Approaches: An Interdisciplinary Journal of Music Therapy

Advance Online Publication

ISSN: 2459-3338 | www.approaches.gr



REPORT

Together in Sound: Music therapy groups for people with dementia and their companions — moving online in response to a pandemic

Claire Molyneux

Anglia Ruskin University, UK

Thomas Hardy

Saffron Hall Trust, UK

Yu-Tzu (Chloe) Lin

Anglia Ruskin University, UK

Katie McKinnon

Saffron Hall Trust, UK

Helen Odell-Miller

Anglia Ruskin University, UK

ABSTRACT

Together in Sound is a partnership project between the Cambridge Institute for Music Therapy Research at Anglia Ruskin University (ARU) and Saffron Hall Trust, an arts charity based in rural Essex, England. Established in Autumn 2017, the project offers music therapy to people living with dementia and their companions and includes a practice-based research element. This co-authored report concerns the impact of the global COVID-19 pandemic on the project and presents the team's experience of moving music therapy sessions online in March 2020. Continuing online provided continuity, support, and ongoing connection for participants who, because of the national lockdown in the United Kingdom, were isolated in their own homes. After providing some context about the project, the report explores the challenges and benefits of online delivery of sessions with reflections from the Together in Sound team including potential implications for the future.

KEYWORDS

online music therapy, people living with dementia, caregiving couples, COVID-10 pandemic

Publication history: Submitted 1 Aug 2020 Accepted 11 Nov 2020 First published 19 Dec 2020

AUTHOR BIOGRAPHIES

Claire Molyneux has worked as a music therapist and supervisor in the United Kingdom and New Zealand for over 20 years with people across the lifespan. She is currently a senior lecturer on the MA Music Therapy at Anglia Ruskin University, UK and is undertaking PhD research exploring the impact of group music therapy for people living with dementia and their companions. She is the lead music therapist for Together in Sound. [claire.molyneux@aru.ac.uk] Thomas Hardy is an arts education professional with over 20 years' experience in the sector including at the Barbican, Guildhall School of Music and Drama and Sadler's Wells. He is currently Learning and Participation Director at Saffron Hall Trust with responsibility for the venue's work across schools and communities. [togetherinsound@saffronhall.com] Yu-Tzu (Chloe) Lin is a newly-qualified music therapist, who graduated with an MA in Music Therapy from Anglia Ruskin University in 2020. Born and raised in Taiwan, she studied Life Science as her undergraduate major. During her music therapy training, Chloe specialised in applying

improvisation skills in placement. She joined the Together in Sound project from 2019, working with Claire Molyneux as a music therapy trainee and a co-therapist. [yutzu.musictherapy@gmail.com] Katie McKinnon is a recent music graduate with experience project managing community music and theatre projects across venues and festivals including the Edinburgh Festival Fringe. She is currently the Learning and Participation Coordinator for Saffron Hall Trust, facilitating relationships with local community and beyond with the world-renowned artists who visit Saffron Hall. Katie manages and administrates education and community projects including Together in Sound. [togetherinsound@saffronhall.com] Helen Odell-Miller OBE is a Professor of Music Therapy, and Director of Cambridge Institute for Music Therapy Research, Anglia Ruskin University. Her research and clinical work contributed to establishing music therapy as a profession; specifically to innovating approaches for older people living with dementia, and for adults with mental health issues. She is currently Principal Investigator for Homeside, a large five-country randomised controlled trial investigating music and reading for people living at home with their family carer. [helen.odell-miller@aru.ac.uk]

INTRODUCTION

Together in Sound (TiS) is a partnership project between the Cambridge Institute for Music Therapy Research (CIMTR) at Anglia Ruskin University (ARU) and Saffron Hall Trust, an arts charity based in rural Essex, UK. Established in Autumn 2017, the project offers music therapy to people living with dementia and their companions. It is an innovative collaboration between the arts sector and music therapy and includes placement opportunities for MA Music Therapy trainees and community experience for performing artists involved with Saffron Hall who attend training with the therapists prior to involvement in the project. The focus is on joint music-making and listening with a goal of supporting communication, relationships, and increasing quality of life through a collaborative group process. Working with people with dementia together with their companions brings a new dimension to music therapy practice in this field that has traditionally focused on working with the person with dementia on their own. The project is also the focus of the first author's current doctoral research in progress which is a narrative inquiry with practice-based arts-informed responses to explore the impact of the groups for participants. This report does not present the doctoral research but is an opportunity to share the team's experience of adapting the project to offer online sessions in response to the impact of the global COVID-19 pandemic. The report briefly outlines the context for group music therapy with people with dementia and their companions and provides an overview of Together in Sound. It then focuses on the adaptation required to offer online sessions including reflections from the project team.

CONTEXT

The Alzheimer's Society estimates that there are currently 885,000 people over 65 years old affected by dementia in the United Kingdom. This number is predicted to rise to 1.6 million by 2040 (Wittenberg et al., 2019). The health condition is marked by a progressive and irreversible decline in cognitive functioning, affecting day-to-day life and health. The recently published report from the Commission on Dementia and Music in the United Kingdom (Bowell & Bamford, 2018), comprehensively demonstrates the importance of music for people living with dementia and calls for more accessible services, research and training, to be available nationwide.

There is a growing body of evidence to show that music can unlock communication pathways for people living with dementia, even for those with advanced forms of the disease. Music therapy can help to: sustain relationships and share experiences (Baker et al., 2012; Brotons & Marti, 2003; Clair & Ebberts, 1997; Melhuish et al., 2019; Ridder, 2011;); minimise often-upsetting symptoms including agitation, anxiety and depression (Hsu et al., 2015; Raglio et al., 2008; 2010; Ridder et al., 2009; 2013; Vink et al., 2013; van der Steen et al., 2018); improve wellbeing and quality of life (Ahonen-Eerikäinen

et al., 2007), socially connect people, and reduce isolation (Svansdottir & Snaedal, 2006). In a community music therapy project, Rio comments on the opportunity for participants to "redefine their changing social identity" (Rio, 2018, p.3), a point which is supported by Dowlen (2018) who explored the idea of musicking as a means through which people living with dementia might facilitate active citizenship. Dowlen's research took place with the Manchester Camerata, a similar project to Together in Sound, where music therapy-based groups for people with dementia are facilitated by a music therapist and musicians from the Camerata. This type of collaboration between music therapists and professional musicians has not been well documented in the literature. It provides an additional position from which to consider the role of music in people's lives, where the therapist and musician work collaboratively to attend to health, wellbeing and aesthetic qualities of music making (Pugh, 2016).

Music therapy and couples with dementia

The importance of psychosocial interventions for people with dementia and their 'informal caregivers' is the subject of the systematic review by Rausch et al. (2017, p.591). They suggest further research is needed to "give insight in the relationship within the caregiving dyad, the impact of the dementia on this relationship, and the influence of the relationship on patients' and caregivers' quality of life, to further establish suitable psychosocial interventions for these caregiving dyads." In music therapy, there has been a growing interest in interventions for caregiving dyads. A feasibility study by Tamplin et al. (2018, p.1), "examined the acceptability of a 20-week therapeutic group singing intervention and quantitative research assessments." The study gathered qualitative interview data and conducted a thematic analysis which is reported on in Clark et al. (2018). The authors conclude that "such community-based, dyad-focused therapy interventions hold great potential to fill an important need for social connection and support, as well as addressing personal wellbeing and quality of life for community-dwelling people with dementia and their family caregivers" (Tamplin et al., 2018, p.9). More recently, Baker et al. (2019), describe a novel home-based music intervention where family carers are trained to interact with the family member with dementia daily through music or reading/story telling. Homeside is an ongoing international randomised controlled trial, further investigating music and other approaches that can meet needs at home for this population. Members of Together in Sound are involved in the Patient and Public Involvement (PPI) group, in designing and implementing the study, as well as advising on its move to online delivery, in response to COVID-19.

Community-based music therapy groups for people with Alzheimer's disease and their caregivers within a partnership project between a University and community organisation are described by Rio (2018). The groups are described as including "singing, instrument playing, movement and creation of new musical arrangements and improvisations based on in-the-moment needs, feelings and concerns" (Rio, 2018, p.3). New Zealand-based music therapist, Allan (2018) offers another example of a community-based music therapy project designed to support people living with dementia and their family caregivers where singing, playing instruments and listening to music were the focus of the intervention. Melhuish et al. (2019) report on the benefits of individualised homebased music therapy for caregiving dyads and emphasise the unique value of working in the home which enabled music therapists to respond to individual and sometimes challenging situations. Ridder

et al. (2013), similarly to Hsu et al. (2015), recognised three areas (catching attention and creating a safe setting, regulating arousal to a point of self-regulation, and musical interactions leading to communication for psychosocial needs) as central to effective music therapy technique and practice using improvisation with people with dementia. Both studies emphasise that the music in music therapy can incorporate live improvised music, song, and structured directed instrumental work, to meet identified aims. These examples demonstrate the growing interest in documenting different approaches to working with people with dementia and their caregivers.

TOGETHER IN SOUND

Together in Sound, an innovative collaboration between the arts sector and the music therapy department at Anglia Ruskin University, offers group music therapy and some dyad sessions in tenweek blocks. It includes placement opportunities for MA Music Therapy trainees and community experience for performing artists involved with Saffron Hall who attend training with the therapists prior to involvement in the project. This training includes induction and information about working with people with dementia as well as experiential music making and guidance. This ensures a shared understanding of how music is used in the sessions and the roles of the therapists and musicians. There are usually between four to nine couples per group with a maximum group size of 18 participants plus two therapists. Group sessions, which are co-facilitated by a registered music therapist and MA music therapy trainees, usually take place weekly in a community venue in the town and the team typically delivers three groups on each project day. The venue has been chosen for its relaxed environment and the availability of a social space that is separate from the therapy space.

Together in Sound is open to people living with a diagnosis of dementia who attend with a companion who is typically a family member or close friend and occasionally a professional carer. Usually the same companion attends each week to provide continuity and to support the relationship. Some exceptions are made to this to support regular attendance for the person with dementia. In the third year of the project and in response to feedback, group membership was extended to companions who had previously accompanied a person with dementia who was no longer able to attend the sessions (because they had moved into care for example or had died). While this has changed the dynamics of the groups to some extent, it has been an important commitment to the community who are at the heart of the project. Sessions last for 90 minutes with the first 30 minutes being an opportunity for socialising over drinks and biscuits. Volunteers from Saffron Hall play an important role before and after sessions to assist with teas and coffees, greeting and saying goodbye to participants.

Music therapy sessions are usually framed by a greeting and goodbye activity or song and a physical and vocal warm-up is included. A range of therapist-directed and non-directed activities are used including song singing (both familiar and new songs), listening to music, improvisation (free, theme and imagery-based improvisations are offered) and conversation. Participants are invited to share something of themselves and their experiences during the ten weeks; this may involve bringing in objects, photographs, music, songs, or stories to share with the group. This process supports relationship-building and enables participants to use the group for support and self-expression. The sessions are co-facilitated and take place within a closed, confidential, and time-limited group setting

with an additional element of a 'sharing' event. These sharing events usually happen once in every ten-week block of sessions and provide an opportunity for participants to share some of their experience with family, friends, and other invited stakeholders. Bringing in the wider community and guest musicians positions dementia as a community concern. The approach to music therapy therefore has elements of community music therapy in that it is a culturally and socially engaged practice where music is situated within the local context (Stige & Aarø, 2012). The sharing events are viewed as having a bridging function from the closed confidential therapy space to the wider community, thus creating a circle of support for those living with dementia. Participation in this context involves a commitment and willingness to "listen to all voices involved" (Stige & Aarø, 2012, p.148), to fostering inclusion, and building what Stige and Aarø refer to as "cultures of connectedness" (Stige & Aarø, 2012, p.149). Issues of power within the concept of participation evoke useful debate (Gregory, 2000; Stige, 2006) and the project team strives to create opportunities for discussion and reflection on the nature of participation with those concerned.

The overarching project aims are detailed below, however, each group process is distinct and evolves through the client-centred approach taken by the music therapist and trainees on placement. The following aims were generated collaboratively through conversation with participants and the project team:

- To support communication, healthy relationships, and quality of life through a collaborative group process.
- To provide opportunities for people with dementia and their companions to engage in music making.
- To provide opportunities for socialisation, forming support networks and relationships outside of the home environment with a view to reducing isolation.
- To share music with friends and family through 'public' sharing events.
- To provide 'up-close' opportunities to interact and listen to professional musicians.
- To support participants to 'live differently' through encouraging the use of music and musicbased strategies at home.

Participation with carers and family aims to instil confidence, increase resilience, help social communication and awareness, and support the search for purpose and meaning. With this in mind, the project's approach is congruent with a biopsychosocial-spiritual perspective of dementia which helps us to consider health and wellbeing from a multi-faceted view of relationships that include physical, internal, external and existential concerns (Scott, 2016; Spector & Orrell, 2010; Sulmasy, 2002; Swinton, 2012). Furthermore, for the first time, in 2019, the National Institute for Health and Care Excellence (NICE, 2019) included music therapy in guidelines for people living with dementia. The different dimensions of this project are in line with these guidelines which advise that "activities such as exercise, aromatherapy, art, gardening, baking, reminiscence therapy, music therapy, mindfulness and animal assisted therapy" (NICE, 2019) are included in care to help promote wellbeing.

Impact of Together in Sound for participants

Together in Sound has provided a valuable opportunity to undertake research with participants in a natural setting utilising data such as video and audio recordings of music therapy sessions and clinical

notes. Evaluating the project has involved qualitative and quantitative methods of data collection including written feedback, focus group interviews and pre and post session questionnaires. As mentioned earlier, the first author is currently working towards completion of doctoral research using a narrative inquiry approach to explore the impact of the groups for participants.

Evaluation results have been positive over the past three years with the majority of participants and companions stating that they liked being able to meet new people, sing and share experiences with others, play instruments together and participate in the sharing event. Participants described Together in Sound as the "highlight of the week", "calming, encouraging", "fulfilling and relaxing." In both written evaluations and focus group meetings, participants have commented on the sense of unity in the groups: "Divisions vanished, and we were all one", "Dementia doesn't come into these sessions. We are just friends." Another theme that emerged in the evaluations was that the groups were as important for the companion as they were for the person with dementia: "I assisted [the participant] to enjoy herself and benefit from the music therapy – and I think I benefitted from the time out and being in the moment just as much as she did!" Pre and post session quantitative data demonstrates that sessions have a positive effect on participants' self-assessment of their sense of wellbeing, social connection with others and energy levels.

Collaboration and partnership are central to the project and feedback has enabled growth and development, such as extending the group membership to include solo companions as described earlier. Other changes implemented in response to feedback include the use of lyric sheets; objects, photographs, and themes to stimulate and engage; and for some groups, more structured activities to support engagement with improvisation.

IMPACT OF COVID-19 PANDEMIC ON TOGETHER IN SOUND

The impact of the COVID-19 pandemic and subsequent lockdown and isolation measures to protect public health has been significant for participants of Together in Sound. Already isolated by the impact of dementia, the lockdown has confined many participants to their homes. This section of the report will begin by presenting some relevant literature before turning to the team's response to the lockdown, the practicalities and considerations of offering sessions online, and reflections on the impact for participants and therapists.

Published research about the impact of COVID-19 upon people living with dementia, and how music therapy contributes, is sparse at the time of writing. In general terms, Galea et al. (2020) emphasise that in the wake of a global pandemic there is sometimes more focus upon immediate physical needs and the impact of the medical disease itself, than upon social and mental health needs. Unsurprisingly they highlight global early indications of a rise in poverty, mental health problems and social isolation, which supports adapting music therapy interventions to address these needs. Gaddy et al. (2020) discuss an early survey of music therapists' employment styles during the pandemic in the United States. They suggest results indicate that music therapists adapted to service delivery changes, continuing to provide services to clients, despite the many difficulties faced in the pandemic. Simonetti et al. (2020), in a medical facing study, conclude that the neuropsychiatric symptoms for people living with dementia appear to arise not only from the disease itself but from social restrictions in place as a consequence of the pandemic. Their findings so far indicate that the implementation of

caregiver support and skills of nursing and care staff are required to help restore social interaction. Relevant to our study, they cite the importance of adjusting technology in response to the pandemic. Further, Killen et al. (2020), in a study specifically examining the challenges of COVID-19 for people with dementia with Lewy bodies and their family caregivers, highlight the physical, cognitive and neuropsychiatric challenges associated, which may make this group particularly vulnerable to COVID-19. In addition, they advocate a multidisciplinary approach to support family caregivers, and recognise there may be adverse effects occurring from social isolation, also possible reductions in routine treatments and support, leading to a negative impact upon carers.

Three music therapy groups were meeting weekly at the beginning of 2020 and six sessions out of a ten-session block had been completed when the lockdown began. The Together in Sound team had already begun considering how to continue offering sessions in anticipation of the need to end inperson meetings. One of the frustrating aspects at this time (early March 2020) was not being able to plan while awaiting guidance from the UK government. The groups were in the middle of a therapeutic process and the lockdown would mean a sudden and unplanned ending. This, coupled with the knowledge that opportunities for connection and engagement outside the home were going to be seriously limited over the coming months and the feedback already gathered about the impact of the sessions for participants, created an imperative to continue.

While it was clear that using an online platform to deliver group music therapy sessions would be a very different experience for participants, it felt important to try in order to offer some continuity. On reflection, the desire to maintain a connection with and for participants was the main motivator. The final four weeks of sessions were offered to the three groups online and a further block of six sessions was offered during June-July. The reality of delivering sessions online and the impact of this is explored in more detail below.

Moving delivery online

Addressing the aims

When reflecting on the move to online delivery, it is worth returning to look at the aims for Together in Sound as outlined earlier in this report. The groups had already been working together for some time and some participants had been involved since the project began in 2017. Therefore, a significant investment in relationships and a strong sense of belonging already existed and had been expressed in the project evaluations and focus group meetings. This provided a strong foundation for moving online. In relation to the aims, online sessions could continue to support communication, healthy relationships, and quality of life through a collaborative group process. Opportunities for music making could be offered but would be limited by the musical resources participants had in their own homes. In terms of providing opportunities for socialisation and support networks, this felt vital and was a significant catalyst to continuing online. With the lockdown, came a complete loss of routine and structure for participants. Continuing to meet on a Friday would at least offer something stable amongst the sudden change everyone was facing. The sessions continued to provide opportunities to listen to professional musicians and it has been possible to host online sharing events. The final aim,

which concerns encouraging the use of music and music-based strategies at home, could also be addressed.

Practicalities of online delivery

Live sessions

Technical and pastoral support from Saffron Hall was essential to enable many participants to access the online sessions. Among other things, this involved the creation of a simple but detailed 'How to access Zoom' document for participants, practice sessions to access Zoom, telephoning participants prior to and during sessions to provide technical guidance and support, and following up with participants after sessions. Replicating the format of the in-person sessions as much as possible provided familiarity and consistency. To achieve this, sessions began with an informal time for chatting and sharing a cup of tea. This allowed time to resolve any technical issues and enabled people to arrive at the session when they were ready. A member of the Saffron Hall team stayed online during this tea-time which also replicated, to some degree, the presence of the volunteers who would have been at the in-person sessions. When ready to start the music therapy session, the Saffron Hall team member turned off their video and microphone but stayed online in case of technical issues.

Sessions continued to be co-facilitated by two therapists which made it easier to manage practical issues such as sharing lyrics on screen and song-writing. A typical session included the following:

- Hello song with guitar participants' microphones are muted, and they are invited to sing with the therapist.
- Warm-ups physical and vocal warm-ups, often involving simple stretches, breathing and playful vocal activities.
- Action song or call and response song participants' microphones are muted and they are invited to participate vocally and physically.
- Pass the sound this is an activity that was used frequently in in-person sessions and has transferred effectively to online sessions. Participants sometimes generate a theme to support the vocal sound they make such as animal or bird sounds, and sometimes engage with free vocalisations.
- Opportunity to listen to music provided by one of the therapists or a guest musician followed by time for reflection.
- Song singing familiar and new songs with lyrics available on the screen and sent to participants beforehand.
- Song-writing using predictable structures such as 12-bar blues or a simple harmonic framework has worked effectively online with participants offering ideas for both lyric and musical content.
- Improvisation or playing together (discussed further below).
- Time for reflection this is sometimes an open space or linked to a particular musical interaction, song, or piece for listening.
- A familiar song to close the session.

Practical considerations that were learned early on include the importance of looking at the camera rather than at the screen which can help participants experience a sense of connectedness and using big gestures and simple verbal communications to support actions or instructions. Adjusting the audio settings on Zoom has assisted in improving the experience for participants. Another practical consideration that came from participants was the idea of 'curating the frame': participants began to bring objects, such as a vase of flowers, pictures, soft toys, or a colourful backdrop into the online frame as shown in Figure 1. This provided the opportunity for different interactions, to personalise the experience and offer something new to each other.



Figure 1: Curating the frame

Recorded content

Each of the live online sessions was recorded and made available for one week following the session on a password protected page for participants. This has been important for those who were unable to join the sessions live for whatever reason. Encouraging feedback from companions has been received reporting that they have used the recordings at other times during the week to provide stimulation and engagement for the person with dementia. Furthermore, in the weeks where there has been a break from online sessions, recorded content has been provided for participants to access. This has consisted of short videos recorded by Claire including songs, warm-ups, relaxation activities and musical content as well as recordings from guest musicians. The benefits of this resource bank are discussed further below.

Challenges and benefits of online delivery

Music making

With online delivery, the opportunities for musically rich group improvisations are limited as the technology does not allow groups to play or sing together synchronously. Thinking carefully about the

aims of specific musical invitations is helpful. For example, is the focus on the aesthetics of the experience, or is it more to do with social interaction and communication? This helps to make informed choices about whether participants are asked to mute their microphones to offer an experience of singing with the therapist. Or whether the group takes turns to sing individually and unaccompanied, which can emphasise the collaborative nature of creating and making music together.

For in-person sessions, a wide variety of engaging instruments was available. Meeting online has required creativity in relation to making music from home-made and found objects, and has provided opportunities for participants to demonstrate their resourcefulness. Improvisation might take place within the context of a song; for example, a recent song that was used included a volcanic eruption for which participants created sound effects. Alternatively, improvisation might be within the context of passing the sound around the group or creating a theme and variations. Participants have engaged with this experience and report that creating loud sounds from household objects such as saucepan lids has been cathartic or more meditative improvisations using gentle sounds from glassware are relaxing. Interestingly, the use of household items to make rhythmic sounds is included in the music intervention described by Baker at al. (2019) for the Homeside study which has been adapted for online delivery since the pandemic. Although changes have had to be made, the principles of using music to support communication, relationships and quality of life remain central. In relation to international trends in music therapy approaches in this field, Gold et al. (2019) report that core principles of the MIDDEL trial include the use of singing and musical instruments, which facilitate relationship between the music therapist and person living with dementia, whereas Baker et al. (2019) emphasise similar ingredients as necessary for the Homeside study, but focus upon how music facilitates the relationship between the person living with dementia and their home-based family caregiver. Both studies also highlight a core principle of affect regulation through active reciprocal music making, and the importance of focusing upon personal strengths, cultural background and social history.

Engaging online

For some participants living with dementia, there has been a high degree of engagement with the screen, while for others, it has been much harder to engage. There have been some couples where the person with dementia has chosen not to sit in front of the screen but might stay in the same room. Acknowledging the participant's presence during the session and imagining their experience of what they might be hearing in order to include them has been valuable. Using each other's names is important to help engagement and can provide orientation for the person with dementia to the screen.

In the first week, more than half of the usual participants joined the online sessions. This number increased over subsequent weeks. However, some participants did not join the online sessions at all, and it has not always been possible to gather feedback as to the reasons why. For some, it may be that they do not have the capacity to learn the new technology required to access the sessions or may not have the necessary equipment. Offering technical support, including individual opportunities to trial the online technology, has resulted in some participants joining the sessions. For other participants, the emotional impact of not being able to continue to meet in-person informed their decision to not join the online sessions. When this has been the case, the project team has tried to maintain contact with the participant, and invited them to stay connected through watching the

recordings of the live sessions. There were also several couples where the person with dementia moved into residential care during the lockdown. In these cases, the companion/s continued to attend the sessions and spoke of the importance of the group as support at this time of change in their lives.

One of the unexpected benefits of online delivery has been the capacity to reach participants who otherwise would not be able to attend sessions in the community. This included a participant who was bed-bound and nearing the end of life. Other group members expressed delight to see this participant join the sessions and there was opportunity to sing significant songs together. Melhuish et al. (2019) discuss the prominence of issues of loss and bereavement in their home-based work. For our project, online delivery brought the group into each other's homes. While this could be potentially intrusive, the relationships and trust previously established appear to have increased the group's capacity to support each other.

Non-verbal communication

For online delivery to work effectively, the therapists have found that communication has had to be more explicit. When working in the same physical environment, body language, gesture and eye contact can be used in ways that aim to engage and support interaction with participants. Online, these same resources are not available, and it is therefore helpful if the therapists' actions and invitations are more obvious. For example, turn-taking cannot be communicated through eye contact, but needs to be stated clearly using a person's name. Physical modelling cannot be directed so easily at an individual participant and needs to be moderated for the group as a whole. Giving clear, concise instructions and taking time to clarify or ask a participant to repeat something are simple, but important strategies for online delivery.

At times, the online sessions are easily dominated by verbal expressions instead of body or facial expressions, which means that it is more difficult to 'hear' from people with dementia who are less verbal. Checking in with movements or facial expressions from the small boxes on-screen is essential and easier with two therapists. Moreover, due to the limitation of the technology, it is difficult to hear more than one person talking at the same time. This presented a new difficulty which was sometimes resolved by 'muting' certain participants if they were talking over somebody or had background noise such as dogs barking or the telephone ringing that interrupted the conversation. For the therapists, however, it has felt uncomfortable to control the situation in this way, especially when the aim is for participants to be relaxed and talk as much as they want.

Follow up

A social tea-time is facilitated at the beginning of sessions and is an opportunity for participants to chat with each other. However, the opportunity for casual conversations or individual follow-up at the end of sessions is limited. It has therefore been important to be sensitive to any concerns about a participant's wellbeing and follow up individually with a telephone call or email communication after the session. For one participant, this included an opportunity for the therapist to sing a song over the telephone and for others, it has involved a supportive conversation and signposting to other support services as appropriate. Follow-up is done by either the therapist or Saffron Hall staff depending on the need.

The following section of the report presents reflections from the project team relating to their specific roles and are written in the first person.

Reflections from therapists (Claire Molyneux and Yu-Tzu Lin)

Working as co-therapists

As stated earlier, sessions are co-facilitated by Claire (registered music therapist) and trainees from the MA Music Therapy at ARU, with Yu-Tzu (Chloe) Lin co-facilitating during this period of online delivery. When delivering in-person, we had established a routine of setting up the room together and taking time to review our plan for the session; this time also allowed space to settle and focus our minds. In the sessions themselves, we were familiar with each other's musical and verbal repertoires and could easily engage in eye contact or gesture to support one another. These cues and the physical cooperation of preparing together were unavailable to us during online delivery as we were working from our own homes. One helpful strategy has been to meet online to plan at least an hour before the first session. This provided time to talk through the session plan, reflect on the previous session, anticipate potential needs, agree on roles (who is leading or supporting), play through or try out any musical material and plan for technical considerations such as screen sharing. Deliberately holding in mind our roles as co-therapists has been important. For in-person sessions, we were able to work as a dyad, providing a mirror for relating to one another musically and interpersonally through our physical presence. With online delivery, it is harder to present as co-therapists since the screen divides every pair of participants or individual into little boxes. Meeting prior to sessions and having co-supervision provided a space for us to connect as co-therapists, check in with each other, reflect on and explore our practice – endeavours which supported the coordinated delivery of therapy.

Continuing delivery online felt vital at this difficult time and it has been encouraging and heart-warming to see so many of our participants engage with what we have offered. One particularly emotional moment was seeing a couple connect online where the participant with dementia was bed-bound and had not been able to attend the sessions in the community for some months. In the new online format, it was possible to bring the music therapy sessions to this person's bedside. At the same time however, we were both acutely aware of those who were unable to join us for reasons described earlier. These experiences have connected us with feelings of being helpless and powerless; feelings that hold some resonance with the wider experience of the global pandemic. Supervision and space for reflection have been essential to ensure we can continue to offer a space where participants feel safe and confident to express their feelings and emotions. Staying connected with the ways that we might feel disempowered by the online delivery because the full extent of our communicative resource is unavailable may enhance our empathy and capacity to connect with the experiences of participants.

Using our imagination

Using our imagination is something with which we are familiar as therapists. By this, we do not necessarily mean imagination to create a variety of different musical experiences, rather the process of imagining the other person's experience. When working online, this has been critical. We have had to imagine what it might be like to experience the session on the other side of the screen. How do

participants experience the therapist's presence? And how can we use our online presence to convey intention and feeling? Full discussion of these questions is beyond the scope of this report. However, being open to each other's feedback as co-therapists and inviting feedback from participants has helped to bring a variety of perspectives for reflection and learning. For Yu-Tzu, as an international student with English as her second language, she reflected that 'there were times that I lost the words or couldn't follow the content from people on the screen. Therefore, I needed to pay more attention to the facial expressions from others and try to guess the meaning behind the communication' which may also resonate with the experience of some of our participants.

A lifeline

One of the main questions of our research concerns the impact of music therapy upon the wider community and lives of people living with dementia and their families. This will be explored in depth in later publications, but one way the participants have been keen to demonstrate impact has been through the public sharing events, interviews and participation with the media including newspapers and the BBC. Our approach to moving online was captured by the BBC early on in the lockdown and the resulting piece was broadcast first on local news, then on the BBC World news website and on the National News at One (BBC News, 2020). Participants welcomed this media coverage and saw it as an opportunity to contribute to dementia awareness which was particularly important during the COVID-19 lockdown period.

In the interview, one of the participants described the sessions as a 'lifeline'. The online Oxford dictionary defines 'lifeline' as follows (Lexico, 2020):

A thing on which someone or something depends or which provides a means of escape from a difficult situation. A rope or line used for life-saving, typically one thrown to rescue someone in difficulties in water or one used by sailors to secure themselves to a boat.

For us as therapists, it felt very powerful for the groups to be described as a 'lifeline', something that could reach across a distance or span a chasm. The connection of lifelines with sea voyages also resonated with an earlier song that one of the groups had written about living with dementia that included images of dementia as a rough sea. While the sessions themselves could not change the physical reality of lockdown, they provided connection, community, shared understanding, and a sense of hope.

Reflections from Saffron Hall (Thomas Hardy and Katie McKinnon)

Together in Sound – a community

Over three years, Together in Sound has evolved to become a community which extends far beyond the group of participants living with dementia and their companions. This community encompasses a team of Saffron Hall volunteers who support each session, Claire and the ARU music therapy trainees, alumni who have had the opportunity to work on the project as a student placement, the former participants who are no longer able to attend – and their carers who in many instances remain part of

the groups, musicians from across the classical, folk and jazz worlds who participated in projects, and numerous friends, family members, supporters and others who have experienced, witnessed or been impacted by the project. Each session is a physical meeting of elements of this community, and termly sharing events give an opportunity for the wider community to come together to share music, food, and conversation. With the move to online delivery, as well as considering the participants, we were mindful of the impact on these other elements which are part of what makes Together in Sound special.

Bringing musicians from Saffron Hall's family of artists into Together in Sound has always been an important part of the project's philosophy. The setting provides musicians with valuable experience of working in the music therapy and dementia contexts, with robust support from Claire and the ARU team. In a world where musicians commonly have a portfolio career, moving between performing, teaching, composing and participatory work, they bring an important dynamic to the sessions, and for early career musicians, Together in Sound can offer a valuable training experience. In Spring 2020 we were working with three young musicians from our resident orchestra the London Philharmonic Orchestra's Future First programme. As well as a training event, they had attended one session and were preparing to participate in the sharing event. Their subsequent involvement in some of the online sessions brought an extra dimension of live performance. In a world where live music making in front of an audience was not possible, it was a powerful reminder of music's power to bridge divides. Figure 2 shows participants listening attentively and singing along with the LPO musician who was playing *Moon River* on her trumpet (top).



Figure 2: Listening to Moon River

Online resources

It was a beautiful surprise to receive video recordings from two musicians who are members of our resident ensemble Britten Sinfonia. The musicians, who had participated in Together in Sound over a year earlier, had heard about the project moving online and wanted to connect with the participants at this difficult time. The music they shared was really appreciated by participants, many of whom

remembered their involvement in the groups. The fact that Together in Sound was on their minds at this time truly reflects the ideas expressed above about the project's wider community being an important element. This reconnection may not have happened without the unprecedented circumstances and has prompted thoughts about ways to maintain connections with others whose direct involvement in the project may not be long-term. In the immediate term we have taken the opportunity to reconnect with other musicians who had participated earlier in the project and have commissioned further videos to share with the participants.

The creation of an online resource bank (described earlier) may have been born in a crisis but might not have happened in more normal times. It has been well used and appreciated by many participants and, we anticipate, will continue to be a part of the project. We are always aware that we are only with participants for a short part of their week, and an accessible online offer could provide support and comfort between sessions.

CONCLUDING THOUGHTS

This report has outlined the Together in Sound project's experience of moving sessions online in response to the COVID-19 pandemic. While all involved are looking forward to returning to in-person meetings in the future, this period of online delivery has opened helpful questions about how to develop what is offered. Accessibility for participants beyond the time they are able to physically attend sessions in the community, an online bank of recorded resources, increased connection with guest musicians, and the possibility of live-streaming sharing events to increase access to those unable to join in-person, are all ideas for consideration. Participant voice is an essential part of Together in Sound and feedback about this period of online sessions has been collected from participants in an online focus group. The team plan to publish these findings in the future to include more participants' voices.

Although not possible to have the usual in-person sharing events, an online sharing event was held in July 2020. Bringing together participants, volunteers, friends and families, guest musicians and others is the truest expression of Together in Sound – and indeed Saffron Hall – as a community. The online sharing, with 'audience' in attendance, was an opportunity to celebrate the strength, resilience and positivity shown by the participants, music therapists and musicians at a difficult time. This community has faced incredible challenges in the last few months, but have remained Together in Sound throughout, and the world is a richer place for it.

REFERENCES

- Ahonen-Eerikäinen, H., Rippin, K., Sibille, N., Koch, R., & Dalby, D. M. (2007). "Not bad for an old 85-year-old!" The qualitative analysis of the role of music, therapeutic benefits and group therapeutic factors of the St Joseph's Alzheimer's adult day program music therapy group. *Canadian Journal of Music Therapy, 13*(2), 37-62.
- Allan, M., (2018). Community music therapy to support the relationship between family caregivers and people living with dementia: A pilot project. *New Zealand Journal of Music Therapy, 16*, 31-54.
- Baker, F. A., Grocke, D., & Pachana, N. A., (2012). Connecting through music: A study of a spousal caregiver-directed music intervention designed to prolong fulfilling relationships in couples where one person has dementia. *Australian Journal of Music Therapy, 23*, 4-19.
- Baker, F., Bloska, J., Braat, S., Bukowska, A., Clark, I., Hsu, M., Kvamme, T., Lautenschlager, N., Lee, Y., Smrokowska-Reichmann, A., Sousa, T., Stensaeth, K., Tamplin, J., Wosch, T., & Odell-Miller, H. (2019). HOMESIDE: Home-based family caregiver-delivered music and reading interventions for people living with dementia: protocol of a randomised controlled trial. *BMJ Open*, *9*(11), e031332. https://doi.org/10.1136/bmiopen-2019-031332

- BBC News. (2020, April 22). Coronavirus: Online music therapy group a 'lifeline' in pandemic. https://www.bbc.co.uk/news/av/uk-england-essex-52375524/coronavirus-online-music-therapy-group-a-lifeline-in-pandemic
- Bowell. S., & Bamford, S. M. (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.
 - http://www.ilcuk.org.uk/index.php/publications/publication_details/what_would_life_be_without_a_song_or_a_dance_what_are_weeter each control of the control
- Brotons, M., & Marti, P. (2003). Music therapy with Alzheimer's patients and their family caregivers: a pilot project. *Journal of Music Therapy* 40, 138-150.
- Clair, A., & Ebberts, A. (1997). The effects of music therapy on interactions between family caregivers and their care receivers with late stage dementia. *Journal of Music Therapy*, *34*, 148-164.
- Clark, I. N., Tamplin, J. D., & Baker, F. A. (2018). Community-dwelling people living with dementia and their family caregivers experience enhanced relationships and feelings of well-being following therapeutic group singing: A qualitative thematic analysis. *Frontiers in Psychology*, 9: 1332. https://doi.org/10.3389/fpsyg.2018.01332
- Dowlen, R., (2018). The 'in the moment' musical experiences of people with dementia: A multiple-case study approach. [Doctoral dissertation, The University of Manchester] The University of Manchester Research Explorer.

 https://www.research.manchester.ac.uk/portal/en/theses/the-in-the-moment-musical-experiences-of-people-with-dementia-a-multiplecase-study-approach(48599400-3e3d-4871-a0e3-94d6b3692a5d).html
- Gaddy, S., Gallardo, R., McCluskey, S., Moore, L., Peuser, A., Rotert, R., Stypulkoski, C., & LaGasse, A. B. (2020). COVID-19 and music therapists' employment, service delivery, perceived stress, and hope: A descriptive study. *Music Therapy Perspectives*, 38(2), 157-166
- Galea, S., Merchant, R. M., & Lurie, N. (2020). The mental health consequences of COVID-19 and physical distancing: The need for prevention and early intervention. *JAMA Internal Medicine*, 180(6), 817-818.
- Gold, C., Eickholt, J., Assmus, J., Stige, B., Wake, J. D., Baker, F. A., Tamplin, J., Clark, I., Lee, C., Jacobson, S., Ridder, H. M. O., Wosch, T., Ceccato, E., Raglio, A., Ruggeri, M., Vink, A., Zuidema, S., & Odell-Miller, H. (2019). Music Interventions for Dementia and Depression in ELderly care (MIDDEL): protocol and statistical analysis plan for a multinational cluster-randomised trial. *BMJ Open, 9*(3), e023436.
- Gregory, A. (2000). Problematizing participation: A critical review of approaches to participation in evaluation theory. *Evaluation*, 6(2), 179-199.
- Hsu, M. H., Flowerdew, R., Parker, M., Fachner, J., & Odell-Miller, H. (2015). Individual music therapy for managing neuropsychiatric symptoms for people with dementia and their carers: a cluster randomised controlled feasibility study. *BMC Geriatrics*, 15(84). https://doi.org/10.1186/s12877-015-0082-4
- Killen, A., Olsen, K., McKeith, I. G., Thomas, A. J., O'Brien, J. T., Donaghy, P., & Taylor, J. P. (2020). The challenges of COVID-19 for people with dementia with Lewy bodies and family caregivers. *International Journal of Geriatric Psychiatry*.
- Lexico, (2020). https://www.lexico.com/definition/lifeline
- Melhuish, R., Grady, M., & Holland, A. (2019). Mindsong, music therapy and dementia care: Collaborative working to support people with dementia and family carers at home. *British Journal of Music Therapy, 33*(1), 16-26.
- National Institute for Health and Care Excellence (NICE). (2019). Dementia: Quality standard Published: 28 June 2019. https://www.nice.org.uk/guidance/qs184
- Pugh, R. (2016). Could music projects cut the cost of dementia care? *The Guardian*, [online] 29 February. https://www.theguardian.com/social-care-network/2016/feb/29/music-projects-cut-cost-dementia-care
- Raglio, A., Bellelli, G., Traficante, D., Gianotti, M., Ubezio, M., Villani, D., & Trabucchi, M. (2008). Efficacy of music therapy in the treatment of behavioral and psychiatric symptoms of dementia. *Alzheimer Disease and Associated Disorders*, 22(2), 158–162. doi: 10.1097/WAD.0b013e3181630b6f
- Raglio, A., Belleli, G., Traficante, D., Gianotti, M., Ubezio, M. C., Gentile, S., Villani, D., & Trabucchi, M. (2010). Efficacy of music therapy treatment based on cycles of sessions: A randomised controlled trial. *Aging and Mental Health, 14*(8), 900–904. doi: 10.1080/13607861003713158
- Rausch, A., Caljouw, M. A. A., & van der Ploeg, E. S. (2017). Keeping the person with dementia and the informal caregiver together:

 A systematic review of psychosocial interventions. *International Psychogeriatrics*, 29(4), 583-593.
- Ridder, H. M., (2011). Effects of music therapy in dementia: Turning practice-based research into an RCT. Music Therapy Today, 9(1), 36-37.
- Ridder, H. M., Wigram, T., & Ottesen, A. M. (2009). A pilot study on the effects of music therapy on frontotemporal dementia developing a research protocol. *Nordic Journal of Music Therapy, 18*(2), 103-132.
- Ridder, H.M., Stige, B., Qvale, L., & Gold, C. (2013). Individual music therapy for agitation in dementia: An exploratory randomized controlled trial. *Aging & Mental Health*, 17(6), 667–678.
- 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. doi: 10.3389/fmed.2018.00293
- Scott, H. (2016). The importance of spirituality for people living with dementia. *Nursing Standard*, 30(25), 41–50. https://doi.org/10.7748/ns.30.25.41.s47
- Simonetti, A., Pais, C., Jones, M., Cipriani, M. C., Janiri, D., Monti, L., Landi, F., Bernabei, R., Liperoti, R., & Sani, G. (2020). Neuropsychiatric symptoms in elderly with dementia during COVID-19 pandemic: Definition, treatment, and future directions. *Frontiers in Psychiatry*, 11
- Spector, A., & Orrell, M. (2010). Using a biopsychosocial model of dementia as a tool to guide clinical practice. *International Psychogeriatrics* 22, 957-965.
- Stige, B. (2006). On a notion of participation in music therapy. *Nordic Journal of Music Therapy, 15*(2), 121-138. DOI: 10.1080/08098130609478159
- Stige, B., & Aarø, L. E. (2012). Invitation to community music therapy (1st ed). Routledge.
- Swinton, J. (2012). Dementia: living in the memories of God. SCM Press.

- Sulmasy, D. P. (2002). A biopsychosocial-spiritual model for the care of patients at the end of life. *The Gerontologist*, *42*(3), 24-33. Svansdottir, H. B., & Snaedal, J. (2006). Music therapy in moderate and severe dementia of Alzheimer's type: A case-control study. *International Psychogeriatrics*, *18*(4), 613-621.
- Tamplin, J., Clark, I. N., Lee Y-E. C., & Baker, F. A. (2018). Remini-Sing: A feasibility study of therapeutic group singing to support relationship quality and wellbeing for community-dwelling people living with dementia and their family caregivers. *Frontiers in Medicine*, *5*, 245 https://www.frontiersin.org/article/10.3389/fmed.2018.00245
- van der Steen, J. T., Smaling, H. J.A., van der Wouden, J. C., Bruinsma, M. S., Scholten, R. J. P. M., & Vink, A. C. (2018). Music-based therapeutic interventions for people with dementia. *Cochrane Database of Systematic Reviews* 7. Art. No.: CD003477. DOI: 10.1002/14651858.CD003477.pub4
- Vink, A. C., Zuidersma, M., Boersma, F., de Jonge, P., Zuidema, S. U., & Slaets, J. P. (2013). The effect of music therapy compared with general recreational activities in reducing agitation in people with dementia: a randomised controlled trial. *International Journal of Geriatric Psychiatry*, 28(10), 1031–1038. https://doi.org/10.1002/gps.3924
- 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, London School of Economics and Political Science. Report funded by Alzheimer's Society. https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

Ελληνική περίληψη | Greek abstract

Μαζί στον Ήχο [Together in Sound]: Ομάδες μουσικοθεραπείας για άτομα με άνοια και τους συνοδούς τους – διαδικτυακή μεταφορά των συνεδρίων ως ανταπόκριση στην πανδημία

Claire Molyneux, Thomas Hardy, Yu-Tzu (Chloe) Lin, Katie McKinnon & Helen Odell-Miller

ΠΕΡΙΛΗΨΗ

Το πρόγραμμα Μαζί στον Ήχο [Together in Sound] είναι μια συνεργασία ανάμεσα στο Ινστιτούτο του Cambridge για την Έρευνα στη Μουσικοθεραπεία του Anglia Ruskin University (ARU) και το Saffron Hall Trust, ένα καλλιτεχνικό φιλανθρωπικό οργανισμό που εδρεύει στα περίχωρα του Essex στην Αγγλία. Το πρόγραμμα ξεκίνησε το φθινόπωρο του 2017 προσφέροντας μουσικοθεραπεία σε άτομα με άνοια και τους συνοδούς τους, και περιλαμβάνει ένα πρακτικά προσανατολισμένο ερευνητικό μέρος. Αυτή η αναφορά, η οποία έχει συγγραφεί από κοινού, εστιάζει στον αντίκτυπο της πανδημίας του COVID-19 στο συγκεκριμένο πρόγραμμα και παρουσιάζει την εμπειρία της ομάδας αναφορικά με τη διαδικτυακή μεταφορά των συνεδριών μουσικοθεραπείας από τον Μάρτιο του 2020. Η διαδικτυακή συνέχιση του προγράμματος παρείχε μια αίσθηση συνοχής, υποστήριξης και συνεχιζόμενης διασύνδεσης με τους συμμετέχοντες, οι οποίοι, εξαιτίας της απαγόρευσης κυκλοφορίας στο Ηνωμένο Βασίλειο, παρέμειναν απομονωμένοι στις κατοικίες του. Μετά την περιγραφή του πλαισίου του προγράμματος, η αναφορά αυτή διερευνά τις προκλήσεις και τα οφέλη των διαδικτυακών συνεδριών μέσα από τον αναστοχασμό της ομάδας Μαζί στον Ήχο, συμπεριλαμβάνοντας πιθανές επιπτώσεις για το μέλλον.

ΛΕΞΕΙΣ ΚΛΕΙΔΙΑ

διαδικτυακή μουσικοθεραπεία, άτομα με άνοια, ζευγάρια φροντιστών, πανδημία του COVID-19