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Exploring the impact of live music performances on the wellbeing of community dwelling people living with dementia and their care partners ☆☆☆★

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ABSTRACT

Background: Music-based initiatives cover a wide range of activity, including music therapy in either an individual or group capacity, choirs, orchestral performances, and apps on digital technology enabling people to engage with individual playlists. The impact of live music performances on the wellbeing of people living with dementia in the community is less well understood.

Objective: To explore if attending a live music café impacts the wellbeing of community dwelling people living with dementia and their care partners.

Study design: Twelve live music performances were hosted at a purpose refit facility at the authors' institution, once a month between April 2018 and March 2019. Participants consenting to be part of the research included 7 people living with dementia, 7 care partners and 3 former care partners. Baseline semi-structured interviews explored the meaning of music and expectations of the upcoming music cafés. Dementia Care Mapping captured 'in the moment' experiences of each music café. Follow-up semi-structured focus groups explored the impact of music on wellbeing and if participant expectations had been met. Interviews were transcribed verbatim and analysed thematically.

Main findings: The findings demonstrate that attending the music café benefitted the self-reported and observable wellbeing of participants in three particular ways: first, by offering opportunities for peer support and a reduction in feelings of isolation through a shared love of music; second, creating opportunities to increase wellbeing through music 'in the moment' that can have lasting effects long after the event; third, group interaction with music meets an unmet need for meaningful musical experiences in supportive enabling environments.

Conclusions and implications: Live music is a powerful medium to promote wellbeing for community dwelling people living with dementia and care partners. A 'music café' format promotes wellbeing through opportunities to interact with others in non-judgemental and supportive environments to experience a shared joy of music.

Introduction

Dementia is an international priority with current estimates of around 50 million people living with the condition, predicted to reach 82 million in 2030 and 152 million in 2050 WHO (2018). Policy recommendations (Balsinha *et al.*, 2019 World Alzheimer's Report; Department of Health, 2015; National Institute for Health and Care Excellence, 2018) promote the development and sustainability of groups

to enhance wellbeing post diagnosis for people living with dementia and their care partners. In 2012 the UK Prime Minister posed the challenge of how to 'promote individual and community-based activities for people with dementia and their carers...and increase their social contacts within their community' (Department of Health, 2012 p. 9) and thereby promote wellbeing.

The concept of wellbeing has attracted many definitions. The Department of Health (2014, p.6) states that: 'Wellbeing is about feeling good and functioning well and comprises an individual's experience of

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their life; and a comparison of life circumstances with social norms and values'. Furthermore, the Department of Health (2014) description of wellbeing posits that it exists in two dimensions, with a subjective or personal perspective, based on life satisfaction and an objective perspective, based on assumptions about fundamental human needs and rights. In contrast, Daykin et al (2016) identified wellbeing to have personal, cultural and social dimensions. Psychosocial approaches to dementia provide humanistic explanations that consider psychological and social factors as influential in the maintenance of wellbeing (Kitwood, 1997; Sabat, 2001). Kitwood conceived wellbeing and personhood differently from previous models which adopted a medical and behavioural focus Kitwood (1997). Kitwood stressed the importance of personhood and person-centred care as fundamental to achieving wellbeing and defined personhood as 'a standing or status that is bestowed upon one human being, by others, it implies recognition, respect and trust' (Kitwood 1997, p.19). Using this definition of personhood 'wellbeing' is enhanced by the presence of recognition and respect received from others.

An increasing number of non-pharmacological interventions (Vernooij-dassen et al., 2019) have emerged to enable people to live as well as possible with dementia; one particular area is the potential of music as an effective way to enhance wellbeing. However, a distinction is helpful between music provision for people living with dementia and music therapy which are considered two different approaches to delivering music. For example, music-based interventions with a therapeutic goal may need to draw on the skills of both musicians and therapists to apply musical parameters, tailored to an individual's needs to address physical, emotional, cognitive, and social needs (van der Steen et al 2018). Music therapy is a psychological intervention, delivered by Health and Care Professions Council (HCPC) registered music therapists and has been applied to people living with dementia to support their psychological, emotional, cognitive, physical, communicative and social needs. Much evidence exists pertaining to music therapy including data from systematic reviews (Tsoi et al 2018; Gallego and García, 2017; Zhang et al 2017; McDermott et al 2012; Raglio et al 2012) and large randomised controlled trials (Murabayashi et al 2019; Vink and Hanser 2018; Weise 2018; Vink et al 2011).

Vink et al., (2003) undertook a Cochrane Review to assess whether music therapy (MT) can diminish behavioural and cognitive problems or improve social and emotional functioning for people with dementia. Ten studies were included in this review although the authors report that the methodological quality of these small, short-term studies was generally poor, as was the presentation of results; no useful conclusions could be drawn. This review was updated by van der Steen et al., (2018) who aimed to assess the effects of music-based therapeutic interventions for people with dementia on emotional well-being including quality of life, mood disturbance or negative affect, behavioural problems, social behaviour and cognition at the end of therapy and four or more weeks after the end of treatment. 22 studies with 1097 randomised participants were included and the authors reported that the quality of the evidence was moderate for depression, overall behavioural problems and for agitation or aggression at the end of treatment. For all other outcomes, it was low or very low. The authors also commented that the quality of reporting for some trials was poor. All of the reviewed trials were undertaken in nursing homes or hospitals. A further systematic review to determine the effect of music therapy (MT) on cognitive functions in people living with dementia was undertaken by Fusar-Poli et al., (2018). Of 1089 potentially relevant records, 110 studies were assessed for eligibility, and 7 met the inclusion criteria, of which 6 contained appropriate data for meta-analysis (330 participants, mean age range 78.8–86.3). Overall, random-effects meta-analyses suggested no significant effects of MT on all outcomes. Critiques of therapeutic approaches relate to the quality of studies involved in the Cochrane Reviews undertaken to date, although some evidence also highlights the benefits of prescribed therapy that can be personalised to meet the needs and skill level of the individual Genoe and Dupuis (2012).

Music provision that is not considered as music therapy (MT), in contrast, may be considered a leisure activity with the aim of contributing to individual wellbeing in dementia and an activity that can be enjoyed in its own right without the therapeutic connotations Sixsmith and Gibson (2006) or indeed a focus on 'behaviours that challenge' (Dowlen et al 2018). The potential impact of music and wellbeing in dementia has mainly materialised in response to the increasing acknowledgement of the accessibility and applicability of music in various settings with people experiencing dementia in different ways. The Commission on Dementia and Music and the International Longevity Centre UK (ILC-UK) Bamford and Bowell (2018), examined the existing landscape and future potential of using music-based initiatives concluding that '*Music can promote a range of hugely beneficial outcomes for people with dementia...and when used appropriately and in a meaningful way, the use of music has no known negative impacts*' (Bamford and Bowell, 2018 p.7). One possible explanation is that music can be more accessible for people with dementia when compared to non-musical forms of activity: enabling opportunities for reminiscence and positive expressions of wellbeing (McDermott, Orrell, and Ridder, 2014). A further explanation would implicate the persons Procedural Memory (PM) which despite the level of impairment caused by dementia, enables certain activities to remain preserved and relatively resistant to decline including engagement with music Sacks (2007). However, caution is required when assuming that music has no known negative effects, as music may incite unwanted memories as well as positive memories.

Recent reviews on psychosocial interventions in dementia concluded that there was evidence for enhanced wellbeing via music-based approaches (Abraha et al., 2017) as well as the potential of music to address declining cognition, anxiety, depression and quality of life (QOL) in dementia (Zhang et al., 2017). In addition, sharing music within a group can have a beneficial psychosocial impact for the person with dementia and their care partners (Rio, 2018). A critical review of the participative arts in dementia (Zeilig, Killick, and Fox, 2014) suggests music-based interventions may have higher benefits when compared with alternate art practices. Tapson, Noble, Daykin, and Walters, (2018) found increased happiness in residents and staff exposed to music interventions and intimate live music performances have been shown to have a positive effect on human contact, care relationships, positive emotions and negative emotions in persons living with dementia in nursing homes (van der Vleuten 2012). Shibazaki and Marshall (2017) reported on the positive impact of concert performances on the wellbeing of people living with dementia showing increased levels of cooperation, interaction, and conversation.

Yet, much of this evidence relates to residential, nursing and hospital settings despite estimations that two thirds of people living with dementia in the UK continue to live in their own homes (Wittenberg, Hu, and Barraza-Araiza, 2019), a desire that has been penned as 'ageing in place' (Wiles, Leibing, Guberman, Reeve, and Allen, 2012). Service developments are driven by commitments to enabling ageing in place (Dawson, Bowes, Kelly, Velzke, and Ward, 2015) resulting in increasing quantities of community-based dementia support services. There is some evidence of community based music initiatives including the BUDI Orchestra (2015) from Bournemouth University and a community-based group singing intervention with people with early-stage dementia and their family carers (Lee et al., 2020). Nevertheless, despite the growing quantity of evidence on the benefits of exposure to music, much of the research has occurred in residential care or nursing homes (Elliott and Gardner, 2018). The importance of music for people remaining in their own homes and attending community groups is under-represented (McDermott et al., 2014). This paper contributes to knowledge of the benefits of a live music café involving people living with dementia who remain in the community and care partners. Our work directly responds to contemporary policy recommendations of enhancing wellbeing post diagnosis, while also addressing the current gap in knowledge about the benefit of live music for people living with dementia in the community.

Methods

A qualitative approach enabled the exploration of the impact of a live music café on the wellbeing of people living with dementia and their care partners. Self-reported lived experience of participants were gathered via semi structured interviews before and after the music café began, and observations were undertaken during the period of the music café sessions.

Context

The music cafés took place in a purpose-built space that had been designed and developed with the input of people living with dementia to meet their needs. The live music café was developed to provide opportunities for community dwelling people living with dementia and their care partners to engage together in monthly live music sessions. Twelve monthly, live music performances were held (April 2018 and March 2019). Each café began at 1.00 pm and attendees enjoyed refreshments together. The music performance began at 1.30pm and lasted for one hour. During each café session professional musicians would perform sets from various genres including classical and opera, country and western, pop and African music. Participation was encouraged by the musicians as the audience engaged and interacted in the music café. After each performance, musicians chatted with the participants about how the music made them feel or the memories it had sparked. Participants were also encouraged to 'have a go' playing the musicians' instruments including the harp, drums and keyboard.

Recruitment and participants

Flyers and posters distributed to numerous community groups in the local area and word of mouth from participants who attended other groups at the authors institution aided recruitment. Existing members of other groups held in the same space were also approached for recruitment purposes. The majority of participants took part as a dyad (person living with dementia and their care partner). Seventeen participants gave their consent to take part in the study: 7 people living with dementia (4 male and 3 female), 7 care partners (1 male and 6 female), 3 former care partners (all female). Of the 7 people living with dementia, 5 took part as a dyad with either their spouse (4) or family member (1) and 2 took part independently. The participants ages ranged from 50–87 years and all were white, British citizens. Process consent [Dewing \(2007\)](#) was followed ensuring independent informed consent was achieved. Capacity was assumed unless proven otherwise, in accordance with the Mental Capacity Act (2005).

Ethical approval was received from the University Ethics Review Committee (HSR1718–031) prior to the study commencing.

Baseline semi structured interviews

Qualitative semi-structured interviews of around one hour, were conducted at baseline to explore how people living with dementia and their care partners defined wellbeing, their motivations to attend and their expectations of the group. The semi-structured interviews took place in the same venue as the music cafés. All interviews were digitally recorded and transcribed verbatim. A topic guide facilitated consistency and was designed solely for the purpose of the study. The topic guide was used to guide the interviews to ensure that certain topics were covered but was not used to stifle or suppress information which participants felt was meaningful allowing new topics to emerge.

Structured observation data (DCM) and unstructured observation data

Unstructured observations and Dementia Care Mapping (DCM) [Bradford Dementia Group \(2005\)](#) were the observation methods used

to capture 'in the moment' experiences of attending the music café. Each session was observed by two researchers. One researcher recorded unstructured observations via descriptive field notes, to capture the 'essence' of the sessions as a whole including participant engagement and interactions with the music and each other within the space.

The other researcher recorded structured observations using the DCM framework. Originally designed to evaluate the quality of care, DCM has increasingly become a popular research tool and works well within multi-method research adding depth to data gathered using alternative methods such as interviews and focus groups and is grounded in the theoretical principles of person centred dementia care [Brooker and Surr \(2006\)](#). Within this framework people living with dementia were observed during the performances in the music café. Observations were broken down into five-minute periods or 'time frames' and during each time frame a predetermined coding framework was used to record participants mood and engagement and captured the precise activities individuals were engaged in on a moment-by-moment basis [Bradford Dementia Group \(2005\)](#). At the end of each time frame the mapper is required to make a judgement about the behaviour that each participant was observed to be engaged in from a set of 23 Behaviour Category Codes. The selection of BCC's is based upon the mapper's own observations and a set of operational rules to support the choice of code should more than one BCC occur in a given time frame.

Dementia Care Mapping also captures the mood and the level of engagement of each participant living with dementia during each time frame by recording one of six Mood and Engagement (ME) values. The ME values range from +5 indicating high positive mood and sustained engagement to -5 representing significant distress. Mood and Engagement values were coded within the context of the accompanying BCC [Bradford Dementia Group \(2005\)](#).

Follow-up semi structured focus groups

Two weeks after the final live music café, 3 qualitative semi-structured focus groups in the music café venue explored whether the expectations of participants had been met and the perceived impact for individual wellbeing. All focus groups were digitally recorded and transcribed verbatim. A topic guide was utilised in the focus groups to facilitate consistency.

Analysis

The interviews and focus group transcripts were coded and analysed drawing on the principles of thematic analysis [Braun and Clarke \(2006\)](#). First interviews and focus groups were coded, and initial themes identified, the next phase involved combining the codes and initial themes into a framework of main themes and subthemes. This was an iterative process, going back and forth with the interview data to ensure the refinement of codes and themes. One researcher generated the codes, and these were checked and verified by another, with any modifications agreed.

DCM data collected using the Behaviour Category Code (BCC) and Mood and Engagement (ME) frameworks was input into a purpose-built Excel template created by the Bradford Dementia Group. This spreadsheet was used to calculate the number of time frames and percentage of time that an individual spent in each of the BCC and ME values. The unstructured observation field notes were thematically analysed and synthesised with the DCM descriptive analysis to provide a complimentary account of the experiences of the music café for all participants across the sessions.

Findings

We found that the impact on wellbeing for the person living with dementia and their care partners to be considerable. The findings from the various data sources demonstrate that participants experienced high

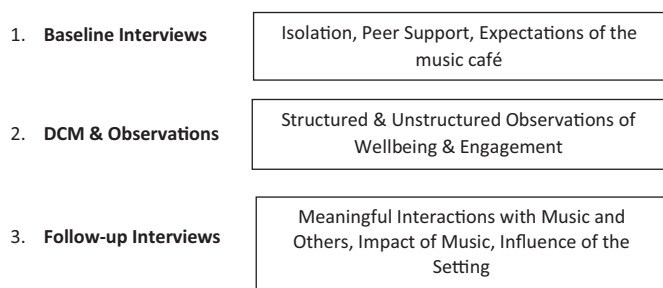


Fig. 1. Overview of findings.

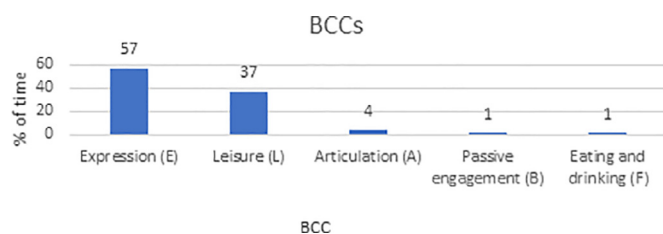


Fig. 2. Individual Behaviour Category Codes.

levels of enjoyment and attending the sessions impacted positively on self-reported and observable wellbeing. Figs. 1,2

The themes that emerged from the analysis of data collected prior to the start of the music cafés were 'Isolation', 'Peer Support' and 'Expectations of the music café'.

Theme 1: isolation

During the baseline interviews, we asked participants 'How do you currently perceive your well-being?' Many participants spoke about the ways their social world had become smaller since they or their loved one had received a diagnosis of dementia.

CP01 - *We had no social life, he just refused to come out of the house*
 CP02 - *We're isolated, there's nothing else, we don't see anybody.... you're completely alone.*

Others spoke about the ways that dementia had altered their loved ones from confident and sociable to becoming apathetic and withdrawn.

FCP01 - *he would have sat in his chair and never got out of it..... he wasn't confident going out places.... he felt people were looking at him. He wasn't a great socialiser...outside his front door.*
 CP04 - *we were pretty much isolated at home; it was such a blow.... he was really withdrawn and fed up....*

One care partner expressed the need for others to acknowledge that it wasn't just the person living with dementia that became isolated but how the social world shrunk for those in caring roles as well.

CP03 - *socially I mean, you put yourself second...its more difficult to socialise. If I didn't come here, I would probably feel more isolated...-socialising for your own mental wellbeing is important.*

It was also very poignant to hear how one person living independently with dementia with no spouse or care partner found the strength to address her increasing isolation.

PLWD06 - *I lost my independence really... but I found this little bit of fight in me.... I could quite easily lock myself away but that's not going to help....*

Participants spoke about their increasing isolation as a consequence of dementia. Participants living with dementia described feelings of apathy and the need to withdraw as their confidence decreased which in

turn had consequences for those in supporting roles as they too became increasingly isolated.

Theme 2: peer support

When asked about their current wellbeing, the majority of participants spoke about the need to be around others who understood their situation and were experiencing life in similar ways. Participants living with dementia spoke about the need to be around others to rebuild their confidence as well as making a positive effort to socialise as a way to combat their increasing isolation. For care partners, the importance of peer support was emphasised as a way of achieving reciprocal interactions with likeminded people on their journey.

CP01 - *We're all in the same boat and if you have a down day you can talk to somebody who actually understands what you're going through*
 FCP02 - *places that were non-judgemental are important as well as support....they understand the strains and stresses...I think it makes a difference all round - we were able to do things together, it was getting out, meeting new people*

Some spoke about the importance of peer support but how this support developed, and new friendships were formed

FCP01 - *We forged nice links and friendships I was so glad that it was something new, everybody in the same boat*
 PLWD06 - *... I would never have gone anywhere on my own.... but when he (husband) died people helped me get out and that was a good thing.... these people had been through this with their husbands so they knew how becoming isolated can make it worse.*

Many expressed that the peer support not only offered new friendships with likeminded people but also added to their confidence in being able to relax and enjoy themselves. One daughter expressed how coming to the group eased her guilt at seeing her Mum happy and relaxed.

PLWD02 - *You're mixing with people, meeting other people...it's a social thing. Personally, its building my confidence up again because I'd lost a bit of confidence.*
 CP06 - *She always says 'they're nice people here.... it's nice coming here' It's really nice seeing mum happy and relaxed and just enjoying things...it makes me feel less guilty.*

The need for friendships, social connections and peer support was a driver for participants to attend the music cafés. Participants living with dementia spoke about the need to be around others to rebuild their confidence as well as making a positive effort to socialise. For care partners, the importance of peer support was emphasised as a way of achieving reciprocal interactions with likeminded people on their journey.

Theme 3: expectations of the music café

Many of the participants were already regular attendees at other groups held at the same venue thus the environment was not new to them. During the baseline interviews participants were asked what had motivated them to become part of the music café and for the majority, it was the opportunity to engage with a love of music. Others spoke about opportunities to do something enjoyable together in a supportive environment as well as engaging loved ones in community activities as their interests became narrower.

CP05 - *My expectations? I didn't know what to expect...only if he didn't like it, we'd have to leave. We hoped that it was something we could both go to and enjoy. I think giving people the opportunity to do what they used to do in a supported environment is really good... it's building new memories as well since dementia that will stick with me when we're having bad days.*

CP06- *in the last 6 months her interests have become much narrower... I was hoping that it (music café) would be something to really engage her*

It was important to most that the music cafés were for the person living with dementia and care partners as well as those attending independently.

PLWD02 - *...a lot of places are just for carers or just for people with dementia, but this is both which is important.*

All participants talked about the meaning that music still held for them despite dementia. It was reported that music was a passion that could be enjoyed together (as it used to be) that had a positive impact on mood and wellbeing.

PLWD02 - *I like music even though I've got some memory problems, ...music relaxes me and there's no need to speak with music, you can sing along if you want or just listen to it...*

PLWD04 - *Music gives me an uplift in my mind, my thoughts, in what I'd done, what I'd heard...it's a big sort of smiley place in my heart...*

Some care partners reported the positive effect that music always had on the person living with dementia and how often this effect can last long after the music has finished. CP04 discusses a live music event that had lasting effects for her husband.

CP04 - *I noticed the impact that it had, that it lasts, ...yeah, you had a lovely evening after thatand I think you slept better... I notice a difference in him after we've engaged with live music, that your mood is better, your language is better....you need to be stimulated, you can still learn things*

It was also important for people to express the enjoyment they get out of seeing people living with dementia engaging with music when often there is little communication.

CP03- *I like music, but I wanted to see the effect it'd have on dad.....he will engage with people, but I notice that he comes out of himself a bit more when he's listening to music...*

CP01 - *Music is great for people with dementia and their carers. Music is so poignant.... because he hardly speaks now, but the music skills are still there. Everybody seems cheerier and lighter, I mean he couldn't remember her name, but he could remember how to dance.*

CP05 - *We both enjoy music...I love watching him enjoy music, just sitting there as a spectator with no pressure to do anything. The impact is in the moment for him. I think music can raise people's mood if you get the right music.... you just see people physically relax and enjoy...*

Music is an activity that can be enjoyed together, enabling people to engage with others when communication has become compromised as well as enhancing mood.

Summary of findings from the baseline interviews

Findings from the baseline interviews relate to Isolation, Peer Support, Expectations of the Music Café. These themes depict a clear narrative of the varying ways participants were experiencing their lives. They spoke about the increasing isolation as a consequence of dementia from the perspective of those who had been diagnosed and those in supporting roles. The importance of peer support and friendships with others experiencing life in similar ways was a clear theme that suggests just one solution to the increasing isolation that was being experienced. Participants expectations of the proposed music café highlighted their clear love of music. It was reported that music was a passion that could be enjoyed together (as it used to be) that had a positive impact on mood and wellbeing.

Observation data (DCM and unstructured observations)

Only people living with dementia were observed using the DCM framework. Nine participants living with dementia regularly attended the music café, however we had consent to observe five. Nine of the twelve music cafés were observed using DCM (Table 1). DCM observations show people living with dementia enjoying the live performances and interacting with the music while singing, dancing, clapping their hands, tapping their feet, or playing a percussion instrument. The more interactive the performance, the greater people's enjoyment was observed to be. Engagement and enjoyment was observed to peak when people expressed themselves creatively.

Mood and engagement (ME) scores

Participants living with dementia spent the majority of their time engaged and experiencing good overall levels of wellbeing. At no point during mapping was illbeing recorded.

The mean individual ME score across 9 music cafés was +3.4 indicating a good and sustained overall level of wellbeing and engagement amongst participants living with dementia. Overall, the group ME scores indicate that participants spent over half of their time (57%) content, happy and relaxed with signs of considerable engagement (+3). As a group, individuals were happy, cheerful, had very high positive mood and deep engagement (+5) for 27% of their time. Participants showed no overt signs of positive or negative mood and signs of intermittent engagement (+1) for 16% of the time.

As a group, individuals were observed to engage with five of the possible 23 BCCs. Participants who were living with dementia engaged in behaviours relating to **self-expression** for 57% of the music performances, this includes activities that have clearly creative or expressive elements such playing an instrument or singing or clapping along. They engaged in **leisure** and expressive activities, in this case engaging with and listening to the musicians, and occasionally dancing if space permitted for 37% of the time during performances. Individuals were observed interacting either verbally or non-verbally with others **articulation** for 4% of the time. They were observed to be eating or drinking **food** for 1% of the time and in a state of passive engagement **borderline**, for example watching their surroundings but not necessarily engaged in watching the musicians, for 1% of the time.

The average ME value recorded alongside self-expressive behaviours (E) was +3.56. Alongside communicating with others (A) the average ME value was +3.4 and activities with a purely leisure element (L) had an average value of +2.72. This demonstrates that individuals experienced high levels of positive mood and sustained engagement when engaged in these behaviours. Eating and drinking (F) and passively observing the surroundings (B) both had an average ME value of +1 indicating limited overt signs of positive mood and limited engagement within these activities. The higher ME levels observed during expressive activities in this study demonstrates the potential for music-based groups to improve the wellbeing of people living with dementia.

Based on the use of a structured and validated method (DCM, Brooker and Surr, 2006), we found that the music sessions were beneficial to the observed in the moment wellbeing of participants illustrated by mood and engagement (ME values) and specific behaviours (BCCs) during each of the music cafés.

Unstructured observations

The unstructured observations were recorded alongside the DCM data and consisted of descriptive field notes providing a detailed log of the interactions of all participants involved in each music café session. The fieldnotes were thematically analysed using Kitwood's conceptualisation of wellbeing (1997: 19) which states that individuals living with dementia had five psychological needs: inclusion, attachment, comfort, identity, and occupation. The majority of interactions in the music café's

Table 1
Individual and Group Mood and Engagement (ME) scores.

Music café	Individual ME score					Group ME score
	PLWD01	PLWD02	PLWD03	PLWD04	PLWD05	
Session 1	/	+3.7	+3.2	+3.3	+4.2	+3.6
Session 2	+2.2	/	+2.5	/	/	+2.35
Session 3	/	+4.0	+2.3	+4.1	/	+3.47
Session 4	+2.1	/	+2.2	/	/	+2.15
Session 5	+2.4	/	+4.1	/	/	+3.25
Session 6	+2.4	/	+3.0	/	/	+2.7
Session 7	/	/	+3.9	+4.1	/	+4.0
Session 8	/	+3.4	+4.0	+4.1	+3.7	+3.8
Session 9	/	/	/	+3.2	/	+3.2
Average Individual ME	+2.3	+3.7	+3.2	+3.8	+4.0	+3.4

centred on the psychological need for Identity, Occupation, and Inclusion.

Participants living with dementia were treated as highly valued members of the group and acknowledged to be making a positive contribution in ways that preserved **identity**. Musicians often thanked them for joining in and said that their participation greatly enhanced the performance. The musicians also appeared to take delight in the skills and achievement of individuals when they were engaged in expressive behaviours. For example, the drummer of the 1950's-60's pop group took his drum over to one of the participants he knew used to be a drummer and encouraged him to have a go. He compliments the participant on his drumming abilities telling him that he has excellent rhythm. His attitude is one of respect for the participants talents and abilities.

People living with dementia were frequently encouraged to join in the performances in any way they wanted to thus fulfilling a need for **occupation**. By encouraging participation, musicians supported the people living with dementia to use their skills. They recognised, encouraged, and facilitated engagement by, for example, handing around the percussion instruments for people to play. The choice of familiar music and the fact that musicians often asked for any requests further enabled occupation or greater participation. For example, one participant got up to dance with the musician/singer. She had initially leaned over the table to hold his hand, but he then got up to dance with her. He ducked down and crawled under the table between people's feet to get to the other side to dance. They danced for the remainder of the song and the next song.

The need for **inclusion** was frequently met. The musicians were skilled at ensuring that every person felt included in the group. For example, one participant had been singing along with the musician/singer. After the song she held his hands and thanked him for singing with her. In this way she entered into a relationship based on respect and a positive regard for him. The musician/singer smiles and takes her by the hand and says 'thank you for singing with me'. She is approaching him as an equal in the performance, acknowledging that he has been as much a part of the music making as she was. It is observed to delight him that she takes the time to thank him for his participation.

The unstructured observations revealed the ways that participating in the music café had an impact on the observable wellbeing of care partners and former care partners. There were many examples of care partners showing delight at the responses of people living with dementia that the music was having. Equally, care partners reported that the positive reactions of their loved ones to the music gave them back some interactions that they previously thought had been lost. There was a sense that people living with dementia and care partners reverted to their original roles, be that husband and wife or mother and daughter, altering their relationship dynamic through the effects of music. For example, one of the performers sings a song from My Fair Lady, the musical, and a daughter turns to her mother and said, 'you used to sing this to me when I was little', both continued to sing the song together, smiling at each other all the way through.

There were also examples of care partners, enjoying the experience equally if not more than the person living with dementia as many would close their eyes and enjoy the music. One particular care partner was videoing her husband on her phone as he danced with one of the singers, something that she would share with him later to show him how much he had enjoyed the music café. Care partners were often observed encouraging their loved ones to sing along and there were numerous examples of positive social interactions across and between members of the audience. Overall, care partners and former care partners were observed to enjoy the music cafés as much as those living with dementia, taking time to relax and bond over a shared love of music.

The higher mood and engagement scores observed during expressive activities in this study demonstrates the potential for music-based groups to improve the wellbeing of people living with dementia 'in the moment'. When combined with the unstructured observations, these findings illustrate that the music café sessions were as beneficial to the wellbeing of care partners as to participants living with dementia.

Qualitative semi-structured focus groups and interviews

Participants were invited to take part in one of three qualitative semi-structured focus groups to capture their perspectives on attending the music cafés. Three themes emerged from analysis of focus group transcripts: 'Meaningful Interactions with Music and Others', 'Impact of Music' and 'Influence of the Setting'.

Theme 4: meaningful interactions with music and others

Engagement, laughter and enjoyment all led to meaningful interactions for participants. This was reported as essential for people living with dementia and care partners and describes the varying ways participants were encouraged to engage with the music, the instruments and others in the music café.

PLWD02- *I enjoyed it all because it was interactive. I've been to other music groups and it's the same songs over and over again*
CP01 - *the people with dementia, I noticed a big difference in them, they were all smiling...were all really interacting and really enjoying themselves. You couldn't get them to smile and interact with you at all, then they suddenly take part when the music starts.*

Some participants described how novel the sessions were as the musicians spoke about their instruments and shared information regarding their passion for music.

FCP02 - *it is the proximity to the musicians and being able to talk to them. I mean, if you go to concerts, you don't get to talk, you know, but you actually, physically, could interact with the musicians and they'd explain things and that is a big plus.*
CP03 - *the musicians interacting and explaining about the actual instruments to us, it's a little bit of education as well about how they learn how to actually use them...absolutely fantastic.*

'Meaningful interaction' with the music and each other including the musicians, emerged as most important to those involved.

PLWD04 - *that's what makes it I think, you know everybody within the room. So, you can have a laugh, you can let yourself go. You can have a joking manner about it all. And then you all go home talking about it, which is an extension of the day*

CP08 - *She interacted better with a group and she felt that she was actually interacting with other people whilst she was holding the instrument, so that focus on being involved has got to do a load of good...*

The theme 'Meaningful Interactions with Music and Others' provides clear indication of the importance of interaction in a shared music activity. When interaction was encouraged, engagement, laughter and enjoyment increased for participants. This was reported as essential for people living with dementia and care partners but equally important for the musicians performing as the music cafés became a collaborative endeavour.

Theme 5: impact of music

The importance of music in people's everyday lives was a strong and recurring theme throughout the focus groups. All participants reported the importance of music in their everyday lives for its calming effects and to enhance mood and communication.

FCP01 - *I found that I went home singing songs or humming tunes. It lasted quite a while, it's the music, it sets the mood, kind of thing... so it is the music that we come for, it is definitely the music*

FCP005 - *I find the music very calming, a lot of it very calming, particularly the more classical music...And I've actually found it very moving, watching people's reactions as well as my own.*

PLWD006 - *It's not about dementia. It's about the music and about...just being in the moment*

CP03 - *music is great for communication, when words are limited, it's a great skill. Music lifts Everybody, lifts your spirits. I mean if you're feeling down when you first walk in you actually go out with a smile on your face. And you can see the impact it has, and it just makes you feel good.*

All participants reported the importance of music in their everyday lives for its calming effects and to enhance mood and communication. In this sense, music could be viewed as especially important to connect people in settings where non-verbal communication is can be more relevant.

Theme 6: influence of the setting

Although the music was of primary importance to participants, the majority talked about the setting and how enabling it was. It appeared that the impact of the setting had important consequences for people living with dementia and those in caring roles. Participants spoke of a safe and friendly environment that was non-judgemental and did not over stimulate and finding the intimacy of the music cafés to be most appealing.

CP03 - *This is more intimate...it makes you feel a little bit more special. It's a safe environment for all of us, and I think that makes such a big difference as you're all equal.*

CP04 - *we know who's going to be there, it's not got that massive fluidity where different people will rock up each time...And I think also for somebody living with a diagnosis they're not being over stimulated by being bombarded by external stimuli, this is quite a contained little place.*

PLWD02 - *It's a safe place and even if I did say the wrong thing, you're accepted so that was the main thing ... I knew I'd be accepted here, and people would understand if I behave different because of dementia...*

The influence of the setting was reported as having important consequences, especially for people living with dementia. Participants spoke of a safe and friendly environment that didn't over stimulate like some larger live music cafés. Importantly, participants reported the intimacy and non-judgemental way of the music cafés to be most appealing.

Our findings demonstrate that it is not just the music that makes a difference to the perceived benefits of the café for participants, but also the setting and other members. By bringing together people in a welcoming environment using the medium of music there was a positive impact on self-reported and observed wellbeing for all café attendees.

Discussion

In the baseline semi-structured interviews participants were asked about their wellbeing and many reported their increasing feelings of **isolation**. Participants living with dementia described feelings of apathy and the need to withdraw which in turn had consequences for those in supporting roles as they too became increasingly isolated. Participants reported their need for friendships, social connections and **peer support** to be a driver to attend the music cafés as one possible way of addressing their increasing isolation. Participants living with dementia spoke about the need to be around others to rebuild their confidence as well as making a positive effort to socialise. Participants' **expectations** of the proposed music café highlighted their clear love of music. It was reported that music was a passion that should be enjoyed together (as it used to be) that had a positive impact on mood and wellbeing. It was important to those participating as a dyad that they could enjoy the music café together as so many community activities catered for one or the other. Participants' expectations of the music café had a social value and a desire to have something to look forward to, keeping people in touch with their communities. Participants all spoke about coming together and sharing a common passion of music as essential to achieving a sense of wellbeing. This is in line with a recent review that suggests music positively impacts the social wellbeing of community dwelling older adults with dementia (Elliott and Gardner, 2018). Evidence suggests that social groups fill an important gap by providing people living with dementia with opportunities to engage with others and activities to look forward to Phinney and Moody (2011). Others spoke of their expectations of the music café to be addressing a common purpose, something that can be enjoyed by both the person with dementia and the care partner. This was reiterated as participants spoke about services just for carers or just for the people with dementia, but the music café provides a meaningful activity that could be enjoyed as a pair and an opportunity to do things they used to do as a couple. This confirms evidence that suggests the most meaningful interventions are those applicable to both the individual with the condition and their informal caregiver Brodaty and Arasaratnam (2012). Expectations of the music café highlighted the desire to reconnect as their worlds had become narrower since receiving a diagnosis. This reflects evidence demonstrating the ways dementia can lessen a person's ability or desire to continue creating their own activities which in consequence may lead to social isolation, apathy, insecurity, and anxiety (Vernooij-Dassen, 2007). Equally, the ways the person living with dementia may be marginalised and stigmatised by 'others' and society as a whole can contribute to withdrawal and decreasing confidence. Kitwood (1997) describes a person's 'wellbeing' as being enhanced by the presence of recognition, respect and trust received from others, or in the absence of such behaviours, that 'illbeing' can occur. Peer Support and the positive impact that socialising with others who experience life in similar ways was a recurrent theme emerging from the data. The Nesta report on "The Power of Peer Support" Rye (2016) proposes 'peer support to have the potential to increase people's confidence, mood and wellbeing, and ultimately health (Rye, 2016 p.4). The outcome suggests that peer support can help people feel more knowledgeable, confident, happy and less isolated and alone. There is evidence to suggest that peer support groups produce a social value greater than the cost of investment, whilst the beneficial outcomes for people with demen-

tia were mental stimulation and a reduction in loneliness and isolation (Willis, Semple, and de Waal, 2018). Carers have reported a reduction in stress and burden of care, whilst community volunteers cited an increased knowledge of dementia (Willis *et al.*, 2018). Peer support has been found to have positive emotional and social impact rooted in identification with others, a commonality of experience and reciprocity of support (Keyes *et al.*, 2016).

Observable wellbeing and engagement was recorded 'in the moment' across all the Music Café sessions for people living with dementia and unstructured observations captured the observable wellbeing of care partners. It was essential to capture the 'in the moment' experiences of people living with dementia participating in the music café as any lasting effects may be challenging to recall (Tuckett, *et al.*, 2015), thus the 'in the moment' effects come to the fore (Osman *et al.*, 2016). The DCM data demonstrates the potential for music-based groups to improve the wellbeing of people living with dementia and when combined with the unstructured observations, the music café sessions were as beneficial to the wellbeing of care partners.

The enjoyment clearly observed and recorded within the framework of DCM showed that participants living with dementia displayed high levels of wellbeing and sustained engagement during the Music Cafés. These findings echo the evidence in a report on Arts, Health and Wellbeing that found regular music groups to enhance morale and mental health-related quality of life and reduce loneliness, anxiety and depression in older people compared with usual activities (All-Party Parliamentary Group, 2017). Moreover, 'live' music can maintain a sense of wellbeing and is perceived as both acceptable and beneficial for older adults in general

Expressive activities (dancing, singing, playing an instrument) were observed to promote the greatest engagement and wellbeing, confirming previous research reporting on the potential of 'live music' when compared with more passive forms of music intervention Prattini (2016). The interactive nature of the music cafés was expressed as impactful by the majority when compared with the more passive endeavour of listening to music. This suggests that interactive music sessions that actively encourage expression through different methods of participation may prove to be more beneficial to an individual's wellbeing than had they been simply watching a music event. This supports existing evidence indicating how active participation in music engages different parts of the brain than music listening activates Yinger and Gooding (2014).

Findings relating to '*Meaningful Interactions with Music and Others*' gave a clear indication of the importance of interaction in a shared music activity. When interaction was encouraged, engagement, laughter and enjoyment increased for participants. This was reported as essential for people living with dementia and care partners. All participants reported the *impact of music* in their everyday lives for its calming effects and to enhance mood and communication. In this sense, music could be viewed as especially important to connect people in settings where non-verbal communication can be more relevant. *The influence of the setting* was reported as having important consequences, especially for people living with dementia. Participants spoke of a safe and friendly environment that didn't over stimulate like some larger live music cafés. Importantly, participants reported the intimacy and non-judgemental way of the music cafés to be most appealing. Findings illustrated that the main motivation for participants attending the music café was the meaning that music held for them. Music is a significant and important component of the everyday lives of many people, including, people with dementia (Sixsmith and Gibson, 2006). There is evidence to suggest that wellbeing, happiness and life satisfaction for older adults in general is associated with participation in social activities that are personally meaningful and valued (Adams, Leibbrandt, and Moon, 2010). Equally, links have been made between personhood and an individual's musical identity, framed by their past life experiences, both personal and cultural, and the particular era with which they associate (McDermott *et al.*, 2014). Participants expressed the increasing importance of music as dementia can slowly take away the person's language and com-

munication skills as music can promote reflection, communication and connection Hannemman (2006).

The majority of participants spoke about the positive impact that the music café had and how that impact can last, sometimes for days after. There was acknowledgment that music can enhance mood and stimulate the person positively impacting on language and sleep patterns. Participant CP04 reported that the lasting effects of the music café were noticeable in her husband's increased mood and improved sleep. CP04 would regularly video her husband on her phone during a music café, something that she would share with him later to show him how much he had enjoyed himself. This could be described as the ripple effect, a term used in music therapy to describe the effects of a music session implicating the micro (effects between person and care partner), the meso (effects beyond the music session) and macro (long term effects in the wider context) (Pavlicevic *et al.*, 2015). The positive impact that the music café had on the person with dementia "in the moment" was observed to be as being as important as any long-term effects on mood reported by the care partner. McDermott reports that '*meaningful connection with others and normal togetherness that happens during a session to be more crucial for the well-being of people with dementia than potential long-term effects*' (McDermott *et al.*, 2014, p. 712).

The influence of the setting emerged as important as participants needed a place to meet that was non-judgemental and that could empower them to be themselves around likeminded people. The setting can have important consequences for the person with dementia as familiarity of a person's surroundings can take on significant meaning and is able to compensate for reductions in physical and mental functioning associated with dementia Chadhury (2008). This is in line with evidence that suggests familiarity of and continuity with the social and physical environment promotes engagement with activities and consequently has implications for wellbeing and sense-of-self (Phinney *et al.*, 2007). Equally, Schweitzer and Bruce (2008) stress that creating supportive environments can be enabling through continued communication as well as maintaining relationships and social inclusion, despite dementia.

The findings illustrate the positive impact that the music café had on participant's relationships with their peers and sharing experiences through music that they had never foreseen. This echoes the review by Dowlen *et al.* (2018) of the benefits of 'musicising' for people living with dementia which found that music groups fostered supportive environments and over time, this group culture provided people with a sense of belonging and togetherness. It is well documented in the literature that participating in activities involving music has social benefits including enhanced relationships with care partners and others, feelings of belonging and inclusion and overall increases in wellbeing (Camic, Williams and Meeten, 2013; Osman *et al.*, 2016). The findings also illustrate the need that people living with dementia and their care partners have for meaningful musical experiences (McDermott *et al.*, 2014) that enable them to promote and facilitate connections with others. Activities that involve music and people living with dementia are generally social in nature and it can be unclear at times whether the sociality of the activity is what influences the observable social interactions of the participants or the music itself or both (Baird and Thompson, 2019). We have found that community groups that offer opportunities to socially interact with others in live music cafés to be a powerful combination in the promotion of wellbeing for people living with dementia and their care partners.

Study limitations

It should be acknowledged that our sample is limited in relation to ethnicity, although there was a representative mix of age, gender, as well as care partners, former care partners and people living with dementia involved. There also remains ongoing challenges of representation involving people living with dementia that are 'hard to reach' and choose not to seek out participation opportunities or are unaware of opportunities in their communities. This is an ongoing issue in dementia research and questions the generalisability of the findings beyond the sample

in this study. It should also be acknowledged that the positive impact on wellbeing could also be impacted by social interaction and a future study could compare the benefits of a regular dementia café and one with music. Nevertheless, the self-reported perspectives of participants illustrated that it was the music that increased their wellbeing.

Conclusions

This paper discusses a live music café designed for people living with dementia and care partners living in the community. The findings demonstrate that attending the music café benefitted the self-reported and observable wellbeing of participants in three particular ways: first, by offering opportunities for peer support and a reduction in feelings of isolation through a shared love of live music; second, creating opportunities to increase wellbeing through music 'in the moment' that can have lasting effects long after the event; third, group interaction with music meets an unmet need for meaningful musical experiences in supportive enabling environments. There is currently a lack of opportunity to attend live music cafés for people with dementia and care partners living in the community. Yet, it is clear that socially interacting with live music and others experiencing life in similar ways is a powerful combination for promoting wellbeing.

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