment

(CP03).

There was a sense of humour about it. You know, you could have a laugh without it being at somebody else's expense

(PLWD06).

I enjoyed it and I thought it was fun and uplifting and we learnt new skills. I think that was one of the best things we've done

(PLWD07).

Participants spoke about the laughter that they experienced being part of the music-making café, always emphasising that the group laughed together. The light-hearted approach enabled participants to experience creating music together that led to a feeling of accomplishment through the learning of new skills.

## 2.6.3 | Exceeding expectations

In the pre-interviews, participants were asked what they were expecting to achieve from the music-making group. In the follow-up interviews it was important to explore if these expectations had been met.

It's great. Its far exceeded my expectation; it's been a lot more fun, it's meaningful, impactful, and similarly wonderful

(CP05).

I hadn't a clue what to expect. At first I thought, I couldn't possibly do anything with that instrument, but it got to the stage where I was thinking, well, I wonder what he's going to choose for me this time?

(FCP05).

Well, I think it's exceeded them because at first I thought, oh, it's all going to be classical music and I won't be able to participate in this... but it wasn't at all. As I say, it was fun, it was inclusive and we enjoyed it, and it gave me some confidence

(PLWD07).

Participants expressed surprise in their accomplishment with the music-making sessions, as their expectations were met and in many cases, exceeded. Some reported that they expected it to be good, but they had not expected to have the opportunity to be involved because they were living with dementia. The findings from the follow-up interviews provide a rich account of the lived experience of participants being part of the music-making café. The findings also highlight the positive outcomes experienced by participants including a sense of accomplishment to laughter, feelings of camaraderie and learning new skills.

## 3 | DISCUSSION

The music-making café was a novel and creative initiative that was developed with people living with dementia and care-partners in the community. The findings from the baseline interviews highlighted that participants were striving to *maintain participation in a shrinking world* as confidence decreased and they became increasingly isolated. Participants searched for opportunities to socially connect with like-minded people to enable purpose, new friendships, and *feelings of belonging*. All participants had a shared love of music and felt that music-making would be a meaningful activity in a non-judgemental environment, this became one of the key findings from the baseline interviews; *where words fail, music speaks*.

The findings from the 'in the moment' data provide a clear indication of the positive impact on well-being created by the music-making café. The responses from the pre- and post-self-report questionnaires illustrated that participants experienced an increase in mood and well-being after each session and accumulatively across the seven sessions. It was essential to capture the 'in the moment' experiences of people living with dementia participating in the music-making as any lasting effects may be challenging to recall (Tuckett et al., 2015). One particular care-partner (CP05) reported that the positive effects of the music-making lasted well into the evening with their loved one exhibiting increased mood and 'rekindling' emotions between them. This could be described as the ripple effect, a term



used in music therapy to describe the effects of a session implicating the micro (effects between person and care-partner), the meso (effects beyond the music-making session) and macro (long-term effects in the wider context; Pavlicevic et al., 2015). The positive impact that the music-making café had on the person with dementia “in the moment” was observed to be as important as any long-term effects on mood reported by the care-partner. McDermott reports that ‘meaningful connection with others and normal togetherness that happens during a session to be more crucial for the well-being of people with dementia than potential long-term effects’ (McDermott et al., 2014, p. 712).

The key findings from the follow-up interviews illustrate that *camaraderie and creating music* in this way was a new experience that had brought participants closer together as a group. They reported on the *laughter and learning* a new skill that had provided them with feelings of accomplishment that seemed to ‘level the playing field’. Overall, participants reported that the music-making café had *exceeded expectations* and provided them with opportunities never anticipated. These findings illustrate the positive impact that the music-making café had on participant’s relationships, bringing them closer as a group and sharing experiences by making music that they had never foreseen. This echoes Dowlen’s review of the benefits of ‘musicking’ for people living with dementia which found that music groups fostered supportive environments and over time, this group culture provided people with a sense of belonging and togetherness (Dowlen et al., 2018). It is well documented in the literature that participating in activities involving music has social benefits including enhanced relationships with care-partners and others, feelings of belonging and inclusion and overall increases in well-being (Camic et al., 2013; Osman et al., 2016).

The findings highlight the need that people living with dementia and care-partners have for meaningful musical experiences (McDermott et al., 2014) that enable them to facilitate connections with others. Activities that involve music and people living with dementia are generally social in nature and it can be unclear at times whether the sociality of the activity is what influences the observable social interactions of the participants or the music itself or both (Baird & Thompson, 2019). This reflects the growing evidence that psychosocial interventions that promote social relationships can enhance the well-being of people with dementia (Dröes et al., 2017). Participants spoke about their feelings of camaraderie within an inclusive environment and the facilitation of the music-making café was found to be enabling and encouraging, thus increasing feelings of well-being. This finding is supported by similar work in the context of hospital settings that found the impact of music-making on well-being was strongly mediated by the staff and the environment (Daykin et al., 2018).

Group members reported experiencing a sense of accomplishment from their participation in the music-making café, which is well documented in the literature (Camic et al., 2013; McCabe et al., 2015; Osman et al., 2016). It is important that we consider the

strengths and maintained abilities of the person living with dementia by creating opportunities to learn new skills. Participants reported that their active participation in the music-making café had the potential to highlight retained abilities more than passively sitting and listening to music. Thus, participants felt that the music-making café was a leveller, providing them with the same opportunities as others to make music. This is supported in the literature as learning new skills through exposure to music has been found to increase individual’s confidence and self-esteem (Dowlen et al., 2018) as well as enabling people living with dementia to participate with others on an equal footing (McCabe et al., 2015).

### 3.1 | Study limitations

It should be acknowledged that our sample is limited in relation to ethnicity, although there was a representative mix of age and gender to involve care-partners, former care-partners and people living with dementia. Also, participants were self-selecting, which highlights challenges regarding representation involving people living with dementia that are ‘hard to reach’ and who either choose to not seek out participation opportunities or who are unaware of opportunities in their communities. This is an ongoing issue in dementia research and questions the generalisability of the findings beyond the sample in this study. It should also be acknowledged that the positive impact on well-being could be influenced by regular social interaction and a future study could compare the benefits of a dementia café with a music-making café. Comparisons of within-participant data pre- and post-music-making sessions were not made as not all participants attended all music-making sessions.

## 4 | CONCLUSION

This study discusses a music-making café that was reported to be ‘fun, meaningful, impactful and similarly wonderful’ by people living with dementia and care-partners living in the community. The findings demonstrate that participating in the music-making café benefited the self-reported well-being of participants in three particular ways: first, an enhanced sense of camaraderie that enables the facilitation of connections with others; second, creating opportunities to ‘level the playing field’ by always assuming a person’s strengths and abilities; and third, group participation in music-making meets an unmet need for meaningful musical experiences. There is currently a lack of opportunity to actively participate as equal members in music-making groups. Yet, such opportunities for music-making fosters camaraderie in group settings. It is clear that music-making and social interaction together are a powerful combination for promoting well-being. The opportunity to create music with a prestigious International Orchestra was reported by participants to be the most meaningful, uplifting opportunity they had experienced in a long time.

## ACKNOWLEDGEMENTS

We would like to thank the Halle Orchestra for their enthusiasm and expert delivery of this initiative. Our thanks go to the people living with dementia and their care partners who participated in our research into the Music Making Café.

## CONFLICT OF INTEREST

No conflict of interest has been identified.

## DATA AVAILABILITY STATEMENT

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

## ORCID

Sarah K. Smith  <https://orcid.org/0000-0002-7356-2042>

Anthea Innes  <https://orcid.org/0000-0002-5591-4083>

## REFERENCES

- Abraha, I., Rimland, J. M., Trotta, F. M., Dell'Aquila, G., Cruz-Jentoft, A., Petrovic, M., Gudmundsson, A., Soiza, R., O'Mahony, D., Guaita, A., & Cherubini, A. (2017). Systematic review of systematic reviews of non-pharmacological interventions to treat behavioural disturbances in older patients with dementia. the SENATOR-OnTop series. *British Medical Journal Open*, 7, e012759. <https://doi.org/10.1136/bmjopen-2016-012759>
- Baird, A., & Thompson, W. F. (2019). When music compensates language: A case study of severe aphasia in dementia and the use of music by a spousal caregiver. *Aphasiology*, 33, 449–465. <https://doi.org/10.1080/02687038.2018.1471657>
- Bamford, S. M., & Howell, S. (2018). *What would life be - Without a song or a dance, what are we? A report from the commission on dementia and music*. International Longevity Centre - UK (ILC-UK).
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Camic, P. M., Myferi Williams, C., & Meeten, F. (2013). Does a 'Singing Together Group' improve the quality of life of people with a dementia and their carers? A pilot evaluation study. *Dementia*, 12, 157–176. <https://doi.org/10.1177/1471301211422761>
- Campbell, S., Ponsillo, N., Budd, P., & Keady, J. (2017). "Music in Mind" and Manchester Camerata: An exploratory qualitative evaluation of engagement in one care home in Northwest England. *Quality in Ageing and Older Adults*, 18(1), 69–80. <https://doi.org/10.1108/QAOA-01-2016-0001>
- Daykin, N., Parry, B., Ball, K., Walters, D., Henry, A., Platten, B., & Hayden, R. (2018). The role of participatory music making in supporting people with dementia in hospital environments. *Dementia*, 17(6), 686–701. <https://doi.org/10.1177/1471301217739722>
- Department of Health. (2012). Prime Minister's challenge on dementia. Delivering major improvements in dementia care and research by 2015, London. [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/215101/dh\\_133176.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215101/dh_133176.pdf)
- Department of Health. (2015). Prime Minister's challenge on dementia 2020. London. [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/414344/pm-dementia2020.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf)
- Dewing, J. (2008). Process consent and research with older persons living with dementia. *Research Ethics Review*, 4(2), 59–64. <https://doi.org/10.1177/174701610800400205>
- Dowlen, R., Keady, J., Milligan, C., Swarbrick, C., Ponsillo, N., Geddes, L., & Riley, B. (2018). The personal benefits of musicking for people living with dementia: A thematic synthesis of the qualitative literature. *Arts and Health*, 10(3), 197–212. <https://doi.org/10.1080/17533015.2017.1370718>
- Dröes, R. M., Chattat, R., Diaz, A., Gove, D., Graff, M., Murphy, K., Verbeek, H., Vernooij-Dassen, M., Clare, L., Johannessen, A., Roes, M., Verhey, F., Charras, K., van Audenhove, C., Casey, D., Evans, S., Fabbo, A., Franco, M., Gerritsen, D., ... Zuidema, S. (2017). Social health and dementia: A European consensus on the operationalization of the concept and directions for research and practice. *Ageing and Mental Health*, 21(1), 4–17. <https://doi.org/10.1080/13607863.2016.1254596>
- Elliott, M., & Gardner, P. (2018). The role of music in the lives of older adults with dementia ageing in place: A scoping review. *Dementia*, 17(2), 199–213. <https://doi.org/10.1177/1471301216639424>
- Kitwood, T. M. (1997). *Dementia reconsidered: The person comes first*. Open University Press. <http://catalog.hathitrust.org/api/volumes/oclc/36074517.html>
- McCabe, L., Greasley-Adams, C., & Goodson, K. (2015). 'What I want to do is get half a dozen of them and go and see Simon Cowell': Reflecting on participation and outcomes for people with dementia taking part in a creative musical project. *Dementia*, 14(6), 734–750. <https://doi.org/10.1177/1471301213508128>
- McDermott, O., Orrell, M., & Ridder, H. M. (2014). The importance of music for people with dementia: The perspectives of people with dementia, family carers, staff and music therapists. *Ageing and Mental Health*, 18(6), 706–716. <https://doi.org/10.1080/13607863.2013.875124>
- Osman, S. E., Tischler, V., & Schneider, J. (2016). 'Singing for the Brain': A qualitative study exploring the health and well-being benefits of singing for people with dementia and their carers. *Dementia*, 15(6), 1326–1339. <https://doi.org/10.1177/1471301214556291>
- Pavlicevic, M., Tsiris, G., Wood, S., Powell, H., Graham, J., Sanderson, R., Millman, R., & Gibson, J. (2015). The 'ripple effect': Towards researching improvisational music therapy in dementia care homes. *Dementia*, 14(5), 659–679. <https://doi.org/10.1177/1471301213514419>
- Pyykonen, K. (2013). *Many memories, many stories. Participatory music project for elderly people with dementia - Music pedagogical applications for elderly care*. Kungliga Musikhögskolan. <http://www.diva-portal.org/smash/get/diva2:633113/FULLTEXT01.pdf>
- Rio, R. (2018). A community-based music therapy support group for people with Alzheimer's disease and their caregivers: A sustainable partnership model. *Frontiers in Medicine*, 5(293), 1–7. <https://doi.org/10.3389/fmed.2018.00293>
- Särkämö, T., Tervaniemi, M., Laitinen, S., Numminen, A., Kurki, M., Johnson, J. K., & Rantanen, P. (2014). Cognitive, emotional, and social benefits of regular musical activities in early dementia: Randomized controlled study. *Gerontologist*, 54(4), 634–650. <https://doi.org/10.1093/geront/gnt100>
- Shibazaki, K., & Marshall, N. A. (2017). Exploring the impact of music concerts in promoting well-being in dementia care. *Ageing and Mental Health*, 21(5), 468–476. <https://doi.org/10.1080/13607863.2015.1114589>
- Sixsmith, A., & Gibson, G. (2007). Music and the wellbeing of people with dementia. *Ageing and Society*, 27(1), 127–145. <https://doi.org/10.1017/S0144686X06005228>
- Tapson, C., Noble, D., Daykin, N., & Walters, D. (2018). Live music in care: The impact of music interventions for people living and working in care home settings. Evaluation report. <https://www.artshresources.org.uk/docs/live-music-in-care-the-impact-of-music-interventions-for-people-living-and-working-in-care-home-settings/>
- Tuckett, A., Hodgkinson, B., Rouillon, L., Balil-Lozoya, T., & Parker, D. (2015). What carers and family said about music therapy on behaviours of older people with dementia in residential aged care. *International Journal of Older People Nursing*, 10(2), 146–157. <https://doi.org/10.1111/opn.12071>

- van der Vleuten, M., Visser, A., & Meeuwesen, L. (2012). The contribution of intimate live music performances to the quality of life for persons with dementia. *Patient Education and Counseling*, 89(3), 484–488. <https://doi.org/10.1016/j.pec.2012.05.012>
- Wittenberg, R., Hu, B., Barraza-Araiza, L., & Rehill, A. (2019). Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040. *Care Policy and Evaluation Centre*, 1–79. [https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec\\_report\\_november\\_2019.pdf](https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf)
- Zeilig, H., Killick, J., & Fox, C. (2014). The participative arts for people living with a dementia: A critical review. *International Journal*

*of Ageing and Later Life*, 9(1), 7–34. <https://doi.org/10.3384/ijal.1652-8670.14238>

**How to cite this article:** Smith SK, Innes A, Bushell S. Music-making in the community with people living with dementia and care-partners – 'I'm leaving feeling on top of the world'. *Health Soc Care Community*. 2021;00:1–10. <https://doi.org/10.1111/hsc.13378>