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'A Light at the End of the Tunnel':

The Experiences of Members of a Therapeutic Community Choir for People Living with Dementia and their Care-Partners who 'Went Online' During the COVID-19 Pandemic – an Arts-Based Phenomenological Study

Zara Thompson [1,2] *, Felicity A. Baker [1,3], Imogen N. Clark [1], Gwladys McLachlan [2], Sue Mountain [2], Dennis Mountain [2], Maria Radford [2], Mark Reid [2], Nena Reid [2], Teuila Reid [2], Vera Tkalcevic [2], Marion Hodgson [2], Jeanette Tamplin [1]

[1] Creative Arts and Music Therapy Research Unit, Faculty of Fine Arts and Music, The University of Melbourne, Australia
[2] The Rewire Musical Memories Choir, Australia
[3] Norwegian Academy of Music, Oslo, Norway
* zara.thompson@unimelb.edu.au

Abstract

Background: This paper presents the results of an arts-based, phenomenological research project in which members of a therapeutic community choir for people living with dementia and their family and friends reflected on their experiences of singing together pre and post the transition to online sessions as a result of the COVID-19 pandemic.

Method: Eleven choir members (three living with dementia and eight family care-partners) participated in interviews about their experience of the choir and its transition to an online format during the COVID-19 pandemic. Interviews were conducted in either a traditional, semi-structured interview format, or as a collaborative songwriting session, and participants were able to choose the format that they preferred. Transcripts of the interviews and songs that were composed were analysed using an adapted Interpretative Phenomenological Analysis and arts-based research method. Participants verified key themes that emerged from the analysis, which formed the basis of an 18-part Song Cycle, which included two original songs by participants, and 16 songs composed by the first author.

Results: Eighteen sub-themes were generated from the analysis, which are expressed as songs and grouped into four overarching themes or 'Movements': i) the dementia experience; ii) the choir experience; iii) the COVID-19 experience; and iv) the virtual experience. The songs depict how participants experienced each of the overarching themes, and revealed challenges, new opportunities and resilience.

Conclusion: Navigating COVID-19 while living with or caring for someone with dementia was challenging. The virtual choir format was acceptable, provided relief from the stress of COVID-19, and kept members connected, however, there were technological limitations that made the experience challenging at times.

Keywords: choir; COVID-19 pandemic; online singing; online choir; dementia; care-partner; music therapy

Introduction

The COVID-19 pandemic has necessitated innovation and adaptations in how people access healthcare and support. In addition to the risk of serious illness and death due to the susceptibility of older adults to the effects of the COVID-19 virus, people living with dementia and their care-partners are also at risk of adverse effects of social isolation and reduced access to supports due to social-distancing measures (Manca et al., 2020). Past research has indicated that social isolation is a risk factor for cognitive decline, poor health outcomes and psychological distress in older adults (Lara et al., 2019; Shankar et al., 2013; Shrira et al., 2020). Moreover, social connections and engagement have been found to have a positive impact on cognitive performance (Bennett et al., 2006) and psychological wellbeing (Lee et al., 2017; Tible et al., 2017) for people with dementia. Therefore, there is a strong need for accessible ways for people with dementia and their families and friends to remain connected during the COVID-19 pandemic to mitigate the effects of social isolation on cognition and psychological wellbeing (Manca et al., 2020; Tible et al., 2017).

Online Singing and Dementia

Group singing, for example in community choirs, has been found to have a positive impact on various aspects of wellbeing for people with dementia and their care-partners, and to provide an accessible space for developing social connections and support (Thompson et al., 2021a). Several existing dementia-specific choirs transitioned to an online format during the COVID-19 lockdown (Dementia Change Action Network, 2020; The Dementia Network, 2021). However, to our knowledge there is a paucity of literature investigating online choir formats for people living with dementia and care-partners. Lee et al. (2021) interviewed choir facilitators who adapted to online formats during the COVID-19 pandemic and found that online choir formats were generally well received by choir participants and facilitators and seen to promote social connections. However, they acknowledged that there were significant barriers to accessing technology for people living with dementia, and that many facilitators were deterred from using live online formats due to the asynchronous nature of the platforms (as participants were unable to sing in unison, and members had to remain on mute to avoid audio interference) (Lee et al., 2021).

An earlier systematic review found only one study that investigated the impact of online singing interventions for people with dementia (Dowson & Schneider, 2021). This review only featured individualised singing interventions, and while results indicated that the format was received positively, the impact of the online format on participants remains unclear (Dowson & Schneider, 2021). The review found that other forms of digital arts-based interventions or online healthcare for people with dementia were generally accessible, however, people with dementia often relied on support from care-partners –

participation was predicated on the enthusiasm and technological competence of care-partners (Dowson & Schneider, 2021). Online music therapy interventions have been reported as an acceptable and accessible format for people in other clinical populations (Baker & Krout, 2009; Baker & Tamplin, 2021; Tamplin et al., 2020). However, poor musical quality, such as the lack of synchronous music making (due to the limitations of online formats) has again been noted to detract from the musical experience (Baker & Krout, 2009; Dowson & Schneider, 2021). In non-clinical populations, virtual choirs have been described as lacking the embodied sense of emotion that comes from singing together live, as participants are not afforded the chance to hear and respond to the contributions of others (Datta, 2020). However, a study investigating the difference between in-person and virtual (individually pre-recorded) choir performances found that despite lower levels of social interaction and sensory input, virtual choir singing can still foster a sense of social connection (Fancourt & Steptoe, 2019). This study also reported that although emotional responses to choir singing were at times somewhat muted in the virtual format, participants in both conditions used singing as a form of distraction (Fancourt & Steptoe, 2019).

Arts-Based Research and Dementia

Arts-based research (ABR) is recognised for its ability to communicate findings on not only an intellectual level, but in a way that is "emotionally and intuitively" felt by audiences (Beer, 2016). In the context of disability, arts-based methods of disseminating research findings can assist in challenging dominant narratives and stereotypes, and centre the perspectives of people who are often underrepresented (Kalenderidis, 2020; Mykitiuk et al., 2015). In addition to humanising the data, arts-based research approaches can enhance the accessibility of the research process, through affording ways for participants to express themselves and explore their experiences on a creative and emotional level, and through creating research outputs that are more accessible than traditional academic dissemination outputs (Boydell et al., 2012).

There are limited examples of arts-based research with people living with dementia, and often these focus on dissemination rather than data generation. Bennett et al. (2019), Moss and O'Neill (2019), and Synnes et al. (2021) illustrate how an arts-based approach can increase public awareness and knowledge of dementia as well as highlight voices and perspectives of people with dementia. Mediums that they used to disseminate their outcomes include dance, visual arts and composition of chamber music (Moss and O'Neill, 2019); movies (Bennett et al., 2019), and poetry (Synnes et al., 2021). Synnes et al (2021) also used reading and writing poetry to aid in data generation and analysis; some poems were created spontaneously by participants during the program, while other poems were created based on transcripts of the group discussion during the program (Synnes et al., 2021).

Songwriting has been used in music therapy research as a form of data generation (Baker et al., 2017; Fairchild & McFerran, 2019; McCaffrey et al., 2021), and as a therapeutic intervention with people living with dementia (Baker & Stretton-Smith, 2018; Clark, Stretton-Smith, Baker, Lee, & Tamplin, 2020). Music therapy researchers have previously described using musical artifacts that were familiar to participants (such as recordings of songs or lyrics composed by participants) to help prompt memory during qualitative interviews (Thompson et al., 2021b). However, to our knowledge, there are no music therapy studies that have used a deliberate arts-based approach with people who have dementia. Given that music - and songwriting in particular - can support people with dementia with communication and emotional expression, we felt it would make sense to incorporate music into the data collection, analysis, and dissemination of results from this project.

Background of Choir

The Rewire Musical Memories (RMM) choir is a community-based, therapeutic choir designed to support people living with dementia and their family and friends who support them with care (henceforth referred to as care-partners). Members include people with a range of diagnoses (the choir is not limited to any type of dementia), including people with younger onset dementia. The choir is facilitated by a credentialed music therapist and is tailored to meet the access needs and musical preferences of participants. The RMM choir began in 2016 as part of a research project led by authors JT and IC, and has since expanded to become a vibrant community choir that rehearses weekly and performs semi-regularly. The first author (ZT) has facilitated the choir since June 2017. During the COVID-19 pandemic in 2020, the choir had to cease singing in-person for several months due to public health measures and transitioned to a virtual choir format during lockdown restrictions. The format of the choir remained essentially the same as in-person; physical and vocal warm-ups, followed by singing familiar songs selected by participants. However, due to the latency and audio limitations of the online platform (Zoom), it was not possible to sing in unison; members had to be placed on 'mute' while singing. Pre-recorded music was used much more frequently than during in-person sessions in order to compensate for the substandard audio quality of the platform. When live music was used, it was performed either by the facilitator, or by the accompanist and his wife (who is also a member of the choir). Members engaged in group discussions, however, a dedicated 'social' time (akin to our usual afternoon tea following choir) was not possible. Despite these differences, attendance at the online choir remained high, and informal feedback from members was positive.

Prior to designing this study, ZT discussed with the choir the idea of creating songs about the experience of COVID-19 lockdown, which prompted one member to compose a parody song for the choir to sing. As ZT was completing research on inclusive choir singing for her doctoral studies at this time, she was inspired by the song to explore the potential of songwriting as a way to make sense of and communicate about the collective experience of transitioning to our online format during the lockdown. ZT met with choir members to discuss study design and feasibility over several months in winter 2020. Members resonated with the idea of arts-based research, as several had previously participated in various research projects, and felt that the arts-based approach may allow for more flexibility and for their unique perspectives to be shared in a way that felt authentic to them. Initially, the aim of this project was to understand the experiences of choir members adapting to the online format during the COVID-19 lockdown. However, many forms of qualitative research, including arts-based approaches, focus on emergent perspectives rather than attempting to search for an objective truth about a phenomenon or experience (Smith et al., 2009; Viega & Forinash, 2016; Wheeler, 2016). Through discussions both prior to and during data generation, the research question shifted from being specifically about the experience of the virtual choir, to more broadly exploring what it has been like to be a member of the RMM choir, both generally and during the COVID-19 pandemic.

Method

Study Design

We selected an 'arts as a primary method in research' design, where arts-based approaches were included as a primary method in data generation, analysis and dissemination (Viega & Forinash, 2016). As we aimed to investigate the unique, ideographic experience of the choir members, we selected phenomenology as the methodological paradigm through which we employed the arts-based approaches (Smith et al., 2009). We chose

Interpretative Phenomenological Analysis (IPA) as the framework to support the arts-based methods, as this methodology emphasises that the interpretation of participants and researchers cannot be separated out but should be acknowledged as a central aspect of the analysis (Finlay, 2011; Smith et al., 2009). In IPA, rather than attempting to exclude the influence of researchers' interpretation, reflexive practices are incorporated to acknowledge and reflect on the role of potential biases (Finlay, 2009). We felt the tenets of this methodology were particularly relevant, as the first author was deeply embedded in the phenomena in her dual role of choir facilitator-researcher. We included aspects of participatory research in the design of this project; this involved consultation with choir members prior to the study design, member-checking, reading the final manuscript, and including participants in the creation of the final recordings (Leavy, 2018). Consequently, several participants are listed as co-authors on this paper. While we strove to include participants as collaborators at various levels of the research process, we also acknowledge that we did not formally design this study as participatory, and due to contextual factors (such as lockdown restrictions and personal circumstances), it was not possible to involve all participants as equal collaborators (Leavy, 2018).

Participants and Recruitment

We invited members of the RMM choir to participate in this project. Members were eligible if they were aged 18 years or older, had attended the choir online at least once, and could provide consent or assent to participate. For members who were unable to provide formal consent, an authorised individual (guardian) was required to provide written consent, while the researcher monitored for assent before, during and after the interview. Participants were excluded if they had not attended any sessions online.

As ZT and the research team from The University of Melbourne all had pre-existing relationships with the choir members, we engaged a third, independent person (unknown to the choir members) to send invitations to participate in this study via email. Members who agreed to participate were directed to contact ZT directly, who provided further information about the study and arranged an interview time. Ethics for this study was granted by The University of Melbourne Human Research Ethics Committee, reference number 2020-20396-12680-3.

Data Generation

We invited choir members who consented to participate to partake in a semi-structured interview, conducted by the researcher-facilitator (ZT). In order to enhance the accessibility of the interview process for participants with dementia, we prepared music or musical artifacts (such as audio or video recordings of the choir performing or rehearsing), which were offered throughout the interview where needed. We also offered participants the choice of one or a combination of two different interview formats:

   a. A 'songwriting style' interview, where participants are supported to write a song about their experience of being involved in the choir.
      and/or
   b. A traditional semi-structured interview (questions and answers)

These two options were provided to maximise the accessibility of the interviews for participants. Past research has found that songwriting can be an accessible form of expression for some participants who found spoken language challenging, as music affords opportunities for non-verbal expression (Clark et al., 2020; Lee et al., 2022; Thompson et al., 2021b). To our knowledge, this is the first time that a 'songwriting style' interview method has been used as a form of data generation with this population. Therefore, we

based the format of the 'songwriting style' interview on Baker's (2015) model of 'therapeutic, insight-oriented songwriting' (p. 209, 212), therapeutic songwriting methods previously used with people living with dementia (Baker & Stretton-Smith, 2018), and examples of songwriting for data generation used with young children who found verbal discussion challenging (Fairchild & McFerran, 2019). The researcher used prompt questions and probes to assist the participants in brainstorming ideas and key words (Baker, 2015), and then reflected these back to the participant by arranging them into lyrics and singing them with guitar accompaniment. Participants were then able to change or add to the lyrics, either through discussion or improvising additional lyrics (based on the preference and ability of the participant) (Baker & Stretton-Smith, 2018; Fairchild & McFerran, 2019).

A more detailed outline of the procedure for the 'songwriting style' interview is included in the Appendix.

While we felt it important to offer the 'songwriting style' interview as an option, we also recognised, based on our existing relationship with participants, that some may not feel comfortable making music on an intimate level. Therefore, the option for a typical interview was also offered.

Participants were asked two overarching questions to guide the data generation process:

1) What is it like being a member of the RMM choir?
   and
2) What has it been like doing choir on Zoom?

An interview schedule with more specific questions was devised to prompt discussion if participants had difficulty recalling their experiences or understanding the question (Appendix), however, this was not needed. Participants were offered a choice between audio only and audio and video methods to record their interviews; all participants chose audio only recordings.

Data Analysis

Analysis of 'songwriting style' interview data. Songs that were composed during the 'songwriting style' interview are included verbatim in the results (without further analysis), because during the generation of these songs, participants and the researcher reflected on, analysed and interpreted the experiences that the songs described. A member-checking phase was used approximately 6 weeks after the initial interview to confirm that participants felt that these songs accurately represented the essence of their experience.

Analysis of traditional interview data. The traditional verbal interviews that were recorded during data generation were transcribed and analysed using an adapted form of Interpretative Phenomenological Analysis (IPA), in which arts-based research (ABR) methods were used to encourage deeper analysis. Figure 1 summarises the steps involved in the analysis process.
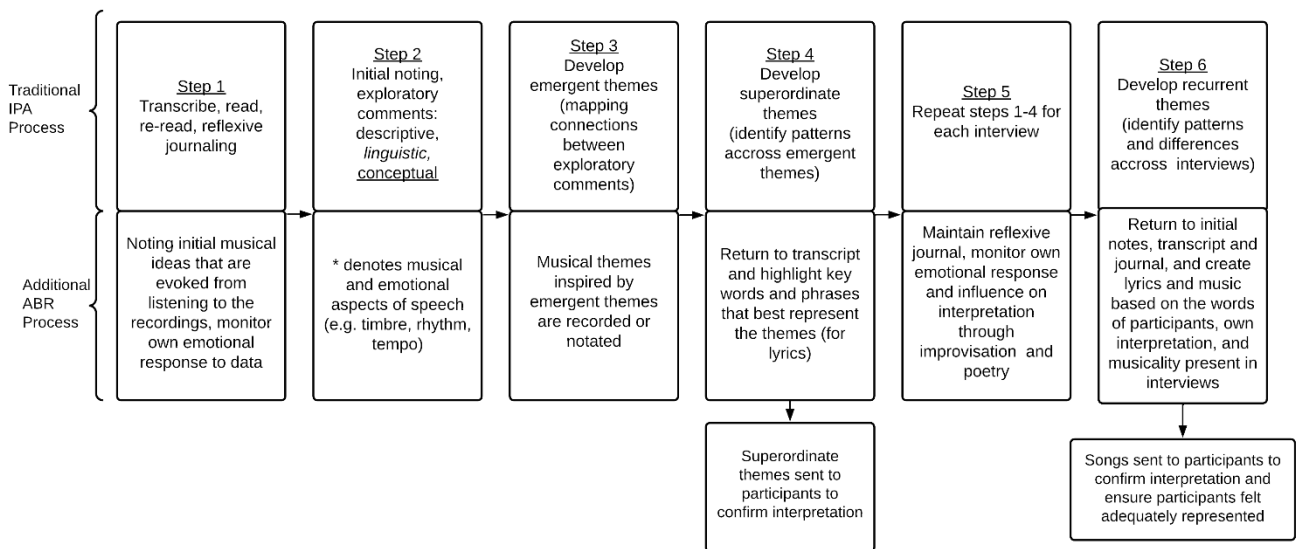
Figure 1. Analysis Process Using Interpretative Phenomenological Analysis (IPA) and Arts-Based Research (ABR) Methods.

Steps 1-2. First, interview recordings were transcribed, re-listened to and re-read several times, during which ZT journaled about emotions that arose while listening to the interviews. Next, ZT undertook an initial noting phase in which she documented exploratory comments reflecting her initial response to the interviews. These comments were categorised into three groups in keeping with IPA protocol: descriptive notes (represented by plain text) labelled general ideas emerging from the data; linguistic comments (italicised) captured the way that words and language was used by participants, including the rhythm, tone, prosody and emotion evident in the way participants spoke; and conceptual (underlined) comments that sought deeper interpretation and interrogation of the data.

Steps 3-5. The exploratory comments developed in step 2 were then re-examined to develop emergent themes, which conceptualised the initial comments in a more succinct manner, and musical themes that were based on the musicality noted in the initial comments were recorded or notated. These emergent themes were then grouped in a process of searching for commonalities or key concepts, following which themes that were less relevant (either by frequency or apparent importance to the participants) were discarded (step 4). During this process, ZT repeatedly returned to the initial notes made in her reflexive journal, and highlighted words spoken or sung by participants that resonated strongly with these superordinate themes as they were developed. This process was repeated for each transcript, and once completed, a summary of key themes for each participant was made and returned to the participants along with a copy of the transcript so that they could confirm that it represented their perspectives, or request any changes. Although IPA typically rejects the need for 'member checking', as it may risk diluting the interpretations (Smith et al., 2009), in this case it felt necessary. Firstly, as ZT was so closely connected to the participants and phenomenon being studied, member checking was an important process in ensure that the participants' perspectives were truly centred. Secondly, from an ethical perspective, this ensured that participants were comfortable with the content that would be shared publicly, given the highly emotional content, and the fact that some participants may not have been able to recall what they disclosed during the interviews. Throughout the analysis process, ZT maintained a reflexive journal to monitor her emotional response to the data, and used arts-based approaches such as poetry

writing and improvisation to process her thoughts; this helped ZT to acknowledge and understand her interpretations and how they differentiated from the data.

Step 6. A final cross-case analysis was then conducted, searching for commonalities, or key differences between participants' perspectives. During this phase, superordinate themes from all interviews were grouped together based on convergence or divergence, to create an overarching picture of the most salient themes for the participants as a whole. These recurrent themes were then grouped into four overarching categories, which formed the basis of 'movements' of the song cycle. ZT returned to the reflexive journal kept during the initial phases of analysis, and colour-coded comments and quotes from participants that were relevant to each recurrent theme and overarching movement. The summaries that were previously presented to participants for member checking were then used to create a nuanced story for each recurrent theme, capturing the ideographic nuances of each experience described.

ZT then returned to the transcripts and copied the text that related to the original superordinate themes into a master document for each recurrent theme. These excerpts from the transcripts and the stories for each recurrent theme were used to inspire the creation of lyrics, using as much of the participants' verbatim words as possible, with some artistic license employed to help the rhythm flow where needed. During this time, ZT repeatedly returned to the initial annotations made in her reflexive journal to ensure that the emotions and embodied ways in which participants spoke in the recordings was also captured in the rhythm and prose of the lyrics as they were formed. Initial musical elements for the rhythms were trialled during the lyric writing process, however, the main musical form and structure of each song was developed through a process of improvisation; ZT took completed lyrics and improvised using either piano, guitar or a cappella singing. ZT once again returned to the initial annotations and listened back to the original interview recordings to re-familiarise with the rhythm, prosody and tone that the participants initially spoke with. Where these elements were used by participants to emphasise a particular word or sentence, they were incorporated into the musical elements of the compositions. Musical styles and forms that are typical of the repertoire that the choir usually sings were selected, as this felt the most authentic way to represent the data through song (Kalenderidis, 2020). Written lyrics and demo recordings of the songs were then shared with the participants, who had the opportunity to provide feedback and make changes if they wished (Mykitiuk et al., 2015).

Initially, we had planned to have willing members of the RMM choir perform and record the songs developed through this project. However, due to ongoing COVID-19 restrictions, a live recording was not possible. Some participants recorded vocal parts to songs that resonated the most with them, and additional vocals were provided by the research team, members of MIND research group, and family and friends.

As ZT held the dual role of researcher and choir facilitator, she kept a reflexive journal throughout the analysis process to keep track of any pre-conceptions, as well as assumptions and emotional reactions to the data that emerged. Rather than attempting to bracket out these assumptions and reactions, ZT returned to the journal frequently throughout the analysis process to 'check in' and reflect on how the data was interacting with these pre-conceptions (Smith et al., 2009).

Findings

Eleven (out of approximately 30) members of the RMM choir consented to participate in this study. These included three participants with dementia (who had a range of diagnoses including Alzheimer's disease, behavioural variant Fronto-Temporal Dementia (bvFTD), and Dementia with Lewy Bodies) and eight participants who were family care-partners of

past (3) or current (5) choir members. The analysis process generated 18 recurrent themes, represented by 18 songs. These songs were grouped into four overarching themes, labelled here as 'movements'[1] (Table 1). The songs are presented in the form of a song cycle[2], where each song is a 'part' of the overarching movements. In the following section, the first author ZT will elaborate on the meaning of each song, and reflect on the composition process – consequently, the voicing of this paper will change to first person during this findings section in order to reflect ZT's individual reflections.

Table 1. Overview of Song Cycle Movements and Parts.

Movement	Song Title
I: The Dementia Experience	Part 1. Assumptions
	Part 2. Finding Supports
	Part 3. Staying Positive
	Part 4. We've Still Got Music
II: The Choir Experience	Part 1. Acceptance
	Part 2. A Different Kind of Support
	Part 3. Sharing Support
	Part 4. Uplifting
III: The COVID-19 Experience	Part 1. Don't Want To Think About It
	Part 2. Everything Stopped
IV: The Virtual Experience	Part 1: Zoom, Not Doom and Gloom
	Part 2: Something To Look Forward To
	Part 3: Audio Limits
	Part 4: Technology Isn't Easy
	Part 5: Too Much Talking/So Much To Say
	Part 6: Staying Connected
	Part 7: Relief
	Part 8: What Makes It Work

Movement 1: The Dementia Experience
This movement captures the way that participants spoke about their experiences of living with dementia or caring for their loved one with dementia. Part 1.1 – Assumptions reflects comments from both care-partners and participants with dementia about the lack of accessible activities for them, often impacted by assumptions that people make about their ability to participate. When composing this song, I aimed to capture the frustration that I heard in participants' voices as they described the stigma that influenced the lack of care and opportunities that they received. At the time of data collection, results from a Royal Commission into Aged Care Quality and Safety were being released and discussed in the media (Commonwealth of Australia, 2021), which may have additionally framed the perspectives of participants at this time. Participants made minor changes to the lyrics at the start of the third line (adding in 'it feels like') to emphasise that the subsequent statements were not universal, but that this was how they perceived others' behaviour towards them.

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[1] The term 'movement' in music refers to a self-contained section of a larger musical work, that can be performed alone or as part of the complete work (Benward & Saker, 2015)

[2] A song cycle is a group or collection of individual songs that are thematically linked and composed to be performed in a specific sequence, often to convey a story or narrative (Bingham, 2004)

Part 1.1: Assumptions

https://soundcloud.com/user-380537750/11-assumptions/s-IdyHBG46Q7S?si=42072d5d6424458c8d2bc3b4a611e915

People think we're happy to just stay home
That we're too old. Not capable, to learn

It feels like no one knows how to treat us?
Is it that, or no one cares?
People think that we don't notice
Or that it's not worth it
It's too hard
Trying to include us

Even if we can't remember
We have feelings don't you know?

It's a shame to make that judgement, without giving us a go

There's not enough credit given
To what we can do
We're not in kindergarten
Give us a chance and we'll show you

We want to be where the action is
We want to get out the door
And we can do it
With the right support

Like Lennon and McCartney said
We get by with a little help from our friends

Part 1.2 – Finding Supports reflects the perspectives of three care-partners who described the challenges of finding appropriate and accessible supports or activities for their partners. Two care-partners discussed how their experience of working in healthcare settings gave them knowledge of what supports were available, while the third described the challenge of knowing where to start and what could be helpful. Again, a sense of frustration and exasperation was evident in the voices of participants as they described these challenges, as well as a sense of urgency to find appropriate supports in a timely manner for their family member with dementia. I aimed to capture this sense of frustration through tonality (minor key), tempo (increased from the previous song), and articulation (staccato piano accompaniment), which mirrored the prosody of participants' voices during the interviews.

Part 1.2: Finding Supports

https://soundcloud.com/user-380537750/12-finding-support/s-vaozwGgwG2d?si=8139553b5a8142778e8a6f81050189b7

If you're in the biz
Then you know where to go
You know who to ask
To get the show on the road

You've got to know who to call, know what to ask for, know where to go

But if you're just one person
A son or daughter, partner, friend,
How do you find out?
If you don't know what's about

Where do you go, who do you ask for, what do you do?

It's a whole new world, and that ain't easy

Part 1.3 – Staying Positive represents the words of one participant with dementia who described how they felt about living with memory challenges. Several other participants (both with dementia and care-partners) spoke of the importance of staying positive and enjoying the moment, particularly as positive feelings were often maintained, even when memories of specific events were lost. I aimed to capture the jovial nature with which this participant spoke these words, and adopted a style that is preferred by the participant.

Part 1.3: Staying Positive

https://soundcloud.com/user-380537750/13-stay-positive/s-3lBh9o5RRjz?si=1b9814837357479aa441ab055b52428e

Don't let it bother me
but occasionally it's a shit

So we just try and enjoy the moment

Part 1.4 – We've Still Got Music. Two participants with dementia highlighted how their retained musical abilities brought them much joy, despite the memory challenges that they experienced. Care-partners also described how music helped them to connect to their family member who had reduced ability to express themselves verbally. Music helped participants to maintain a connection to memories, sense of competence, and to each other, and singing was highlighted as something that was accessible and inclusive. When participants described the importance of this retained musical ability, I noticed a sense of relief, almost like a sigh in their voices, and attempted to capture this with the gentle melody. The first two lines are a paraphrased quote from one participant with dementia. In doing so, I attempted again to capture the jovial nature of their comments, as they described feeling a combination of pride and surprise at their sustained memory of lyrics.

Part 1.4: We've Still Got Music

https://soundcloud.com/user-380537750/14-weve-still-got-music/s-bCGnpqRfe0N?si=19cc6822c85049e7a271f1cf3b3d3ce1

Name any song and I'll sing the whole thing
But don't ask me what I had for breakfast this morning...

When memories are fading
We've still got music

Memories of times gone by
Flow back with the songs

When memories are fading
We've still got music

Some of us might not talk much
But we can still sing along

When talking gets tough
We've still got music
When words escape us
We've still got music

We can still get together and sing
It helps us get out the door

Movement 2: The Choir Experience

The second movement depicts themes relating to the experience of choir participation more broadly, and do not necessarily relate to the online aspects of the choir. Part 2.1 Acceptance depicts the way that participants described feeling accepted due to the inclusive and accessible nature of the choir, particularly how the shared experience of dementia helped them to feel comfortable and accepted. The backing vocals in this piece are intended to create an open, warm and welcoming sound.

Part 2.1: Acceptance

https://soundcloud.com/user-380537750/21-acceptance/s-giL0P2xG4LO?si=97a5b1a250b3423eaf50839c329b9263

If you're feeling embarrassed
Or like you won't belong
If other groups aren't accessible
well here, you can sing along *[you can sing along]*
We're here to say welcome
You can sing along [*you can sing along*]

You're free to join in as we like
no matter who you are or where you're at
it might be a good day, it might be a bad day
but it doesn't matter...
We're here to say welcome
We'll accept you as you are *[just the way you are]*

Part 2.2 – A Different Kind of Support captures the ways that the participants felt the choir differed from more traditional support groups. Participants felt that singing provided a unique opportunity for them to connect with others because they were working together in the moment towards a common goal. They also described an unspoken understanding between members due to their shared experiences of dementia, and that singing strengthened their connections. Participants acknowledged that there was not one aspect of the choir alone that made the choir successful, and this is reflected in the song through the inclusion of different phrases that participants used to summarise their thoughts about what makes the choir a unique form of support.

Part 2.2: A Different Kind of Support

https://soundcloud.com/user-380537750/22-a-different-kind-support/s-vIs13AAVFor?si=a182ce9e090347eeb8cf515f6e37c32d

Well some groups like to talk, but talking's not our style
Some people might find it helpful, but here, singing takes us the extra mile

When we sing together, we achieve together
It's something much deeper than just talking together

When you come along to choir everybody understands
Without saying a word
You don't have to explain, we're all going through it too
Experiences shared help us connect

When we sing together, we achieve together
It's something much deeper than just talking 'bout the weather

Singing helps us to connect no matter our ability
An unspoken understanding, a nod, a sing, a cup of tea

And singing unites us, we're sharing a moment
Singing connects us on a level that talking never could

It's what we want do, that's why we do it
We share a common goal when we sing together

And you can see our friendship so solid and deep
We really love each other like a big old family

Without saying a word, everybody understands
Just a nod, then sing, then a cup of tea
It's like indirect therapy

Part 2.3 – Sharing Support. Participants described the way that the social support they received from other group members was a crucial aspect of the choir, and also how being able to support others was equally important to them. As theme of support continued from the previous song, I chose a similar country feel so that the two are stylistically similar. However, I chose a gentler triple metre for this song, to reflect the tenderness with which participants described feeling supported and supporting each other within the choir.

Part 2.3: Sharing Support

https://soundcloud.com/user-380537750/23-social-support-2/s-wlLQc5yrypT?si=a209684c350f4f05abd11b0af79fc4d5

That's what keeps us coming
That's why we come along
To see the joy on each other's faces
Makes us feel strong

When times get tough, we support one another
We've got our own problems, but we'll still lend a hand

You can share with us what you're going through
And know that we'll understand

You get a lot more out of giving than taking
And choir is a place where you can give
Sharing our knowledge, sharing our skills
Sharing our voices, and lend a caring ear

The final part for this movement, 2.4 Uplifting, reflects the positive feelings that participants experienced when singing. When speaking of the effects of the act of singing in the choir, participants became emphatic; their speech was energetic, and became bright and rhythmic, as they were excited to talk about the positive impact of singing. Compositionally, I have tried to capture this energy and brightness through a complex rhythm and time signature, changing articulation between staccato and legato, and a melody that ascends throughout the song.

Part 2.4: Uplifting

https://soundcloud.com/user-380537750/24-uplifting-1/s-szSwvxhKwyx?si=ff98262b7522489c9f152c375ee93603

Singing lifts the spirits and soothes the soul
Better than just medicine, wish we could bottle it
That amazing feeling

It doesn't matter what we sound like, professional or just for fun
The feeling we get when we sing together
If we didn't get it, we wouldn't come

When you're chatting away, and a favourite comes on
You can feel it in the air, everyone's happy and ready to sing
It's a feeling of joy we can share

Singing together brightens your brain
Happiness and wellbeing, it helps to maintain

Sing your worries away

Movement 3: The COVID-19 Experience
This movement depicts the ways that participants felt about the experience of living through the COVID-19 pandemic and subsequent lockdown. At the time of the interviews, we had recently come out of our third lockdown, and were cautiously planning to resume face-to-face singing. As participants reflected on their experience of the pandemic and subsequent lockdowns, there was a sense of tension and anxiety.

Part 3.1 Don't Wanna Think About It was composed by one participant who has memory challenges throughout their interview. They improvised lyrics and melody following a brief discussion about how they felt about COVID-19.

Part 3.1: Don't Wanna Think About It

https://soundcloud.com/user-380537750/31-dont-think-about-it/s-Wrl7parUva4?si=c9b15d9b002e48598be12269a7086374

Don't wanna think about it
Get it out of my head
'Cause if I think about it
I'm gonna end up dead

Get this COVID out of my street, out of my town
It's just bringing me down

Part 3.2 – Everything Stopped attempts to capture the anxiety and isolation that participants experienced as a consequence of the pandemic and lockdown. When participants described these experiences, anxiety and frustration was evident in their voices; prosody became restricted and tense, and occasionally participants exclaimed loudly about their exasperation at the situation. The tempo, staccato bass line and tonality of the piece aims to reflect the tension and anxiety that was evident in the voices of participants.

Part 3.2: Everything Stopped

https://soundcloud.com/user-380537750/32-everything-stopped-2/s-RL4j5dn1ftg?si=80a11b952e6345829ce4ee118d316233

Everything stopped
Every day was the same
Nothing else to do but worry
Nothing to distract

Everything stopped
At least if we'd had work or home-school
We'd have something else to do
But every day, more of the same

Worry, fear, anxiety
Overwhelming me

Everything stopped
Our loved ones in aged care
No one to tell us how they were
Every day was more bad news

'If anything happens, we'll let you know'
Try to keep busy, try to stay on the go
But it's hard when you're stuck at home

Everything stopped
Sadness and frustration
When you can't see your loved ones
No way to contact, at the mercy of staff

Everything stopped
No activities
No films, no plays, no galleries
No concerts, no visits from family

None of the things that we used to do
I want to call my friends
But I don't want to intrude

Everything stopped
Not even help or usual supports
All cancelled, all had to stop
Hard to find someone who can meet our needs

There's nothing much, what can we do?
Nothing much, just sit at home and

Worry, fear, anxiety…

Movement 4 – The Virtual Experience

The final movement depicts the various ways that participants experienced the virtual choir. On the whole, the experience was perceived as positive and an important substitute for choir during a time where we could not meet. However, the virtual format was not without its limitations, which members described in relation to accessibility and enjoyment. Part 4.1 – Zoom, Not Doom and Gloom, was composed by one participant, who brought the idea to the interview, and refined it following our discussion. This song summarises the transition from in-person to virtual singing. As the song is a parody of Sheb Wooley's 1958 song 'The Purple People Eater'. We have not included a recording due to copyright reasons. However, we have included the lyrics as they contextualise the experience and honour the creative contribution of the participant.

Part 4.1: Zoom, Not Doom and Gloom

Well we saw the thing comin' onto our screens
A big blue Z and what does it mean?
We commenced to cheerin' and said 'ooh-eee'
It looks like Zoom has arrived – yipee!

Chorus
It was a 54 eyed, 27 mouthed
Singing Zoom Memory Choir
Nothing can stop us from singing

Zara had been working hard we could see
'Blue Z, double O, M, said she
Here's how I can visit you all each week
Link you together – now no more cheek!

Chorus

Cos that purple spiky virus has us all at home
No more singing in the chapel – we were alone
But we really need to connect real bad
To keep us smiling and not feeling sad

Chorus

So thank you Zara and your blue Zoom
We love to see each other from our living rooms.
Damn that spikey virus that has changed our lives
But it can't stop our Friday musical vibes!!!!

Chorus

Part 4.2 Something To Look Forward To, highlights how participants described the weekly virtual choir sessions as something that they looked forward to each week. They felt that the fact that almost all choir members (who were able to) attended, and that being able to maintain our connection was something they valued. I chose a gentle melody to reflect the sense of calm that the choir appeared to bring for participants each week. Towards the end of the song, I brought back the lyrics and melody from Part 1.4 – We Still Have Music, as I felt that the way in which the online choir provided ongoing connection for the group was analogous to how music provides participants with dementia an ongoing connection with their identity.

Part 4.2: Something To Look Forward To

https://soundcloud.com/user-380537750/42-something-to-look-forward/s-gqglOdTTaYZ?si=283577141fcc480abce82e4cf128f280

Something to look forward to
Something to look forward to

Nothing locks us down
Something to look forward to
A light for us each week
Something to look forward to
Almost everybody came along
Something to look forward to
Nothing locks us down
Something to look forward to

A special time for us each week
Something to look forward to
The only way for us to meet
Something to look forward to

Something to look forward to
We still have music

The reduced musical quality and inability to sing in unison over the online format appeared to be one of the major drawbacks described by participants. In composing Part 4.3, Audio Limits, I have attempted to demonstrate the limitations of the virtual choir that participants experienced, contrasted with the benefits they felt when singing together, through changes in the texture of the vocal part and tonality of the melody. For example, the first verse and chorus are sung solo, to reflect the feeling of singing alone at home – the tonality here is minor to reflect the sullen nature of singing alone compared to in a group that participants described. In contrast, the following choruses shift to a major tonality and are sung by a chorus, to depict a more joyous feeling of singing together with others.

Part 4.3: Audio Limits

https://soundcloud.com/user-380537750/43-audio-limits/s-srRQarm6DqB?si=0895a82d9d1f462089784d3b33996b0e

When you're singing on your own, it doesn't feel the same
I see lips moving on the screen, but can't hear what they sing

No harmonies, nothing unique
It's like we're not a group
Some songs drag on when we can't hear the fun parts
But I guess it will have to do

Other voices lift you up, so you cannot sing wrong
Safety and motivation is missing in our virtual song

With harmonies it's encouraging us all to raise our voices
Hearing others sing is guiding
And much more satisfying

When we sing together, it's a common goal
It lights up our brain
Hearing every voice, every contribution
Brings us together again

It's not ideal to sing alone
We want to get out the door
And sing together but we sacrifice
To keep everybody well

Part 4.4 – Technology Isn't Easy: Participants spoke about the challenges of accessing and learning to use new technology. They highlighted that being able to access the technology to join the virtual choir was predicated on having the right equipment and having someone to help them learn to use it, which was difficult during lockdown. The repetition of 'need[ing] the right kind…' of support is intended to represent the participants' repeated search for assistance.

Part 4.4: Technology Isn't Easy

https://soundcloud.com/user-380537750/45-technology-isnt-easy/s-CVZO9Y4rwxI?si=6df29c6f4f444ebf9a8dccb312a1a505

Technology it isn't easy
You need the right kind of help
You need the right kind of help

Right time right place, right person
It's hard in a lockdown when you rely on the right kind of help

Technology it isn't easy
You need the right kind of gear
You need the right kind of gear

No computer, no phone, nothing fancy
If things cost money, don't you see
It's not accessible for everybody
You need the right kind of gear

It's a wonder we had anyone there
And that we're still going after a year

Technology isn't easy
When you rely on staff who are busy

Needing help, feeling reliant
Takes some of the shine of our choir
When you need the right kind of help

Part 4.5 – Too Much Talking/So Much To Say depicts the tension between the competing needs of group members. The format of virtual platform meant that only one person could speak at a time, which resulted in more discussion as a whole group. Some participants reported that they enjoyed this aspect, as it allowed for increased sharing of important information, and was a way for those having a hard time to share their experiences. However, others found that increased chatter during the choir session was not accessible for everyone, particularly for members who had communication difficulties or challenges with focusing on the screen. In this song, I have used an a capella accompaniment to represent the chaotic audio environment that can sometimes occur on the online platform when multiple people attempt to speak at once.

Part 4.5: Too Much Talking, So Much To Say

https://soundcloud.com/user-380537750/44-too-much-talking/s-ITcUfck2DUl?si=78a51e98219c44b58aba857180090ca7

Too much talking so much to say

How can we balance
Everyone's needs
On a platform that's not ideal

One voice at a time
Gives space for us to share
Information, feelings, updates
With everyone together

One voice at a time
More talking than before
It's not accessible
For some of us who find
Conversations hard

How can we balance
Everyone's needs?
On a platform that's not ideal

Despite acknowledging the challenges of the online format, participants were keen to ensure me that the format was generally a positive experience, as it helped them to stay connected during the lockdown in a way that telephone calls and emails could not. They described how the online choir format allowed for whole group interactions, compared to individual phone calls or unidirectional emails. The virtual choir also provided a way to include members who lived too far away or were not well enough to attend in person after lockdowns ended, and helped participants to envision how this technology could be used beyond the end of the pandemic. In Part 4.6 (Staying Connected) I recall the melody from Part 3.2 – Everything Stopped, to highlight the contrast between other supports stopping, but the choir continuing. As the song progresses, the melody from Part 2.3 – Sharing Support also returns (this time in duple metre), as I felt that it connected with the idea of mutual support that participants described as an essential motivator for them to attend. The reprise of this melody also signifies that this sense of 'shared support' was still present in the online format.

Part 4.6: Staying Connected

https://soundcloud.com/user-380537750/46-stay-connected/s-jfGVEyoed9Q?si=aa712370c9c5475c98363c73adc09f07

But it's not all doom and gloom…
When everything stopped, Zoom kept us together
When emails and telephones call weren't enough

Showed us a way to welcome other people
Who live too far away or can't get out the door

It filled a void every Friday afternoon
And helped us see the future, what's possible to do

We are still here, it helped us stay together
We kept that connection when COVID locked us down

Had to learn new skills beyond our imagination
Technology ain't easy but look at us now

Participants spoke emphatically about the way that the online choirs provided relief from the stressful reality of lockdown. Although participants were grateful for the relief that the choirs provided, a sense of tension in describing the need for relief during lockdown remained. In Part 4.7 – Relief, I have attempted to capture this through the harmonies and contour of the melody. Towards the end of the song, theme from 2.4 – Uplifting returns to draw a connection between the relief felt from regular participation in the online choir, and the positive feelings that singing stimulates.

Part 4.7: Relief

https://soundcloud.com/user-380537750/47-relief-1/s-mgaQQrt0mtf?si=f736c33cb6854322b0735868e674b52f

Takes us away from reality
Takes us away from reality
Something we needed every week
Something we needed every week

Choir on Zoom brought us some relief
Choir on Zoom brought us some relief
From the stress and monotony
Of lockdown every week

Gives us a break from reality
Gives us a break from reality
Of lockdowns every week
Of lockdowns every week

The light at the end of the tunnel each week
Singing lifts the spirits and soothes the soul

The final song, Part 4.8 – What Makes It Work, captures participants' reflections on what they felt made the online choir format successful. Factors including leadership, structure and familiarity were noted as important. I chose an upbeat tempo blues style for this song to reflect the musical preferences of participants.

Part 4.8: What Makes It Work

https://soundcloud.com/user-380537750/48-what-makes-it-work-1/s-ij33BZziumL?si=192249e86d10460fb7f436d8f0ab6a7b

You need a good leader
To help us balance our needs
You need a good structure
To help us understand the routine

Staying as close to what we've always done
Helps to keep the Zoom format feeling fun

Our friendships and connections helped us to make it work
Knowing each other made it feel less awkward

Singing together is our thing
We gave it a go because we needed to sing

That's what makes it work
That's what made it work

Discussion

The songs created through this research process reveal nuanced experiences of living with or caring for someone who has dementia, singing in a community choir, living through the COVID-19 pandemic, and attending choir virtually. Stigma, assumptions about ability, and lack of access to community and supports captured in Movement 1 reflect challenges described by people with dementia in the extant literature (Swaffer, 2015). Similarly, the way that participants described singing as being uplifting, soothing, and providing relief reflects previous findings that suggest that singing has a positive impact on mood for people living with dementia and their care-partners (Thompson et al., 2021a).

Accessibility of Singing and Music

Some participants with dementia described feeling a sense of joy and/or pride at their retained musical skills, particularly as they had difficulty recalling other things throughout the day, while care-partners also expressed how singing and music more broadly helped those who were unable to use language to communicate to share emotions and memories with their loved ones. This is consistent with research that indicates musical ability and memory of music can be retained despite a dementia diagnosis (Beatty et al., 1999; Ho et al., 2019), and that being able to participate in music is empowering for people with dementia (Baker & Stretton-Smith, 2017). Participants described choir singing as an activity that was accessible for people living with dementia; the choir is a place where people could come and be themselves, without judgement of their abilities or disabilities. The idea that group singing can provide a safe and inclusive space has been acknowledged

in the literature previously, due to the comfort provided by hearing other voices and being surrounded by people with similar experiences of dementia (Lee et al., 2020; Osman et al., 2016).

Notably, the biggest limitation of the virtual choir format was the audio/musical quality and lack of synchronous singing due to latency. Some participants felt uncomfortable singing alone due to the lack of auditory feedback from other voices; one care-partner even described how the lack of other voices made singing less accessible for their partner who had language difficulties. Datta (2020) theorised that the lack of auditory and environmental feedback in a virtual choir could preclude embodied emotional responses that are typically present when singing together in-person. This seems to align with the way that participants in the present study described feeling discomfort, less motivation to join in and less satisfaction from virtual singing. This finding of reduced motivation and satisfaction with the virtual choir format has important implications for practice, as it suggests that online singing may not be as accessible for some people with dementia, and as some of the benefits of singing may not be as impactful when singing in virtual spaces.

Importance of Social Connection and Support

The importance of social opportunities and support was echoed throughout each of the four movements in the song cycle. The lack of social opportunities for people with dementia and challenge of finding appropriate supports were highlighted in Movement 1 (1.1 and 1.2), while Movement 3 demonstrated how COVID-19 risk and restrictions exacerbated social isolation. Lack of accessible opportunities for social engagement and connection for people with dementia continue to be described in the literature despite advances in dementia advocacy (Swaffer, 2018) and preliminary research confirms the significant impact of COVID-19 restrictions on the social opportunities and support (Manca et al., 2020).

Participants described how the choir afforded both social connection and support (Movement 2, Parts 2.2 and 2.3), and emphasised the importance of the virtual choir in maintaining these connections during COVID-19 lockdowns, despite the limitations of online platforms (Part 4.6). This supports findings from Lee et al. (2021), who found that online choir formats during the COVID-19 pandemic helped to maintain connections and reduce social isolation for participants with dementia. This is notable, as social connection and support are recognised as key benefits and motivators of choir singing for people with dementia and care-partners (Lee et al., 2020; Unadkat et al., 2016). It is encouraging that participants in the present study felt that the virtual format aided in maintaining these benefits, despite the limitation of only one person being able to speak at a time. Some participants reported that they appreciated this group conversation aspect, as it allowed for the whole group to hear member contributions, particularly when it came to sharing important information or personal stories. However, other participants described that the group conversation format was not accessible for some participants with dementia who found spoken communication challenging. Balancing the need for conversation with the needs of those for whom this was not accessible was the primary challenge of the virtual choir format (Part 4.5 – Too Much Talking, So Much To Say). A scoping review of online singing groups recommended the use of 'break-out' rooms, where members can have small-group discussions, as a way of mitigating the lack of natural conversation in a virtual group (Dowson & Schneider, 2021). Since the completion of this study, we have implemented 'break-out' rooms at the end of our singing session, which have generally been well received, although members report that they still appreciate some level of group discussion within sessions as well.

Suitability of Online Format

Although the online choir format was well received, participants noted that the technological aspects were challenging, particularly as they were often having to learn to use the technology independently or remotely (e.g. being guided over the phone) due to restrictions preventing someone assisting them. The reliance on family or staff to support participants who were unable to use the technology independently reflects challenges identified by facilitators navigating transitions to online choir formats during the COVID-19 pandemic (Lee et al., 2021). The cost of the technology to access the virtual choir (e.g. tablet/computer and internet connection) was also flagged as a barrier for some participants. Despite these challenges, participants also commented on how proud they were that they were able to learn new technological skills.

Several participants commented that the virtual format made the group more accessible for people who could not reach the choir in-person due to geographical distance, and some also noted that this may be an accessible for option for people with dementia who may have difficulty attending in person due to medical or psychological reasons. These reflections add support to the growing body of literature that recognises online interventions as a suitable support, particularly for older people who are isolated geographically or due to COVID-19 restrictions (Baker & Tamplin, 2021; Laver et al., 2020; Lee et al., 2021; Merrell, 2015).

Participants described the factors that they felt made the virtual format work, including the importance of structure and leadership, which have previously been cited as important factors in the success of in-person choirs (Thompson et al., 2021a). However, the existing connection between choir members was seen as a crucial element that made the transition to the virtual format accessible (Part 4.8 – What Makes It Work). Participants were unsure of whether the format would have been as successful if participants were not already familiar with each other. While there is evidence of other music groups forming successfully online (where participants did not know each other prior to joining) (Fuller & McLeod, 2019; Thompson & Khalil-Salib, 2021), to our knowledge, there are no published studies on forming a new singing group specifically for people living with dementia online.

Reflections on the Arts-Based Approaches – Benefits and Limitations

In designing this study, arts-based approaches were selected for three reasons: a) to provide an accessible alternative to traditional qualitative interviews; b) to aid in reflexivity of data-analysis, and c) to disseminate the findings in a way that is accessible for people with dementia and non-academic readers, and that assists audiences to understand the experiences of the participants on an emotional level. In regards to the first reason, only two participants (one who experienced memory challenges, and one care-partner) opted to trial the 'songwriting style' interview, and both also opted to join in a traditional interview as well (with one participant completing their song following the interview and sending it to the researcher). The reluctance to try the 'songwriting style' interview option generally seemed to stem from apprehension of trying something a bit out of participants' comfort zones (as participants reported feeling hesitant to try it) , and also a desire to have a deeper conversation with the researcher. This may have been due to the fact that the interview was the first time that the researcher (who is also the choir facilitator) had seen the participants in person in several months, and therefore was the first opportunity for a proper conversation that was not in front of the group on Zoom. While the participants who engaged in songwriting reported that they enjoyed the experience, they were also able to engage in verbal interviews easily; the songwriting therefore acted more as an enjoyable addition to the interview, rather than as an accessible alternative. Therefore, no conclusions about the accessibility of songwriting as a data-collection method for people with communication difficulties can be drawn.

In relation to the use of arts-based methods throughout the analysis process, ZT felt that this was a useful tool in maintaining reflexivity, particularly as during the data-analysis stage, the choir went back into lockdown, and some of the stresses and anxieties that participants described in the interviews became reality again. Using improvisation and poetry writing was a useful way to process this anxiety and ZT's reactions to the data during the analysis, to ensure that it did not override the interpretative analysis. Participants commented that they felt the songs accurately reflected their experiences and the perspectives that they shared during their interviews. Several commented that they wanted to share the songs publicly, as quickly as possible, for self-advocacy purposes; they felt it would help others to understand their situations, particularly in relation to their experiences of COVID-19 risks and restrictions. One participant even requested that the choir sing one of the songs (Part 1.4 – We Still Have Music) during our online choir session, and other members of the choir who were not part of the research commented that this song was particularly meaningful for them as it also represented their experiences.

General Limitations

Although this study provides an important insight into the experience of transitioning to virtual choir sessions for people with dementia and their care-partners, the findings are based on the unique, ideographic perspectives of participants. Therefore, these findings cannot be generalised, and should be considered within the context of the choir, particularly during the COVID-19 pandemic period. In this study, we incorporated an arts-based approach to data generation in the hopes that it would enhance accessibility for participants with dementia. However, only three participants with dementia consented to be involved in the project. While the care-partners who participated in this project were able to provide important insights into the experience, the perspectives of people living with dementia are still underrepresented. Although our analysis revealed similar perspectives between all participants, we have generally not distinguished between the perspectives of participants with dementia and care-partners in the findings. This was partly due to our commitment to viewing all choir members as equal, and acknowledging the shared experiences that arose throughout the analysis. However, this also contributes to underrepresentation of perspectives from people with dementia, as their individual views are not presented independently.

While our study aimed to utilise an arts-based approach to data collection (through the 'songwriting-style' interview), this was limited as the majority of participants declined to try this method, and those who did opted to combine it with a traditional interview format. This reflects challenges experienced by Synnes et al. (2021) who found that participants with dementia were often hesitant to engage in poetry writing as a form of data generation for fear of failure or making mistakes. Notably, in the present study, participants who were care-partners reported similar anxiety relating to their musical abilities. A further limitation is that our study included only one participant with a diagnosis of dementia who was unable to engage in fluent verbal conversation, and this participant also declined to trial the 'songwriting style' interview option (they instead chose to sit in on the interview and made brief comments, while their care-partner responded to most of the questions). As it was hoped that the 'songwriting style' interview method may be more accessible for people with communication difficulties, this study lacked participants for whom we anticipated this method would benefit. Although our rationale for offering the choice of a traditional format in addition to 'songwriting style' interview was to maximise accessibility and participant comfort, this freedom of choice resulted in a limitation in regards to understanding the feasibility and acceptability of using this arts-based method in future projects.

Implications for Future Research

As the accessibility and cost-effectiveness of online technologies improves, we are already seeing a trend in incorporating technology into dementia care. This study demonstrates that a virtual choir is not only achievable, but acceptable, particularly in circumstances where other options are not available (e.g., due to lockdown restrictions). However, the findings regarding the lack of motivation and satisfaction from online singing compared to in-person singing are important to note, as they may indicate that some of the benefits that people with dementia and care-partners regularly report receiving from singing may not be felt during virtual choir sessions. Similarly, the success of the online format was partially attributed to the strong bonds that existed between choir members prior to transitioning online. Further research is required to determine whether virtual choir participation can be successful and beneficial alternative for people living with dementia, when in-person options are not restricted.

Conclusion

This paper aimed to share the perspectives of people living with dementia and care-partners as they navigated the challenges of dementia and the COVID-19 pandemic while singing together in a therapeutic, community-based choir. The findings reveal that the choir provides important opportunities for connection and positivity that can mitigate the challenges that participants experience due to both cognitive changes and societal stigma. Transitioning to an online format was challenging and, at times, less accessible than in-person singing, however, participants continued experiencing benefits from participating online, and valued the opportunity to stay connected during a time of unprecedented isolation and anxiety. Both the findings and the contributions made by participants throughout this study demonstrate the resilience of people living with dementia and those who care for them. This study has highlighted ways that caregivers and care recipients can support each other and also contributes helpful information for other people who are navigating a diagnosis of dementia.

Acknowledgements

About the Authors

Dr Zara Thompson is a post-doctoral research fellow and music therapist at The University of Melbourne. Her clinical and research interest relates to using music to support people living with dementia and their care-partners, and how music can create accessible and inclusive communities. Zara also works clinically with NDIS participants, and facilitates the Rewire Musical Memories choir – an inclusive and therapeutic choir for people living with dementia and their care-partners.

Professor Felicity Baker (music therapy) is Associate Dean (Research) for the Faculty of Fine Arts and Music and Director, International Research Partnerships for the Creative Arts and Music Therapy Research Unit. She is former Australia Research Council Future Fellow (2011–2015) and, during this fellowship, built models of songwriting as practiced through the lenses of different orientations (*Therapeutic Songwriting: Developments in Theory, Methods, and Practice*, Palgrave 2015). Professor Baker is currently leading a series of trials with people living with dementia. Felicity has attracted more than $15.5 million in competitive research funding including Principal Investigator on 3 National Health and Medical Research Council grants, (NHMRC), an Australia Research Council Discovery Grant and a Medical Research Future Fund.

Dr Imogen Clark is a Senior Lecturer in Music Therapy at the University of Melbourne. She has an active research agenda with focus on music therapy and healthy ageing, music listening and physical activity, guided imagery and music, and music therapy pedagogy. She was awarded the Hazel Hawke Dementia Australia grant in 2018 to investigate the effects of songwriting on the health and wellbeing of families living with dementia and received the La Trobe University Nancy Millis Award for PhD of exceptional merit in 2016. In 2022, she received a University of Melbourne Early Career Researcher grant to investigate online songwriting with people with dementia and their care partners.

Associate Professor Jeanette Tamplin (music therapy) is a Registered Music Therapist and researcher at The University of Melbourne, specialising in neurorehabilitation for people with neurological injuries or conditions. A/Prof Tamplin is a previous NHRMC-ARC Dementia Research Development Fellow (2016-2019) and has over 25 years clinical music therapy experience. A/Prof. Tamplin is also President of the Australian Music Therapy Association. She has been invited to contribute chapters to several edited books on music therapy and has also co-authored a book on *Music Therapy Methods in Neurorehabilitation: A Clinician's Manual* (Jessica Kingsley Publishers) and co-edited a book on *Music & Dementia: From Cognition to Therapy* (Oxford University Press).

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References

Baker, F., & Krout, R. (2009). Songwriting via Skype: An online music therapy intervention to enhance social skills in an adolescent diagnosed with Asperger's syndrome. *British Journal of Music Therapy, 23*(2), 3–14. https://doi.org/10.1177/135945750902300202

Baker, F. A., & Stretton-Smith, P. A. (2017). Group therapeutic songwriting and dementia: Exploring the perspectives of participants through interpretative phenomenological analysis. *Music Therapy Perspectives, 36*(1), 50–66. https://doi.org/10.1093/mtp/mix016

Baker, F., Tamplin, J., MacDonald, R., Ponsford, J., Roddy, C., Lee, C., & Rickard, N. (2017). Exploring the self through songwriting: An analysis of songs composed by people with acquired neurodisability in an inpatient rehabilitation program. *Journal of Music Therapy, 54*(1), 35–54. https://doi.org/10.1093/jmt/thw018

Baker, F. A., & Tamplin, J. (2021). Music therapy service provision via telehealth in response to COVID-19 restrictions: A survey of Australian practitioners and consumers. *Australian Journal of Music Therapy, 32*(2).

https://www.austmta.org.au/public/151/files/AJMT/2021/Issue%201/3_%20AJMT%2032(1)%20-%20Baker%20%26%20Tamplin.pdf

Beatty, W. W., Rogers, C. L., Rogers, R. L., English, S., Testa, J. A., Orbelo, D. M., Wilson, D. A., & Ross, E. D. (1999). Piano playing in Alzheimer's disease: Longitudinal study of a single case. *Neurocase, 5*(5), 459–469. https://doi.org/10.1080/13554799908402740

Beer, L. E. (2016). From embedded to embodied: Including music in arts-based music therapy research. *Music Therapy Perspectives, 34*(1), 33–40.

https://doi.org/10.1093/mtp/miv006

Bennett, D. A., Schneider, J. A., Tang, Y., Arnold, S. E., & Wilson, R. S. (2006). The effect of social networks on the relation between Alzheimer's disease pathology and level of cognitive function in old people: A longitudinal cohort study. *The Lancet - Neurology, 5*(5), 406–412. https://doi.org/10.1016/S1474-4422(06)70417-3

Bennett, J., Froggett, L., Kenning, G., Manley, J., & Muller, L. (2019). Memory loss and scenic experience: An arts based investigation. *Forum: Qualitative Social Research, 20*(1). https://doi.org/10.17169/fqs-20.1.3126

Benward, B., Saker, M. (2015). *Music in theory and practice.* Ninth Edition. McGraw-Hill.

Bingham, R. O. (2004). The Early Nineteenth-Century Song Cycle. In J. Parsons (Ed.), *The Cambridge companion to the lied* (pp. 101–119). Cambridge University Press.

Boydell, K. M., Gladstone, B. M., Volpe, T., Allemang, B., & Stasiulis, E. (2012). The production and dissemination of knowledge: A scoping review of arts-based health research. *Forum: Qualitative Social Research, 13*(1).

https://doi.org/10.17169/fqs-13.1.1711

Clark, I. N., Stretton-Smith, P. A., Baker, F. A., Lee, Y. C., & Tamplin, J. (2020). "It's feasible to write a song": A feasibility study examining group therapeutic songwriting for people living with dementia and their family caregivers. *Frontiers in Psychology, 11,* Article 1951. https://doi.org/10.3389/fpsyg.2020.01951

Commonwealth of Australia. (2021*). Royal commission into aged care quality and safety final report: Care, dignity and respect Australia.* Retrieved from

https://agedcare.royalcommission.gov.au/publications/final-report

Datta, A. (2020). 'Virtual choirs' and the simulation of live performance under lockdown.

Social Anthropology, 28(2), 249. https://doi.org/10.1111/1469-8676.12862

Dementia Change Action Network. (2020). Distancing with dementia - join a virtual choir. Retrieved from https://distancingwithdementia.org.uk/join-a-virtual-choir/

Dowson, B., & Schneider, J. (2021). Online singing groups for people with dementia: Scoping review. *Public Health, 194,* 196–201.

https://doi.org/10.1016/j.puhe.2021.03.002

Fairchild, R., & McFerran, K. S. (2019). "Music is everything": Using collaborative group songwriting as an arts-based method with children experiencing homelessness and family violence. *Nordic Journal of Music Therapy, 28(2),* 88–107.

https://doi.org/10.1080/08098131.2018.1509106

Fancourt, D., & Steptoe, A. (2019). Present in body or just in mind: Differences in social presence and emotion regulation in live vs. virtual singing experiences. *Frontiers in Psychology, 10,* Article 788. https://doi.org/10.3389/fpsyg.2019.00778

Finlay, L. (2009). Exploring lived experience: Principles and practice of phenomenological research. *International Journal of Therapy and Rehabilitation 16*(9), 474–481.

https://doi.org/10.12968/ijtr.2009.16.9.43765

Finlay, L. (2011). *Phenomenology for therapists: Researching the lived world.* Wiley.

Fuller, A. M., & McLeod, R. G. (2019). The Connected Music Therapy Teleintervention Approach (CoMTTA) and its application to family-centred programs for young children with hearing loss. *Australian Journal of Music Therapy, 30,* 12–30.

https://www.austmta.org.au/public/151/files/AJMT/2019/The%20Connected%20Music%20Therapy%20Teleintervention%20Appproach.pdf

Ho, P. A., Stern, T. A., & Rustad, J. K. (2019). "Moon River": Intact musical appreciation and performance in a man with semantic variant primary progressive aphasia. *Psychosomatics, 60*(1), 70–74. https://doi.org/10.1016/j.psym.2018.03.013

Kalenderidis, Z. (2020). The great reveal: The experiences of a Registered Music Therapist with a disability: an arts-based research project. *Voices: A World Forum for Music Therapy, 20*(1). https://doi.org/10.15845/voices.v20i1.2873

Lara, E., Martín-María, N., De la Torre-Luque, A., Koyanagi, A., Vancampfort, D., Izquierdo, A., & Miret, M. (2019). Does loneliness contribute to mild cognitive impairment and dementia? A systematic review and meta-analysis of longitudinal studies. *Ageing Research Reviews, 52,* 7–16. https://doi.org/10.1016/j.arr.2019.03.002

Laver, K., Liu, E., Clemson, L., Davies, O., Gray, L., Gitlin, L. N., & Crotty, M. (2020). Does telehealth delivery of a dyadic dementia care program provide a noninferior alternative to face-to-face delivery of the same program? A randomized controlled trial. The *American Journal of Geriatric Psychiatry, 28*(6), 673–682.

https://doi.org/10.1016/j.jagp.2020.02.009

Leavy, P. (2018) Introduction to arts-based research. In P. Leavy (Ed.), *Handbook of arts-based research* (pp. 3–21). The Guilford Press.

Lee, K. H., Boltz, M., Lee, H. & Algase, D. L. (2017). Does social interaction matter Psychological well-being in persons with dementia? *American Journal of Alzheimer's Disease & Other Dementias, 32*(4), 207–212.

https://doi.org/10.1177/1533317517704301

Lee, S., O'Neill, D., & Moss, H. (2020). Promoting well-being among people with early-stage dementia and their family carers through community-based group singing: A

phenomenological study. *Arts & Health, 14*(1), 85–101.
https://doi.org/10.1080/17533015.2020.1839776

Lee, S., O'Neill, D., & Moss, H. (2021). Dementia-inclusive group-singing online during COVID-19: A qualitative exploration. *Nordic Journal of Music Therapy*, 1–19.
https://doi.org/10.1080/08098131.2021.1963315

Lee, Y. E. C., Stretton-Smith, P. A., Tamplin, J., Sousa, T. V., & Baker, F. A. (2022). Therapeutic music interventions with people with dementia living in residential aged care: Perspectives of residents, family members and care home staff from a cluster randomised controlled trial. *International Journal of Older People Nursing, 17*(3)*,* Article e12445. https://doi.org/10.1111/opn.12445

Manca, R., De Marco, M., & Venneri, A. (2020). The impact of COVID-19 infection and enforced prolonged social isolation on neuropsychiatric symptoms in older adults with and without dementia: A review. *Frontiers in Psychiatry, 11*, Article 585540.
https://doi.org/10.3389/fpsyt.2020.585540

McCaffrey, T., Higgins, P., Monahan, C., Moloney, S., Nelligan, S., Clancy, A., & Cheung, P. S. (2021). Exploring the role and impact of group songwriting with multiple stakeholders in recovery-oriented mental health services. *Nordic Journal of Music Therapy, 30*(1), 41–60. https://doi.org/10.1080/08098131.2020.1771755

Merrell, R. C. (2015). Geriatric telemedicine: Background and evidence for telemedicine as a way to address the challenges of geriatrics. *Healthcare Informatics Research, 21*(4), 223–229. https://doi.org/10.4258/hir.2015.21.4.223

Moss, H., & O'Neill, D. (2019). Narratives of health and illness: Arts-based research capturing the lived experience of dementia. *Dementia, 18*(6), 2008–2017.
https://doi.org/10.1177/1471301217736163

Mykitiuk, R., Chaplick, A., & Rice, C. (2015). Beyond normative ethics: Ethics of arts-based disability research. [Au-delà de l'éthique normative : déontologies de la recherche provenant du disability arts (French)]. *Ethics, Medicine, and Public Health, 1*(3), 373–382. https://doi.org/10.1016/j.jemep.2015.07.005

Osman, S. E., Schneider, J., & Tischler, V. (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 - International Journal of Social Research and Practice, 15*(6), 1326–1339. https://doi.org/10.1177/1471301214556291

Shankar, A., Hamer, M., McMunn, A., & Steptoe, A. (2013). Social isolation and loneliness: Relationships with cognitive function during 4 years of follow-up in the English longitudinal study of ageing. *Psychosomatic Medicine 75*(2), 161–170.
https://doi.org/10.1097/PSY.0b013e31827f09cd

Shrira, A., Hoffman, Y., Bodner, E., & Palgi, Y. (2020). COVID-19-related loneliness and psychiatric symptoms among older adults: The buffering role of subjective age. *American Journal of Geriatric Psychiatry, 28*(11), 1200–1204.
https://doi.org/10.1016/j.jagp.2020.05.018

Smith, J. A., Larkin, M., & Flowers, P. (2009). *Interpretative phenomenological analysis: Theory, method and research*. Sage.

Swaffer, K. (2015). Dementia and Prescribed Disengagement (TM). *Dementia, 14*(1), 3–6.
https://doi.org/10.1177/1471301214548136

Swaffer, K. (2018). Human rights, disability and dementia. *Australian Journal of Dementia*

Care, 7(1), 25–28.

  https://journalofdementiacare.com/human-rights-disability-and-dementia/

Synnes, O., Råheim, M., Lykkeslet, E., & Gjengedal, E. (2021). A complex reminding: The ethics of poetry writing in dementia care. *Dementia, 20*(3), 1025–1043. https://doi.org/10.1177/1471301220922750

Tamplin, J., Loveridge, B., Clarke, K., Li, Y., & Berlowitz, D. J. (2020). Development and feasibility testing of an online virtual reality platform for delivering therapeutic group singing interventions for people living with spinal cord injury. *Journal of Telemedicine & Telecare, 26*(6), 365–375. https://doi.org/10.1177/1357633X19828463

The Dementia Network. (2021). Sing your heart out - the rise of the virtual choir. Retrieved from https://dementia.network/sing-your-heart-out-the-rise-of-the-virtual-choir/

Thompson, Z., Baker, F. A., Tamplin, J., & Clark, I. N. (2021a). How singing can help people with dementia and their family care-partners: A mixed studies systematic review with narrative synthesis, thematic synthesis, and meta-integration. *Frontiers in Psychology, 12*, Article 4446. https://doi.org/10.3389/fpsyg.2021.764372

Thompson, Z., Baker, F. A., Clark, I. N., & Tamplin, J. (2021b). Making qualitative interviews in music therapy research more accessible for participants living with dementia – Reflections on development and implementation of interview guidelines. *International Journal of Qualitative Methods, 20*, Article 16094069211047066.

  https://doi.org/10.1177/16094069211047066

Thompson, Z., & Khalil-Salib, L. (2021). Online music therapy groups during COVID-19: Perspectives from NDIS participants and caregivers. *Australian Journal of Music Therapy, 32*, 52–63.

  https://www.austmta.org.au/public/151/files/AJMT/2021/Issue%201/1_%20ONLINE%20Volume%2032-1%2C%202021.pdf

Tible, O. P., Riese, F., Savaskan, E., & von Gunten, A. (2017). Best practice in the management of behavioural and psychological symptoms of dementia. *Therapeutic Advances in Neuroligical Disorders, 10*(8), 297–309.

  https://doi.org/10.1177/1756285617712979

Unadkat, S., Camic, P. M., & Vella-Burrows, T. (2016). Understanding the experience of group singing for couples where one partner has a diagnosis of dementia. *The Gerontologist, 57*(3), 469–478. https://doi.org/10.1093/geront/gnv698

Viega, M., & Forinash, M. (2016). Arts-based research. In B. L. Wheeler & K. M. Murphy (Eds.), *Music therapy research* (Third ed., pp. 990–1006). Barcelona Publishers.

Wheeler, B. L. (2016). Priniciples of interpretivist research. In B. L. Wheeler & K. M. Murphy (Eds.), *An introduction to music therapy research* (Third ed., pp. 97–107). Barcelona Publishers.

Wooley, S. (1958). *The Purple People Eater* [Song]. Single release.

Appendix

1. Interview Questions and Prompts for Choir Participants (who choose a traditional interview)

As interviews will be conducted using a semi-structured format, the following questions will be used as a guide, however other topics will be able to be explored should they arise during the course of the interview.

Questions are on the left, with some probing/prompting options on the right – prompts in italics are general, prompts in bold are simplified options for people who may be having challenges in responding due to memory or verbal processing etc.

Question	Additional Prompts
1. How long have you been part of the Rewire Musical Memories Choir?	
2. What is it like being a part of the choir in 'normal' times (pre-COVID)?	**What do you like about RMM Choir?** **What don't you like about RMM Choir?**
3. How would you describe the experience of singing with this group?	*What do you like about singing in this group/choir?* *Is there something you don't like about singing in this group?* *How do you feel when you come to this group?*
4. How did you feel when you found out we had to cancel our regular in-person choir sessions due to COVID-19?	
5. How did you feel when you found out we would try choir using Zoom?	*How did you feel about attending choir online/via video call?* *Had you ever used online video call/Zoom before?* **Show recording of online choir**
6. What would you say to others (who might be going through similar challenges) about joining a group like this?	**Would you recommend online choir to others? Why/why not?**

** particularly if verbal discussion is challenging: How do you feel about sharing music this way?
 (maybe share a song with the participants via Zoom)
	[Use the music itself as a prompt]:
	 Do you like this song?
	 What do you like about it?
	    - **How does this song make you feel?**
	    - **What is it like listening to this song over our video call?**
	    - **Is it different from when we sing together in person?**

2. Prompts for 'Songwriting Style' Interview

For participants who opt to write a song instead of a traditional interview format, we will use similar prompts and probing questions to the above to initiate a brainstorm for lyrics. These may be presented verbally, or sung to an improvised tune by the student-researcher, depending on the needs and/or preferences of the participant.

The student-researcher will arrange ideas from the brainstorm into lyrics, and present these to the participants by singing the lyrics (and playing guitar or keyboard where appropriate), and ask the participants for feedback. Participants are able to make changes to the lyrics and musical content throughout the session, both verbally and through singing and improvising new lyrics, depending on their ability and preference. This procedure is repeated until the participant is satisfied with the resulting song.

Prompts:

- Tell me about what it's like to be in the choir?
- What words would you use to describe the RMM choir?
- How do you feel about singing in RMM?
- How do you feel about singing over Zoom? [what is different, what is the same?]
- What do you like/dislike about the choir?
- What do you like/dislike about singing over Zoom?
- What should other people know about our choir?