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Still Together in Sound: narratives from online music therapy with people living with dementia and their companions during lockdown.

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Abstract

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Described as a ‘lifeline’ by one participant, the role of online music therapy for people living with dementia and their companions is explored in this article. Together in Sound, established in 2017, is a partnership project between the Cambridge Institute for Music Therapy Research at Anglia Ruskin University and Saffron Hall Trust, an arts charity in rural Essex. Delivery of group music therapy moved online rapidly at the end of March 2020 in response to lockdown in the United Kingdom due to the COVID-19 pandemic. This move was welcomed by participants but presented challenges for some in terms of accessing or making sense of the sessions through the screen. An ongoing narrative inquiry within a practice-based research project exploring the impact of the groups for participants has established a culture of consultation and collaboration within the project. Participants regularly attend focus group discussions to share their experiences and to help shape future directions of the project. Evaluation of the project shows that it has a role in supporting communication and relationships, providing opportunities for socialisation and self-expression, and increasing awareness of living with dementia in the wider community. This article invites the reader to witness the stories and experiences of those involved in Together in Sound during a time of change and uncertainty. Reflections and narratives were collected from clinical material including video from music therapy sessions, clinical notes, and song lyrics. Further data was generated from a focus group interview and written contributions from co-authors. Searching the data for stories and metaphors helps our understanding of the role of online music therapy in supporting wellbeing and continued connection with others when people are physically isolated. The article also presents songs composed by the groups to illustrate ways in which participants used song-writing to communicate, express and make meaning of their experiences.

Keywords: Dementia. Music therapy. Online. COVID-19. Narrative inquiry.

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1. Introduction to the group

The music therapist and trainee welcome fourteen participants to the therapy room including four couples, where one person has a diagnosis of dementia; and six individuals, who had previously attended as couples but now attend individually, either because the person with dementia has moved into care, or has died. Also joining this session are two young musicians from the London Philharmonic Orchestra's (LPO) Foyle Future First scheme. The group has been working on a song, 'Togetherness', for the past six weeks, generating lyrics from their experiences of being part of Together in Sound, a community project delivering music therapy to people living with dementia and their companions. After greeting each other with a hello song, engaging in some physical and vocal warm-ups and a musical improvisation, the group turns its attention to the song. A companion, whose partner with dementia has recently moved into residential care, speaks the opening words:

*Our song it tells a story,
A story of coping, a story of love
There's a kindness around the group
A kindness we give and receive*

"It sets the scene doesn't it?" comments one participant over the music. The group continues, singing together, supported by the therapists and two LPO musicians, one playing the trumpet, the other the oboe:

*Together in sound, what a wonderful thing
We meet on a Friday to laugh and to sing,
Everyone happy full of good cheer,
A smile on our faces from ear to ear.*

*We come in a rush and we come in a moil,
We come in a muddle and a bit of fuddle,
Come with our worries, come with our cares,
Come with some anger and sometimes fear.*

*Saffron Hall helpers welcome us all,
Drinking tea or coffee, chatting in the hall.
Caring and sharing, the kindness is real,
Patiently listening to sense how we feel.*

*Singing along and beating on drums,
Playing the flute with fingers and thumbs,
Making some music with our hearts and our minds,
Sharing our message with all man-kind*

*So short a time but filled with so much,
Music and song releases the mind
Quiet and listening, playing and singing,
Peace for a while, together in sound.*

*Self-control and patience, love and respect,
These are the important things that see us through each day.
Togetherness, acceptance; fun and laughter too,
These are the special things we have.*

*Our song it tells a story
A story of coping, a story of love,
Memory fades, but feeling remains,
Feeling remains*

*Together in sound, what a wonderful thing
We meet on a Friday to laugh and to sing,
Everyone happy full of good cheer,
A smile on our faces from ear to ear.*

As the final phrase is played, there is a murmur of satisfaction around the group, smiles and a sense of achievement. Someone reiterates the importance of including contributions from the participants with a diagnosis of dementia. The group agrees the following phrases should be spoken over humming at the end of the song:

*“It’s great fun and you don’t have to be musical. You accept us all.”
“I like coming.”
“It’s a privilege to be part of and I feel that each time.”*

One week later, the music therapist and trainee deliver the first online session, initially working together in a university teaching room before delivering from their own homes due to lockdown restrictions. The rapidly escalating COVID-19 crisis meant that in-person delivery of sessions was no longer safe or possible. In subsequent weeks, most (though not all) participants are able to join the online sessions from their homes. In one session with the LPO musicians, participants sing ‘Togetherness’. Following the song, Kathy, a carer whose husband has dementia, reflects:

Kathy¹: It’s quite poignant isn’t it when you think about what’s happening. Everybody’s in the same boat now although it’s not together in sound it’s together with families at home or being together with one person or maybe a whole family.

LPO musician: It’s amazing that we can do it like this and that we’re together like this it’s actually so incredible that we’re able to do that and even though everyone is self-isolating it’s amazing that we can come together in this way.

Kathy: I think it’s brilliant actually.

Katie: Maybe we need a new line: ‘Together in Sound via Zoom’

(Laughter)

Kathy: [singing] how it sounds in the room.

2. Context

¹ The research has ethical approval from the Faculty Research Ethics Panel at Anglia Ruskin University. Names have been changed to protect confidentiality.

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. Established in Autumn 2017, the project delivers music therapy to people living with dementia and their companions. An innovative collaboration between the arts sector and the music therapy profession, 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. The focus is on joint music-making and listening with the goals of supporting communication, relationships, and increasing quality of life through a collaborative group process. Each ten-week block of music therapy sessions includes a sharing event where family, friends and other stakeholders are invited to witness aspects of the groups' music making and process. Sharing original compositions and working with a local primary school choir have been highlights of recent sharing events which help increase awareness of dementia and provide a bridging function to the local community. The project is the focus of the first author's doctoral research which is a narrative inquiry with practice-based arts-informed responses exploring the impact of the groups.

This article invites the reader to witness the stories and experiences of those involved in Together in Sound as the project moved to online delivery because of the COVID-19 pandemic. Reflections and narratives were collected from clinical material including video from music therapy sessions, clinical notes, and song lyrics. Further data was generated from a focus group interview and written contributions from co-authors. The article moves between the voices of participants and co-authors, weaving reflection and experience within the wider context of music therapy practice with the aim of gaining understanding of the role of online music therapy in supporting wellbeing and continued connection with others when people are physically isolated.

3. Music Therapy and Dementia

Co-author Russell reflects on his experiences caring for his wife Brenda who has Alzheimer's Disease:

To those of us that are on the dementia /carer journey, it can be a very isolating one as our loved ones gradually recede into their own world in which we try, but for periods of time, we cannot be part of. Acquaintances may say to me: "I feel so sorry for you" or "I don't know how you do it". They mean well, but there is no place for pity or self-pity in this journey. We do it out of love, not duty or because we feel we have to do it. However, there does come a time when the inevitable stress takes a toll on the carer's health.

During our journey, we have become more aware how important social interaction and music is and this is when Together in Sound came into our lives. It fulfils these needs and music has taken on a different meaning. I know for sure that there is a special place in our brains for music, apparently playing and singing music helps your brain function more than any other activity. Our weekly sessions of Together in Sound are one of the most important times in our weekly calendar. The half hour tea and biscuits is all part of the coming together because we are all making this same journey.

The importance of psychosocial interventions for people with dementia and their 'informal caregivers' is the subject of the systematic review by Rausch, Caljouw and van der Ploeg (2017, p.591) who suggest that 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'. As Russell states above, "we are all making this same journey", and in music therapy practice, there has been a growing interest in interventions for caregiving dyads. A feasibility study by Tamplin, Clark, Lee and Baker (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 (Clark, Tamplin & Baker, 2018). Tamplin et al. (2018, p.9) 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'. More recently, Baker et al. (2019), describe a newly designed music intervention delivery for couples living at home where one is living with dementia, through which family carers are trained to interact daily through music or reading/story telling. Homeside is a current international Randomised Controlled Trial (RCT) on-going research study, further investigating music and other approaches that can meet needs at home, for this population and their families. 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.

Recent publications have described community-based music therapy groups for people living with dementia. A project described by Rio includes 'singing, instrument playing, movement and creation of new musical arrangements and improvisations based on in-the-moment needs, feelings and concerns' (Rio, 2018). New Zealand-based music therapist, Allan (2018) offers an example of a community-based 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, Grady and Holland (2019) report on the benefits of individualized home-based 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. These examples demonstrate the growing interest in documenting different approaches to working with people living with dementia and their caregivers. As Russell emphasises above, coming together for social interaction and to make music is one of the most important weekly commitments in his calendar.

4. Theoretical Frame: narrative perspectives

As stated earlier, this article invites the reader to witness the stories and experiences of those involved in Together in Sound. Narrative inquiry preserves individual voices and extended accounts (from interview transcripts or video data for example), enabling an exploration of these accounts rather than fragmenting the data into discursive meaning-laden moments or thematic categories. Maintaining narrative units (Kendall & Murray, 2004) is important in the context of research with people living with dementia where the impact of dementia itself might be experienced as a personal narrative being deconstructed. Preserving participants' stories and experiences is an attempt to conduct research that is congruent with anti-oppressive practice and research principles of addressing power inequities and seeking ways for research to be empowering and emancipatory (Baines & Edwards, 2015; 2018). Furthermore, using poetic forms of narrative to present units of text can provide a counterpoint to the 'fragmentation and decontextualising' (Kendall & Murray, 2004, p.68) of traditional coding of interview transcripts. Narrative inquiry focuses on the 'act of telling' and context of production as well as the content of the story enabling researchers to 'see different and sometimes contradictory layers of meaning, to bring them into useful dialogue with each other, and to understand more about individual and social change' (Squire, Andrews & Tamboukou, 2008, p.1). Individual stories are situated within the wider social, political, and cultural context which can reveal both dominant discourses and counter-narratives, a point emphasized by Frank (2012) who considers storytelling to be a dialogical process.

From Frank's point of view, identifying core narratives helps us understand the resources available to people and how accessible these are in circumstances of vulnerability (Frank, 2012). For Together in Sound participants, an overarching story of finding togetherness and community through adversity appears to be present. Their story is connected to hope and in particular, the concept of radical hope as described by Frank: 'Hope is believing in the future, and acting to bring that future into being, in

the absence of any specific imagination of that future' (Frank, 2013, p. 217). Returning to the song, 'Togetherness', Bob (participant and carer) reflects:

"I think for me it sums up so many feelings most of which are not actually sad because they brought wonderful times (.) still do (.) for me it's a case of what wonderful memories it stirs (.) but also it details hope not only for the likes of myself but those of us who are still partnered and those in the future who are going to have a hard time that some of us have been through (.) all I would say is I think it sums up a lifetime (.)" (Molyneux, C. 2020a, lines 129-133)

5. Method

This practice-focused article aims to increase understanding of the role of online music therapy in supporting wellbeing and connection with others. A qualitative descriptive design within a narrative framework was used for data collection and analysis. Data were collected from online music therapy sessions, including song lyrics from original compositions and clinical notes. Recordings of sessions were viewed, looking specifically for stories about participants' experiences of the sessions and the impact on their lives since lockdown. Some participants had taken part in an interview with the BBC early in lockdown which was also transcribed and analysed.

Additionally, participants were invited to an online focus group interview to gather feedback about their experiences. Facilitating the focus group online reduced the flexibility for open-ended discussion to emerge naturally. We therefore provided structure using a mixture of open discussion and polls to hold participants' attention. Further written material was collected from co-authors: Thomas Hardy, Yu-Tzu Lin, Katie McKinnon, Hannah Merchant and Russell Smith, who were asked to write about their experiences or a particular memory of this period.

Analysis was performed using what Brinkmann and Kvale (2018, p.132) describe as a 'bricolage approach'. The data was searched specifically for stories, metaphors and to capture meaning and understanding in relation to the central question: what has the role of Together in Sound been for you during the lockdown? For the purposes of this article, stories were identified by searching for speech, actions, or text where there is a 'complicating action' and a 'resolution' to this action. For example, in Russell's opening story, he describes the journey of dementia as isolating (the complicating action). Together in Sound provided social interaction and music (resolution) which can be viewed as resolving some of the isolation. Narrative themes and thematic relationships were searched for across the stories to gain insight to the 'shared narrative resources' (Caddick, 2018, p.4) that were present.

An over-arching theme emerged which was neatly summarized by one participant in the BBC interview who said: "Music brought us together, but it is so much more than this". After providing context about the process of moving the sessions online, this article will look more deeply at the implications of this statement; exploring in particular two narrative themes which demonstrate how Together in Sound became "so much more" during the lockdown period:

Together in Sound as a 'lifeline' - Lockdown brought loss of freedom, structure and routine – Together in Sound has helped to restore aspects of structure and routine and provide space for self-expression.

Coming together in a creative endeavour can offer hope and mutual encouragement – Together in Sound has created the conditions for individuals to become a community.

6. Music Therapy and Telehealth

We return to Russell's story:

As a result of the lockdown, our Together in Sound sessions could no longer be held face to face, so 'Zoom²' came into our world, this is the platform whereby we can all still meet. Zoom of course cannot replace the face to face sessions but it's not a bad substitute, it fulfils our need at this time for interaction. One of the disadvantages, which of course is a technical one, is that Claire has to mute us all when we sing together because of the delay, but that is a small price to pay. We all enjoy the experience of being with and listening to professional musicians when they have visited and that can continue on Zoom. I did find that Bren found it difficult to concentrate on the small screen during our online sessions, but maybe that was to be expected. For over three years, we have not been able to follow TV programmes with dialogue, but we have spent far more time listening to music. It appears that we may have Zoom in our lives for a very long time, thank goodness for that, because without it, all the friendships we have established through Together in Sound would be harder to maintain. I have become a Zoom addict and go to three meetings a week.

Together in Sound participants had varying degrees of digital literacy. In a qualitative descriptive study, Nissen, Hersch, Tietze and Chang (2018) explored perceptions of people living with dementia and caregivers to occupational health services delivered via telehealth. Initially uncertain, participants reported willingness to use various platforms but emphasized the importance of 'in-person' support 'to assist with technology education and problem solving' (2018, p. 375). Other studies (Tsai, Shillair, Cotton, Winstead & Yost, 2015; Tsai, Shillair & Cotton, 2017) recommend the use of tablet devices for older adults which they conclude 'have the potential to become indispensable in connecting older adults to health information, communication, and feeling connected to the outside world' (Tsai et al., 2015, p. 705). For Together in Sound participants, support offered by Saffron Hall was essential in the transition to online sessions as outlined by Katie McKinnon:

Once we knew we intended to deliver sessions online I was tasked with teaching the participants and companions how to use video-conferencing software. Initially many of the participants and companions expressed distrust with not only using the internet ("The only person that ever emails me is you!", "You hear so many stories about people being scammed.") but also their own devices, which ranged from tablets to smartphones, laptops to iMacs. I created both generic and bespoke 'how-to' documents and in many cases worked with companions over the phone to get them online whilst reassuring and ensuring their safety online. Since we began online delivery all but four couples have been able to use Zoom to join Together in Sound sessions and many have expressed their gratitude in learning to use their devices and Zoom software to keep in contact with family and friends. Some of the participants and companions I worked with had not ever used their devices and weren't sure how to turn them on; now they are emailing and 'zoom-ing' from them. A particularly memorable success is the companions who now use the software to keep in touch with each other outside of Together in Sound sessions.

On reflection, and with hindsight, I would perhaps have engaged all companions sooner with resources to build their digital literacy skills to enable a network of support across not only their Together in Sound groups but with family and friends. In reality, the strength of friendships and a desire to support each other has seen participants build their confidence and, through their own agency, create some of the support they require. This empowerment and improvement of their digital literacy is a worthwhile side-effect of lockdown.

² Zoom is a form of video-conferencing software that was used to deliver online music therapy sessions.

There is a paucity of literature written about music therapy and telehealth. Claire remembers reading the article by Baker and Krout in 2009 and being unable to imagine delivering music therapy remotely via video-conferencing software in the way described. However, as she became more comfortable and experienced at facilitating supervision online, the idea in 2020 of delivering music therapy in this way, felt possible. Vaudreuil, Langston, Magee, Betts, Kass and Levy (2020) report on the delivery of music therapy via telehealth for military populations. Delivering arts therapies to this population (art, dance movement therapy and more recently music therapy) has been established since 2014 and increases access to those who live remotely or ensures continuity at times of ‘treatment transitions’, for example when those accessing services are posted to different locations. Vaudreuil et al. (2020, p.8) state that ‘Shared experiences that enhance creative expression, support emotion, and promote communication through enjoyable experiences can serve as a protective factor from isolation, which is commonly experienced during treatment transitions and can have grave consequences if not addressed’.

For Together in Sound, the move to delivering our sessions online was forced upon us by the COVID-19 pandemic. It is not something we had planned or even discussed; if it were, we could have signposted participants to opportunities to develop their digital literacy in preparation. Recognising that living with dementia already brings aspects of isolation, our motivation was to continue to provide opportunities for connection and support in the face of the nationwide lockdown, a sudden and imposed ‘treatment transition’. For further context about the practicalities of moving Together in Sound online, see Molyneux et al, 2020.

Returning to the song that set the scene at the beginning of this article, Thomas Hardy, Learning and Participation Director at Saffron Hall, describes his experience of sessions moving online:

Although I oversee Together in Sound for Saffron Hall at a strategic level, the nature of my role and the fact that we have an incredible team of volunteers and staff ‘on the ground’, means that sometimes my direct contact with participants and presence in weekly sessions is limited. As a clinical intervention, the in-person music therapy sessions are delivered ‘behind closed doors’ without visitors who are not directly involved, in order to create a safe and confidential environment for participants. Oddly, therefore, the move to online sessions has brought me closer to the practice of Claire and her team. I had the privilege of ‘sitting in’ on the earliest online sessions, as we supported participants with technology, established ways of working, and iteratively developed the model from one session to the next.

In one of the earliest online sessions, the group continued working on ‘Togetherness’. I remember the first online run through of this composition vividly. We hadn’t yet worked out all the details of how to mute and unmute groups of participants, or resolved all the audio issues inherent in this new way of working, but Claire shared the lyrics on the screen and, despite glitches, the group ran through the whole piece.

The song was remarkable. The lyrics, which had been developed by the group, captured their experience of attending Together in Sound and what it meant to them. It didn’t shy away from referencing the difficulties presented by living with dementia, but captured, perhaps better than any of our more formal evaluations, a story about how music making, shared experience and the sense of community created through Together in Sound provided a framework which provided comfort and support throughout these challenges.

Listening to this song, just before the formal lockdown period, was, however bittersweet. The piece captured so well the values which have driven my career in the arts – the value of shared experience, and of a community coming together to experience and create music. It suddenly felt as though none of these things were possible anymore, and that with its audio glitches and latency issues, nothing we did online would quite replace this. At the end of the song

however, Claire and the participants did not discuss any of the sound issues, or the challenges the online environment was presenting. Instead there was discussion about some lyrics, and the structure of the song, particularly around a spoken word introduction, and I witnessed the group collaborating and sharing ideas for improving and developing what they had created together. I took a lot from this; this wasn't a time for moping or mourning over what we had lost, but a moment to be seized, to make the most of.

The article will now present the narrative themes outlined earlier: Together in Sound as a 'lifeline' and Coming together in a creative endeavour can offer hope and mutual encouragement.

7. Narrative Theme One: 'Together in Sound as a 'Lifeline''

The idea of Together in Sound as a 'lifeline' was first expressed by participants in an interview with the BBC (BBC News, 2020):

BBC reporter: So I'll go around each of you if you wouldn't mind just to sort of say to ask really how you would sum up how important having these sessions online and keeping them going has been to you over the last few weeks?

Philip: Well. I think it's a lifeline really (.) that's all I can say is just something to look forward to and we can't wait for it to come

Tina: Well I think for us again it's been a lifeline (.) our normal course of events we're out every week day doing something socially dementia friendly so the lockdown has hit us hard and we do really miss that so this is a big relief for us.

Our participants told us that lockdown brought loss of freedom, structure, and routine as well as loss of physical contact and being able to see loved ones. Russell's story continues:

When the 'lockdown' came as a result of coronavirus, it changed all our lives. We were initially all confined to our homes and everyday life became more difficult. Our two or three visits to the town every week were not possible; we only used to walk around the town but it was something different to do as Bren had reached the stage where she was not capable of doing all the things she used to.

Brenda moved into a care home during the lockdown and has been there for nearly three months. Of course, because of the lockdown, I have not been able to visit her. This is the longest period that we have been apart for 65 years, it has been heart-breaking for me and I'm sure it has been the same for her. On our 63rd wedding anniversary the [care] home allowed me to see her from a distance. It did not go well. She thought I had abandoned her because I had not been to visit her. The carers explained to her that no loved ones are allowed to visit, but she and most others in care cannot understand what is happening. In the last week, the home has started allowing visits to a special designated room. I have visited Bren three times this week and she has been her usual lovely self, the carers all love her, who wouldn't. She spends some of her time back in the classroom in front of her class, the carers go along with it and pretend they are talking to the children too.

Russell's experience is echoed by another participant who shared her story in the focus group of visiting her husband who has dementia in a care home:

“When I go to see him I have to wear a mask and the first time I saw him it was through a window and that just didn’t mean anything to him and he just wandered off because it wasn’t a connection (.) I’ve been able to go and see him recently with an appointment and I have to get checked and wear apron and gloves and mask and things and it’s a bit better now (.) I’m not sure whether he knows who I am (.) or recognise but I take little photos for him and he looks at those (pause) he obviously wants to give me a hug and that is very difficult because obviously he’s not allowed to (.)”

(Molyneux, 2020b, lines 439-447)

Together in Sound was seen as providing structure and something to look forward to at this difficult time. Some participants with dementia found it difficult to engage with the screen: “they need someone to interact with and on a screen, it doesn’t make sense.” Although this was hard for the carers at times, they expressed how much they valued the sessions. Philip, in the BBC interview explained: “things like this is such a break that you can go on to and enjoy it and it seems to take you out of yourself even if my wife doesn’t always take part.”

In contrast, others living with dementia found it easier to engage with the screen and stayed for whole sessions, participating fully. One participant living with dementia told us: “Music does something for me, especially singing (.) it really encourages me”. Andrew, also living with dementia, spoke eloquently of his experience of the sessions:

“It has meaning and well contributes (.) perhaps contributes to one’s understanding about things about the small things and large things and one likes to be honest shall we say as far as one can and I must say I admire the you know the quality of what’s being said and what’s happening and it seems to flow (.) flow well (.) and it helps and I’m conscious of the fact that I probably have a number of what’s not misgivings (.) things that I don’t do well and I should do but I think I do try and I think there is something credit worthy there in that it helps me and if I listen and watch (.) watch the screen and all the rest of it and I hear this or see that I feel it helps my understanding and that’s good and long may it continue (.)”

(Molyneux, 2020b, lines 585-600)

One of the unexpected outcomes of online delivery has been the creation of a resource bank of videos. These include recordings of sessions, short videos of songs, music and activities by music therapist Claire, and commissioned recordings from visiting artists. Shared with participants in weeks where live sessions are on a break, the videos have been well used by participants. For one couple, the videos became a resource used several times a day “depending on how difficult life becomes”. Andrew’s wife described their experience in the focus group:

“Well Andrew (.) without Claire’s videos each morning (.) they have been just a godsend (.) because he thinks he’s going somewhere to either dancing or to the music therapy group and I have to grab the computer and say ‘come and see Claire’s latest video’ and they’ve been they’ve just been a godsend (.) It’s been something that is natural for him to participate in I suppose (.) He’s had long conversations with Claire after each song she’s sung and I then rush in from the bathroom or making a bed and turn the next video on (.) So from your point of view [talking to Andrew] although you find Zoom more difficult (.) the actual videos with songs and a face you know have gone really well.”

(Molyneux, 2020b, lines 209-218 and 288-292)

The impact of living through lockdown, the loss of freedom, and experience of Together in Sound providing a routine is expressed in a song that was written by one of the groups. Set to a 12-bar

blues framework, the refrain ‘We’re stuck at home, but we’re not alone, we’re singing the blues with you’, emerged quickly as the group reflected on their situation. One participant, Esther, suggested structuring the song around the days of the week which enabled participants to identify things they were missing as well as new things such as clapping for the National Health Service (NHS) on Thursday nights³. Co-therapist, Yu-Tzu Lin reflects on the song-writing process that resulted in ‘Virus Blues’ (see Appendix 1 for full lyrics):

At first, participants focused more on the inconvenience they had encountered and compared the difference in daily life before and after lockdown. However, one participant started to express how fortunate we were, giving another perspective. Not everyone was allowed or able to even access the internet and sing or enjoy the music as we did. Participants started to appreciate the front-line workers around them, including the NHS, delivery drivers and the local traders, who continued to contribute their time against the pandemic, serving people day and night. I never thought it would be such a creative and powerful way to compose a song together online. Not only did the lyrics express the fears and worries towards the virus but also the beauty and hope from outside the world. When creating the song with participants, I felt the sense of togetherness, kindness and courage from them.

The songwriting process enabled many different experiences to be shared by participants with the song structure acting as both container for emotions and as a catalyst for reflection and sharing experiences (Wigram, 2005, p.257). The structure provided by the songwriting process mirrored something of the structure that Together in Sound was seen to provide participants during lockdown, when much of their routine had been changed or taken away. The song adds to the body of artefacts created by participants and, as discussed by Baker (2015, p.106), the song was ‘refined, discussed, and reflected upon in subsequent sessions, and/or sung, recorded, performed, or shared with others’. Songs such as ‘Virus Blues’ have an immediate role during their creation, become a memory and reference point for participants, and can be shared with others to describe experience.

8. Narrative Theme Two: Coming together in a creative endeavour can offer hope and mutual encouragement

Hope and mutual encouragement emerged as a narrative theme for participants, expressed in the sessions through songwriting, in the focus group, and in the interview with the BBC reporter as illustrated here by Russell:

“When you’re living with somebody with Alzheimer’s, it’s a very challenging thing for both the carer and obviously for the person that’s suffering from Alzheimer’s and it can be a very isolating experience for everybody and these sessions that we’re having now, to see all these faces looking back at me, it’s lovely, it’s just lovely because we’re keeping up that connection. Because I mean, we’re all in it together but it doesn’t feel sometimes that we’re all in it together because we’re all self-isolating. So I think that these sessions are very important because it keeps us all going, it keeps us going. We need that. People with Alzheimer’s and their carers, we need, we need it.”

Interestingly the narrative of finding hope is not a new one for the groups, but has taken on new meaning in the light of the pandemic and experiences of lockdown. In our first few online sessions, one group revisited a song for which they had previously composed lyrics pre-pandemic. ‘Hopeful Calypso’ (Skinner & Raphael, 2007) is a song framework that helped the group identify things that were important

³ Clap for Our Carers was a social movement created as a gesture of appreciation for the workers of the United Kingdom’s National Health Service (NHS) and other key workers during the global COVID-19 pandemic.

and hopeful for them during the journey of dementia. The song opens with the lines ‘If you will listen, here comes a new song, full of the things we pin all our hopes on’. The group created their own lyrics to complete each stanza, including: sunshine and family, good food and drink; good health and happiness, good friends and laughter; comfort and love, caring and sharing, kindness and patience all day; peace in our hearts and a restful sleep, waking to greet a new day (see Appendix 2 for full lyrics).

After singing this song in a session, participants reflected:

Kathy: “I think it is apt for today where really all we have is hope (.) hope that things will (.) for everyone for the whole country (.) not just me and David, or you but for everybody that’s in a situation that we would never have chosen to be in and I think we have to be mindful that everybody is going through turmoils of some sort or other at this time not just us and we have to be mindful of that and sometimes I’m not and I must admit to that but when you listen to the news and what happened you realise that actually you’re sharing something that no other people have shared (.) news has never been so instant so we’re sharing everybody’s fear from all over the world and it’s quite frightening really so hope is the thing we must grasp.

Elizabeth: And mutual encouragement”

Another participant suggested that the song lyrics could be shared with the local news as a “message of hope”.

Like Thomas’ reflections above that rather than discussing the challenges of the online environment, the group focused on improving and developing the song ‘Togetherness’, having a musical and creative focus was valued and seemed to offer hope. In a poll during the focus group meeting, participants were invited to rank which activities they liked the most. ‘Listening to music (including visiting musicians)’ and ‘singing together’ were ranked highest. The second ranking included four activities: ‘Action songs’, ‘Discussion about personal experience’, ‘Playing instruments’ and ‘Chatting before the session starts’.

Participants were familiar with songwriting from attending in-person sessions. As with ‘Virus Blues’ above, songwriting provided an important container for thoughts and feelings. In the following example, the song ‘Just be kind’ seems to take on the role of providing hope and encouragement for participants.

As co-therapist, Yu-Tzu Lin describes:

In the morning group, we adapted the song ‘Just be kind’ from Bet and Deb (2020) as our group song. The original lyrics offer a simple message:

*Just be kind, just as kind as you can be,
Cos we’re all in this together, you and me.
Just be kind, just as kind as you can be,
And we’ll come through this together, wait and see.*

I think the repetitive kindness and positive attitude throughout the song were important for all of us during this difficult time. After a brief discussion in the session, we decided to use this song as a foundation to develop more themes and personal perspectives.

Despite the restrictions of lockdown, participants learned to appreciate what they can do and shared with others the ways they had to adapt in daily life. Within three weeks, these

elements became part of the group song. One week, a participant talked about the beautiful flowers she noticed in the fields, another replied that various plants in her garden had started to bloom, while someone else shared the pictures of a lovely swan's family by the riverside. In the following week, a participant shared a poem she wrote that was inspired by her morning walk and commented that songwriting in our sessions had inspired her to have a go at writing more poetry.

Apart from the physical elements above, some of the lyrics came from participants' feelings. Several participants shared how they appreciated the cats or dogs in their home, accompanying them during the lockdown. Some stated how important the weekly online sessions were for them because it was the only time that everyone can meet together on the screen. Participants could wave hands, talk to others and even make music together despite the lockdown situation.

When singing the song, it brings back the lovely moments during the online sessions, which meant a lot to me in the lockdown period. It also reminds me to appreciate the abundant resources that I have and utilize this time as an opportunity to connect with people in different ways.

As Yu-Tzu's reflections indicate, the lyrics (See Appendix 3) had resonance for her personally. The pandemic and lockdown was something that we were all experiencing. For co-therapists Claire and Yu-Tzu, reflexive practice including time to plan, debrief, and ongoing clinical supervision with co-author, Helen Odell-Miller, was crucial to enable us to focus on our role as therapists while managing the extraordinary circumstances in which we all found ourselves.

9. Discussion: "Music has brought us together, but it is so much more than this"

Participant, Esther, reflected in the BBC interview:

"We've made connections with people in all sorts of different ways (.) and there's lots of people who've got all sorts of different things in common (.) we've shared a little bit of our life story together and the music is what's brought us together but it's so much more than that (.) but the music in itself is just a lovely way of switching off from other things (.) there's just something special in singing and making music together in a group."

(BBC News, 2020)

Connecting with others, sharing things in common and making music together may seem like simple actions. However, in the context of living with dementia (including both the person with the diagnosis and the companion), and the added complexity of a sudden and enforced lockdown, accessing these things can be far from simple. The stories, song lyrics and reflections shared above demonstrate that Together in Sound played a role in restoring structure and routine which had been lost with the lockdown.

The music therapy groups provided vital opportunities for support and connection with others. Participants not only had to deal with numerous pandemic-related challenges, but also ongoing challenges of living with dementia which, for at least three of our participants during this time, meant a move into residential care.

Two narrative themes emerged from this study:

1. Together in Sound as a ‘lifeline’ – Lockdown brought loss of freedom, structure and routine. Together in Sound has helped to restore aspects of structure and routine and provide space for self-expression.
2. Coming together in a creative endeavour can offer hope and mutual encouragement – Together in Sound has created the conditions for individuals to become a community.

While these narratives relate specifically to the period of online music therapy sessions during what has become an extended lockdown for participants due to the need for shielding from COVID-19, they also relate to the experience of Together in Sound as a collective resource for participants. This can be seen in the song lyrics for ‘Togetherness’ (written before the pandemic) and ‘Virus Blues’ (created during the lockdown). Created in very different circumstances, there are significant parallels in the lyrics as outlined in Table 1 below.

Table 1. Parallels between song lyrics

	Togetherness	Virus Blues
Structure brought by Together in Sound	‘We meet on a Friday to laugh and to sing’	‘Friday we’re composing songs, Making music with our friends.’
Connection and a sense of community	‘Togetherness, acceptance; fun and laughter too, these are the special things we have’	‘We’re not alone, we’re singing the blues with you’
Appreciation	‘Caring and sharing, the kindness is real’ ‘Sharing our message with all mankind’	‘We’ll use this time to appreciate what we’ve got. Local traders, helping the neighbours, all kinds of key workers, delivery drivers.’
Acknowledgement of hardship	‘We come in a muddle and a bit of a fuddle, come with our worries, come with our cares, come with some anger and sometimes fear.’	‘Can’t hug our loved ones.’ ‘Weekends can be lonely.’

Hope and mutual encouragement are present in both songs too, but more explicitly in ‘Hopeful Calypso’, created before the pandemic and ‘Just Be Kind’, created during lockdown. We would suggest that an ‘essence’ of Together in Sound has survived the transition from in-person to online working and are important factors in leading participants to describe it as a ‘lifeline. This theme is worthy of further analysis and raises questions about how the ‘lifeline’ metaphor (for example Gorst, Coates & Armitage, 2015; Martindale-Adams, Nichols, Burns & Malone, 2002) is used in health and illness studies; an area that will be addressed further in the first author’s doctoral research.

In relation to illness narratives, Frank (2013) helps us understand how the stories people tell about living with illness become resources that can create communities; an experience that was already present for participants of Together in Sound before the pandemic. The lockdown was a sudden interruption to the ongoing therapeutic process in which participants were engaged and invested. Vaudreuil et al. (2020, p.8) emphasise that treatment transitions can lead to isolation and give examples of online therapy where shared and creative experiences can be a protective factor against isolation. Making music together, composing lyrics and sharing experiences can be viewed as examples of making meaning of experience through storied or narrative accounts. Such accounts can help support continuity of identity in the face of disruption (Breheny & Griffiths, 2017).

10. Concluding Comments

Through the words of participants, co-authors, and the collaboratively written song lyrics, we have shown how, despite music being the thing which ‘brings us together, it is so much more than this’. Together in Sound creates the conditions in which participants can tell hopeful stories about their experiences, stories that do not exclude suffering and pain, but place this within a context of supportive fellowship and companionship with others who understand. This has been true since the beginning of the project. It was captured in the in-person session described in the opening of this article and the lyrics of ‘Togetherness’. During lockdown this sense of community and coming together has become especially important and, particularly as other elements of routine and socialisation have been unavailable as described in ‘Virus Blues’, has increasingly become a ‘lifeline’ for participants.

Co-author Hannah Merchant joined Together in Sound sessions as part of her final year MA music therapy placement from September 2020 – April 2021. Hannah joined the online ‘summer party’ sharing event and focus group. Her reflections provide a fitting conclusion to this article as we reflect on what we have learned and the values that will support Together in Sound to continue despite the legacy of the lockdown and the continued presence of COVID-19.

It was a pleasure to witness the powerful bond shared by the participants at Together in Sound. I was touched by the many conversations and quickly understood that the group was a place to talk, give support, listen, and find hope during these uncertain and difficult times.

Some of the tough experiences that participants had undergone during lockdown were shared, and despite the group not being able to meet in person, their bond had remained strong. There was a strong sense of unity, solidarity and mutual understanding. Conversations arose very naturally; many participants nodding in agreement with others who were sharing their thoughts.

I was struck by a moment of real support shown by the whole group towards Russell, when he shared his experience of Brenda moving into care. Tina responded: “If I could Russell, I’d give you a big hug. You’ll just have to have a little virtual one at the moment.” Another participant said: “I think he’s having a big one from all of us.” Later in the session, Russell poignantly described the bond that the group had and how he felt lucky. Esther responded by acknowledging how much Russell had been through and said: “you’ve said so many times how lucky you are Russell, and that’s so admirable to hear you say that.” This was a powerful moment as it showed me the support within the group, especially during difficult times.

The group reflected upon what it meant to have written songs together. Kathy described a performance of the songs as a “moment in time,” and Esther referred to them as ‘time capsules.’ These descriptions highlighted the benefit of writing songs that can help participants process emotions as well as feel comforted by others who perhaps describe their emotions similarly. The song lyrics reminded me of a sense of solidarity that was present in the group.

At the online summer party, there was a sense of genuine enjoyment when the groups performed songs to their loved ones. It demonstrated the power that music can have in uplifting emotions, even in the most uncertain of times. The summer party gave the family and friends of the participants an opportunity to witness their music, many of whom had not seen each other for months due to COVID-19 restrictions. Music was bringing people together, in a safe and special way.

At the end of the focus group session, Andrew shared what the group had given him: "Thank you for your smiles...because they mean a lot. They mean almost everything." Andrew's comment summed up the powerful bond within the group, the appreciation for each other. It was a privilege to be welcomed into such a special community, where music can be an anchor, epicentre, and constant companion.

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Appendices

Appendix 1: Virus Blues

Lyrics by Together in Sound participants (2020)

The days are long, so long
The days are long, really really long
We're stuck at home, but we're not alone
We're singing the blues, with you

Monday should be dementia café
Tuesday should be singing
Wednesday should be bowls
Everything's had to change
We're stuck at home, but we're not alone
We're singing the blues, with you

But Thursday night we're clapping our hands
Bless, bless, bless the NHS
We're out in the street, we're tapping our feet
And banging our saucepan lids
We're ringing the bell, blowing the whistle
And crashing our cymbals too

We may be stuck at home, but we'll use this time
To appreciate what we've got
Local traders helping the neighbours
All kinds of key workers, delivery drivers
Can't hug our loved ones but we can keep singing
We're singing the blues with you

We're stuck at home, but we're not alone
We're stuck at home, but no we're not alone
We're stuck at home, we're not alone
We're singing the blues with you
We're stuck at home, but no we're not alone
We're singing the blues with you

Friday we're composing songs
Making music with our friends
Confined to our room, learning 'bout Zoom
What a boom when zoom is in your room
We're stuck at home, but we're not alone
We're singing the blues with you

Weekends can be lonely
We can't go shopping, no drinks in the pub
No garden centre lunches, no singing in churches
Everything's had to change
We're stuck at home, but we're not alone
We're singing the blues with you

We may be stuck at home, but we'll use this time
To appreciate, what is fine
More walks in the country, true blue skies
Allowing nature back into our lives
We're enjoying our home and we're not alone
We're singing the blues with you

Go into the garden, watch the birds and the bees
Peace and quiet, we can feel at ease
The grass is still growing, the doggies need walking
Watch the wind blowing through the trees
We're enjoying our home and we're not alone
We're singing the blues with you

We're stuck at home, but we're not alone
We're stuck at home, but no we're not alone
We're stuck at home, we're not alone
We're singing the blues with you
We're stuck at home, but no we're not alone
We're singing the blues with you

Appendix 2: Hopeful Calypso

Lyrics by Together in Sound participants (2020)

Original music and lyrics adapted by Nick Skinner and Julian Raphael from a traditional Caribbean melody (2007)

If you will listen here comes a new song
Full of the things we pin all our hopes on
Sunshine and good times that's when we feel fine
Singing our song all day

If you will listen here comes a new song
Full of the things we pin all our hopes on
Sunshine and family, good food and drink
Singing our song all day

If you will listen here comes a new song
Full of the things we pin all our hopes on
Good health and happiness, good friends and laughter
Singing our song all day

If you will listen here comes a new song
Full of the things we pin all our hopes on
Comfort and love, caring and sharing
Kindness and patience all day

After our new song, here comes the evening
Full of the things we pin all our hopes on
Peace in our hearts and a restful sleep
Waking to greet a new day

Appendix Three: Just be kind

Original music and lyrics by Bet and Deb (2020)

Adapted and extended by Together in Sound participants (2020)

Just be kind, just as kind as you can be
'Cos we're all in this together, you and me

Just be kind, just as kind as you can be
And we'll come through this together, wait and see

Just be kind, just as kind as you can be
And we'll always smile together you and me

Just be kind, just as kind as you can be
And we'll come through this together, wait and see

Plant some flowers, plant for everyone to see
We'll enjoy them all together, just you see

Eat some chocolate, drink some wine or even tea,
Then we'll all feel much happier, you and me

Just be kind, just as kind as you can be
'Cos we can laugh together, you and me

Just be kind, just as kind as you can be
And we'll all meet up, just you wait and see

Just make cakes, just make cakes and buns for tea
And we'll eat them all together, wait and see

Walk the fields, drive the lanes and dance with me
There is so much in this world, for us to see

Just be kind, just as kind as you can be
'Cos we're all in this together, you and me

Just be kind, just as kind as you can be
We'll be waving hands together, wait and see

Just be kind, just as kind as you can be
And we'll all meet up, just you wait and see

Just be kind, just as kind as you can be
And we'll come through this together, wait and see

We'll come through this, just you wait and see