TITLE PAGE

Authors: *Robyn Dowlen, John Keady, Christine Milligan, Caroline Swarbrick,

Nick Ponsillo, Lucy Geddes, Bob Riley

Article title: The personal benefits of musicking for people living with dementia: a

thematic synthesis of the qualitative literature

Journal: Arts & Health: An International Journal for Research, Policy and

Practice

Word Count: 7272 (including references, figures and tables)

Contact Addresses and Qualifications:

*Robyn Dowlen MRes BSc

Division of Nursing, Midwifery and Social Work The University of Manchester The Jean McFarlane Building (Room 6.332) University Place Oxford Road Manchester M13 9PL

Tel: +44 (0)161 306 7732 (Direct Line)

Email: robyn.dowlen@postgrad.manchester.ac.uk

John Keady PhD RMN RNT

Professor of Older People's Mental Health Nursing

Division of Nursing, Midwifery and Social Work/Greater Manchester Mental Health NHS

Foundation Trust

The University of Manchester

The Jean McFarlane Building (Room 6.312)

University Place

Oxford Road

Manchester M13 9PL

Tel: +44 (0)161 306 7854 (Direct Line) Email: John.Keady@manchester.ac.uk

Christine Milligan PhD BA

Professor of Health and Social Geography
Director of the Centre for Ageing Research
Faculty of Health and Medicine
Furness Building
Lancaster University,
Bailrigg
Lancaster LA1 4YT

Tel: +44 (0)1524 592128

Email: c.milligan@lancaster.ac.uk

Caroline Swarbrick PhD MSc MA BSc

Research Fellow
Division of Nursing, Midwifery and Social Work
The University of Manchester
The Jean McFarlane Building (Room 6.311)
University Place
Oxford Road
Manchester M13 9PL

Tel: 0161 306 7337

Email: caroline.swarbrick@manchester.ac.uk

Nick Ponsillo

Director Philip Barker Centre for Creative Learning Faculty of Education and Children's Services Riverside Campus The University of Chester Castle Drive Chester CH1 1BW

Tel: +44 (0)1244 512111

Email: n.ponsillo@chester.ac.uk

Lucy Geddes

Camerata in the Community Manager Manchester Camerata Royal Northern College of Music Manchester M13 9RD

Email: lgeddes@manchestercamerata.com

Tel: +44 (0)161 226 8696

Bob Riley

Chief Executive Manchester Camerata Royal Northern College of Music Manchester M13 9RD

Tel: +44 (0)161 226 8696

Email: <u>briley@manchestercamerata.com</u>

^{*}Address for correspondence: Robyn Dowlen - As Above

The personal benefits of musicking for people living with dementia: a thematic synthesis of the qualitative literature

Abstract

Background: This review aimed to explore the psychological, social and emotional benefits of taking part in music activities for people living with dementia through a systematic review of the qualitative literature.

Methods: Qualitative and mixed-method studies exploring the use of music for people living with dementia in a number of contexts were identified through a search of Psycinfo, CINAHL, Open Grey, Proquest Theses and Dissertations and Web of Science databases

Results: Eighteen studies were identified that covered a wide range of music programmes for people with dementia, with the majority of programs focusing on active musical participation. A thematic synthesis revealed four key benefits of music engagement for people with dementia, namely: *Taking Part, Being Connected, Affirming Identity* and *Immersion 'in the moment'*.

Conclusions: Engaging with music has a number of psychological, social and emotional benefits for people with dementia. However, only seven of 18 studies actively included people with dementia in the research process. Going forward, it would appear essential that people with dementia are encouraged to take a more active role in research exploring musical experiences and that a heightened emphasis is placed upon participatory approaches to knowledge generation.

Key Words: Dementia; Music; 'in the moment'; Participation; Review

Background

There is a growing recognition that the arts can foster improved health and wellbeing in the general population (Cayton, 2007; Stickley et al., 2017), as well as for those living with dementia (Beard, 2012; De Medeiros & Basting, 2014). The arts and health movement promotes a 'wellness agenda' focusing on psychological wellbeing rather than on mental 'illness' or 'distress' (Clift, 2012). In recent years, a growing number of arts-based activities have been developed for people with dementia in order to create meaningful and personally significant experiences, including creating visual art (Camic, Tischler, & Pearman, 2014), theatrical productions (Basting, Towey & Rose, 2016) and improvised music making (Campbell, Ponsillo, Budd & Keady, 2017).

Music is the most commonly reported and accessed arts-based activity for people with dementia (Beard, 2012). Music is viewed not only as a relatively cost-effective and safe means of reducing 'behaviours that challenge', such as agitation and behavioural disturbances (McDermott, Crellin, Ridder & Orrell, 2013), but also as a powerful means of enhancing a person with dementia's sense of wellbeing and agency (Sixsmith & Gibson, 2007). Music programmes have been implemented across all time-points in the trajectory of dementia, from its early onset where retained capacity is a key feature (e.g. Särkämö et al., 2014) to its more advanced stages when communication through the spoken word may be at its most challenging (e.g. Sakamoto, Ando, & Tsutou, 2013). Indeed, the latter focus constitutes the primary area of research to date where the person with dementia's experience has a tendency to be reported through proxy accounts provided by family and/or staff carers (McDermott et al.2013).

To date, the focus of systematic literature reviews in this area has been on the correlated effects of music on 'behaviours that challenge' and cognitive performance (e.g. Raglio et al., 2015). However, in recent years, there has been an emerging interest in understanding how taking part in music-based activities can strengthen familial and care relationships (McDermott, Orrell, & Ridder, 2014), and increase quality of life and wellbeing (Särkämö et al., 2014; Sixsmith & Gibson, 2007). Yet, even with this shift away from using music to ameliorate 'behaviours that challenge', published reviews have so far failed to identify the personal benefits of engaging with music for people with dementia. The exploration of such factors may lead to a greater understanding of why music has positive effects on the quality of

life and wellbeing of people with dementia. Exploring this phenomenon through a systematic process forms the primary focus of this review.

Review methods

Definitions: The term *musicking* modifies the meaning of the word 'music' from that of a noun to a verb, meaning 'to engage with music' (Small 1998). Accordingly, musicking can be used as an umbrella term for any musical activity from listening to music on one's own through to performing opera on stage. Levels of engagement can differ between musicking activities, with the use of instruments and the human voice being viewed as 'active participation', and listening to music deemed as 'passive participation'. It is also possible to combine active and passive approaches within a single musicking activity (Guetin et al., 2013). By adopting the term musicking as a key operational definition for this review, the authors view musicking as a creative activity rather than solely aligning music to therapy. This subtle shift of emphasis allows all levels of engagement with music to be reported in the review.

Aims: The overarching aim of this review is to explore the personal benefits of musicking for people with dementia by systematically reviewing the qualitative literature in order to understand its emotional, psychological and social impacts.

The secondary aim is to report upon the involvement of people with dementia within the research studies as, to date, much of the literature in this area has relied on proxy accounts to understand and represent lived experience.

Search Terms: The search terms were pre-planned and combined terms from MeSH headings with terms observed frequently in the literature (see Table 1). Key terms relating to the topic area were combined with key terms associated with qualitative methods to increase the likelihood of identifying qualitative research studies.

INSERT TABLE 1 HERE

Inclusion/exclusion criteria: Studies were eligible for inclusion if they were written in English, used a qualitative or mixed-methods design, **included** individuals with a diagnosis of a dementia, and focussed on outcomes relating to the impact of music on people with dementia.

Studies were excluded if the focus was solely on caregiver experiences, if music was combined with another activity (e.g. music and exercise programmes) or where it was not possible to disentangle the results of the participants with dementia from other participants (e.g. in mixed populations of participants with dementia and older people without a diagnosis of dementia). Non-primary research articles were also excluded.

Search Strategy: Searches were originally conducted in February 2016 and updated in January 2017 using *PsycINFO* (via Ovid search platform), *Cumulative Index to Nursing & Allied Health Literature* (via Ebsco) and *Web of Science* (Arts and Humanities Citation Index and Social Sciences Citation Index). No date restrictions were placed on the database searches.

Hand-searches of relevant journals and reference lists were conducted to ensure all relevant qualitative research had been identified. Unpublished theses were identified using *Open Grey* and *Proquest Theses and Dissertations: American and International* databases.

Analysis: Analysis was conducted in three phases, in accordance with Thomas and Harden's (2008) guidance on Thematic Synthesis. Firstly, each line of text was examined in its entirety. Following this, each line of data was coded by hand using free line-by-line coding. Newly emerging codes were added to a coding bank which was used iteratively when analysing successive literature.

Secondly, descriptive themes were **formulated and** refined through several meetings of the whole research team.

Finally, analytical themes were developed in order to 'go beyond' what was said in the primary research, which was achieved through understanding the themes in the context of the research questions posed for the review. The research team met regularly to authenticate the inclusivity and representativeness of the final set of generated themes.

Findings

Search Results: A total of 195 articles and 6 theses were identified through database and hand searches (see Figure 1). Duplicate articles were removed, and the remaining 144 texts were subject to title and abstract review. After title and abstract review, 21 articles were fully screened having met the inclusion criteria for the review. Following full text screening, three

studies were removed as on closer inspection they did not meet the inclusion criteria for the review. This resulted in a total of 18 studies being included within the thematic synthesis.

INSERT FIGURE 1 HERE

Characteristics of Included Studies: The characteristics of included studies are presented in Table 2. The majority of studies were from a music therapy discipline, with other studies being from nursing or social science disciplines. Musicking activities varied substantially, but the majority required active participation through singing or playing instruments.

The majority of studies chose to explore the impacts of musicking through proxy accounts provided by caregivers; with only seven studies collecting first-hand accounts from people with dementia (Camic, Williams, & Meeten, 2013; Hara, 2013; McCabe, Greasley-Adams, & Goodson, 2015; McDermott et al., 2014; Osman, Tischler, & Schneider, 2016; Sixsmith & Gibson, 2007; Unadkat, Camic, & Vella-Burrows, 2016).

INSERT TABLE 2 HERE

Themes

Overall, the thematic synthesis of qualitative literature resulted in four themes: *Taking Part*, *Being Connected*, *Affirming Identity*, and *Immersion 'in the moment'*. These themes were interpreted as overlapping, rather than distinct, but provided an emergent understanding about the personal benefits of musicking for people with dementia. The following section will outline each theme in turn, supported by quotations taken from the research studies included in the review (see Table 2).

Theme 1: Taking Part

Music was viewed as an accessible medium where the ability to take part was not determined by cognitive abilities or any previous music training. Musicking was enjoyed on an "emotional and sensory level rather than an intellectual level" (Sixsmith & Gibson, 2007, 134), with people at all 'stages' of dementia (mild, moderate, advanced) enjoying the soothing and motivating nature of music, as seen in the following quote:

All participants discussed the stimulating effect of music and how playing instruments or listening to music instantly caught the attention of many residents who often

appeared less aware or disinterested in other people or activities around them. (McDermott et al., 2014, 710)

People with dementia expressed pride and a sense of accomplishment at having taken part in a musicking activity (Camic et al., 2013; Hara, 2013; McCabe et al., 2015; Osman et al., 2016; Tomaino, 2005). Through this encounter, people with dementia were also able to refresh skills that may have been lost over the progression of their condition and 'learn something new' through exposure to music that may not have been in their personal repertoire (Camic et al., 2013; Hara, 2013; McCabe et al., 2015; McDermott et al., 2014; Unadkat et al., 2016). In turn, this exposure facilitated increased confidence and self-esteem, which was further heightened by the immediate, sensory feedback participants received through musicking.

Moreover, through musicking, people with dementia were able to share in the experience as equals to those who did not live with the condition (Gardner, 1999; Götell, Brown, & Ekman, 2009; Hammar, Emami, Engström, & Götell, 2010; Hara, 2013; McCabe et al., 2015; Unadkat et al., 2016). This appeared to draw attention away from 'the dementia' and onto 'the person'. For example, care staff and family carers often appeared surprised that people with dementia were able to engage with music even after their abilities to verbally communicate had been significantly compromised (Gardner, 1999; Hammar et al., 2010, 2011b; McDermott et al., 2014; Osman et al., 2014; Sixsmith & Gibson, 2007; Unadkat et al., 2016). Being perceived as an equal may have enhanced the person with dementia's sense of identity through the acknowledgement that they were still able to make a meaningful contribution within a shared activity, as in this exchange:

Spouse: "Well, I can't sing, you always sang didn't you?"

Person with dementia: "Yes, I have to teach you! I didn't half laugh at your efforts, it's very funny, you are getting better though." (Unadkat et al., 2016, 9)

Although musicking was seen as accessible, there were a number of barriers to taking part, with the most frequent being access to music. People with dementia may not have been able to bring to mind their enjoyment of music nor had choice in the way in which they engaged with music. For example, within care home environments, music was often engaged with through media such as the radio or CD players, or, alternatively, via pre-determined activity schedules. People with dementia in these situations had little control over when or how they

engaged with music, or had to rely on others to make the decisions for them, as this illustration suggests:

"For some people the problem lay in articulating their musical wishes and preferences to others. As a result, people with dementia tended to become increasingly dependent upon others in order to gain access to music or musical activity. Because of limits on their time and personal resources, carers were not always able to provide regular access to music." (Sixsmith and Gibson, 2007, 137)

Overall, although this theme highlights that music is universally accessible to everyone in the musicking space. However, there appear to be barriers to taking part for people with dementia, especially within care home environments.

Theme 2: Being Connected

Musicking facilitated enhanced connection between people with dementia and their spouses, other family members, care staff, musicking facilitators (i.e. music therapists) and the environment in which the activity took place. The majority of studies in the review explored the use of music within a group setting and as a shared activity between people with dementia and their support networks (Camic et al., 2013; Dassa & Amir, 2014; Hara, 2013; McCabe et al., 2013; McDermott et al., 2014; Tuckett, Hodgkinson, Rouillon, Balil-Lozoya & Parker, 2015; Unadkat et al., 2016). These music groups were viewed primarily as a social activity in which, over time, a supportive group culture could be developed whatever the encountered environment:

"When you see one of those care-home rooms with 20-30 chairs in a huge circle – generally speaking, I feel that that is the worst sort of setup for any socialising any communication anything going on at all. But then this focus of the music, and what music enables, changed that." Music Therapist (Pavlicevic et al., 2015, 670)

This group culture, created through musicking, provided people with dementia with a sense of belonging and a sense of security (Camic et al., 2013; Dassa & Amir, 2015; Hammar et al., 2010; Hara, 2013; Osman et al., 2014; Pavlicevic et al., 2015; Tomaino et al., 2015; Unadkat et al., 2016). Moreover, such an initiative, and the shared enjoyment of musicking, also created a sense of togetherness between those with dementia and those supporting them. Furthermore, musicking provided a space in which the person with dementia was not

dependent on others; in turn, this enhanced the quality of existing relationships with carers and facilitated positive interactions across a number of social and relational networks as these two extracts reveal:

The caregivers described the elements in the caring situation as uninterrupted and this time was described as a nice moment they shared with the [people with dementia], which made them feel close to them. (Hammar et al. 2011b, 105)

"Wherever you go and whatever group of people you're in, singing seems to break down barriers and to open up sort of, not only companionship, but a sense of belonging, and that's great" Person with dementia (Osman et al., 2014, 5)

This sense of being connected was heightened by musicking as it helped people with dementia to connect with family members, music therapists and care staff on a level that did not require words (Baker et al., 2012; Gardner, 1999; McDermott et al., 2014; Sixsmith & Gibson, 2007; Unadkat et al., 2016). Furthermore, musicking facilitated enhanced eye contact and touch between the person with dementia and others, thus making connections across the musicking space (Gardner, 1999; Hammar et al., 2010, 2011a, 2011b; McDermott et al., 2014; Pavlecevic et al., 2015; Tomaino, 1998). Musicking also promoted non-verbal communication and this created a space in which new ways of meaningful communication could be explored, as below:

"...just being able to be together and enjoy and listen to something we both love is a benefit. [...] There were no words or anything...We didn't need to talk. The music did enough." Spouse of person living with dementia (Baker et al., 2012, 14)

Overall, musicking provided an opportunity for people with dementia to connect to others and the environment around them, without the need for words. This connection enabled people with dementia to feel part of a group culture, which enhanced a sense of togetherness and a sense of security.

Theme 3: Affirming Identity

Within each study in the review, it was evident that each person with dementia had a musical identity and musical history. Personal preferences for certain pieces, or genres, of music were

expressed both verbally and non-verbally, for example by foot tapping, conducting and smiling. Music was also bound to cultural and spiritual identities with many people with dementia connecting to religious music that was significant in their life. The expression of musical preferences, in combination with the memories that musicking evoked, resulted in care staff and music therapists actively seeking to understand the life history of the person with dementia (Hara, 2013; Tomaino, 1998). In turn, this enabled people with dementia to strengthen their sense of identity and promoted an understanding of the person that went far beyond a diagnostic label.

This strong affiliation between a person's life history and their musical preferences resulted in the awakening of memories in people with dementia. For example, people with dementia were able to remember past events that were coupled with music, remember lyrics to songs and, in some cases, develop new memories of the musicking activities from week to week. All but one study (McCabe et al., 2013) drew on biographically relevant songs within group musicking activities. The use of familiar, biographically significant songs was twofold: firstly, people with dementia were able to reminisce about memories associated with these songs and affirm a sense of past-present identity; and secondly, the person's confidence in their abilities was enhanced through an ability to remember lyrics and melodies.

The shared musical history of many group members allowed people to identify with others who had grown up in the same era. Musicking was therefore able to stimulate memories of times gone by, which people with dementia shared with others in the same space. This ability to reminisce as a group affirmed a collective identity as this quotation attests:

"...music and singing especially, brings people together, if you are singing then you are sharing in something no matter who you are beforehand because you are all going for it together." Person with dementia (Unadkat et al., 2016, 8)

Furthermore, people with dementia were able to develop new musical tastes throughout the engagement with music activities. This would suggest that although musicking can be used as a tool to reminisce with a person with dementia, it is also important to understand that musical preferences evolve over time. Therefore, as the literature reveals, new musical experiences should be explored in order to expose the person with dementia to new and interesting musical experiences and consequently a new and changing identity as seen in the illustration below:

[...] one of the popular waltz tunes, "Irish eyes are smiling" started to be known as Arnold's [person with dementia] favourite song. I observed the process of how it went from being 'a song' to being 'Arnold's Song' (Hara, 2013, 155)

Overall, this theme highlights that music enables the person to connect with their past through personal musical preferences and a shared musical history with others. This enabled shared reminiscence, which affirmed a sense of personal and collective identity.

Theme Four: Immersion 'in the moment'

People with dementia appeared absorbed in musicking to the extent that they were "lost in its hearing" (Sixsmith and Gibson, 2007, 132), appearing happier, more 'alive' and less agitated. Although these observable changes in wellbeing were described as immediate, doubts were expressed from care staff and family members about the lasting effects of musicking outside of that specific space (McDermott et al., 2014; Sixsmith & Gibson, 2007; Tuckett et al., 2015). However, the positive impact that musicking had on the person with dementia 'in the moment' was seen as being as important as any long-term effects on sociability and mood, for example, as these two slices of data attest:

Many therapists acknowledged they did not know how much staff or family carers noticed sustained communicability following music therapy sessions. Therapists generally seemed to regard meaningful connection with others and normal togetherness that happened during a session more crucial for the well-being of people with dementia than potential long-term effects of therapy (McDermott et al., 2014, 712)

The nature of dementia means that, for those with the condition, the benefit of the sessions is somewhat short-lived as the activity is forgotten in some cases; therefore, the intrinsic value of the sessions becomes most important (Osman et al., 2014, 7)

As well as improved mood and communication, music facilitated many embodied reactions which allowed people with dementia to express themselves and take part in the activity without the need for words. This embodied musical participation resulted in people with dementia being able to express musical preferences through their bodily movements, such as dancing and/or reaching out for instruments. It also empowered the person with dementia to

express their enjoyment of musicking, whether this was expressed outwardly, such as by actively engaging with the music therapist, or more subtly, such as through foot tapping and swaying in time to the music (Gardner, 1999; Götell, Brown & Ekman, 2002; Hammar et al., 2011a; Hara, 2013; Sixsmith & Gibson, 2007; Tomaino, 1998; Tuckett et al., 2015). Such actions enabled the person with dementia to enhance their sense of self and strengthen their relationships with others, as well as to perform embodied memories from the past. Two further examples of the bodily responses by people with dementia to in the moment experiences are shared below:

There were several sessions when Carmen [person with dementia] was very tired and displayed almost no response. On closer observation, however, I could see that her breathing was synchronised with the rhythm of the music. (Tomaino, 1998, 60)

The memory exercises, through singing familiar songs, were supported by the rhythm of the songs [...] these rhythms entrained their bodies, enabling an almost automatic participation with others (Hara, 2013, 223)

Overall, this theme highlights the benefits of musicking for the person with dementia 'in the moment' allowing for a multi-sensory experience that enabled an exploration of sound and self.

Discussion

In recent years, there has been a move away from the view that music is a 'curative' intervention for symptoms associated with dementia, and towards a view that music can enhance the wellbeing and quality of life of people with dementia (Sixsmith & Gibson, 2007). For this review, we conducted a comprehensive search of the qualitative literature surrounding the use of musicking with people with dementia. Overall, 18 studies were identified and a thematic synthesis of the qualitative findings revealed a number of emotional, psychological and social benefits for the person with dementia when engaging with music. These personal benefits were presented under four themes: *Taking Part, Being Connected, Affirming Identity* and *Immersion 'in the moment'*.

The first theme, *Taking Part*, was a common thread running through the literature, emphasising that musicking enables people with dementia to take part without having to rely

solely on cognitive and/or linguistic capabilities. The accessibility of music also enabled people with dementia to take part in an activity that was failure-free, meaning they were viewed as equals within the musical space. This democratisation of the musicking space enabled the stigma associated with dementia to be challenged, with others involved in the activity able to see beyond the diagnostic 'label' of dementia and to the person living with the condition (Batsch & Mittelman, 2012).

This theme also highlighted a number of barriers to musicking, such as control over when and how musicking was engaged with by the person with dementia. Many people with dementia, particularly when they enter a care home setting, may not have control over when and how they engage with music or other arts activities. Such activities may be viewed predominantly as entertainment, with care staff and residents anticipating scheduled activities at a set time on a certain day of the week (Basting et al., 2016). Perhaps thinking beyond music as a scheduled activity, and beginning to explore how musicking can become an integral part of people with dementia's day-to-day lives and linked to the person's biography, the barriers to taking part in musicking can be reduced. Seeking the views of people of dementia in the design of products which enhance access to music would further enhance the usability and acceptability of such technology (Brankaert, 2016).

The second theme *Being Connected* highlighted that musicking provided a space for the person with dementia to be connected: both to themselves, to other people and to the sensory environment. This sense of being connected enabled the person with dementia to feel a sense of security and a sense of belonging, thus providing an opportunity for them to feel part of a community through the meaningful social interactions that musicking afforded (Nolan, Brown, Davies, Nolan, & Keady, 2006). As everyone was able to take part as equals, this enabled the person living with dementia to "connect with themselves, to music and then, perhaps...to another person" (Pavlicevic et al., 2015, 668).

The third theme, *Affirming Identity*, explored the idea that musicking strengthened the sense of identity held by a person with dementia. People with dementia were able to express musical preferences, either verbally or non-verbally, but also developed new musical tastes and preferences across time. The singing of biographically significant music acted as a catalyst for memories for the person with dementia, allowing them to remember key life events that were interwoven with different pieces, or genres, of music. However, it was the

sense of strengthening a sense of identity and creating a meaningful connection with others that appeared more important than the remembrance of particular life events.

The fourth theme, *Immersion 'in the moment'*, highlights the value of embodied musical experiences within the present moment. Although the personal benefits of musicking may not have lasted outside of the musicking space, the immersive, multisensory experience of the moment was still valued greatly by family members, care staff and music therapists. In recent years, there has been a growing body of work that is seeking to understand the benefits of meaningful activity for people with dementia 'in the moment' (Gridley, Brooks, Birks, Baxter & Parker, 2016). Understanding of 'in the moment' experiences, specifically 'flow', are also closely linked to the Positive Psychology movement (Csikszentmihalyi, 1997; Nakamura & Csikszentmihalyi, 2014) in which emphasis is placed not only past experiences, but also on the present moment and the future (Hefferon & Boniwell, 2011).

By placing the focus on music for reminiscence purposes alone, the importance of embodied, 'in the moment' responses, can be overlooked (Killick, 2016). Musicking can, therefore be seen as a platform for 'embodied selfhood' enabling the person with dementia to strengthen their sense of identity through their bodily agency (Kontos, Hydén, Brockmeier, & Lindemann, 2014). Only by shifting the focus of enquiry towards understanding 'in the moment' experiences can we begin to understand the possibilities for music outside the remit of cognitive enhancement or as 'symptom' reduction. Through further exploration of the musical bodies of people with dementia, we can begin to learn more about how music enables a person living with dementia to connect with those around them, and to interact with, the world around them (Phinney, Hydén, Lindemann, & Brockmeier, 2014)

This review has revealed that many music engagement programmes for people with dementia place a significant emphasis on the shared musical histories of people with dementia, but there are very few instances of the creation of new music *with* people with dementia. Of 18 studies, only McCabe et al. (2013) explored the composition of a new piece of music with people with dementia. Although reminiscence-based singing groups appear very beneficial, it is also important to consider how gaining creative control over a musicking project may facilitate enhanced engagement and a sense of agency for people with dementia. As one person with dementia in Unadkat et al's (2016) study expressed:

"all that looking back, it can be a bit mindless maybe, possibly if we were being active and creating something it would be more beneficial, like a sort of new learning for us."
[8]

Going forward it would seem necessary that, in practice, it is important to explore the use of music beyond simply being a tool for reminiscence purposes. By shifting the focus away from reminiscence and towards the 'in the moment' experiences and the creative musical output of people with dementia, we may begin to understand the benefits of musicking further. Highlighting the importance of 'in the moment' creative engagement to those funding, facilitating and taking part in musicking programmes may also lead to more nuanced and participatory approaches to evaluation.

The secondary objective of this review was to understand the involvement of people with dementia in the research surrounding their musicking experiences. Within the identified studies there were relatively few examples of active participation in research by people with dementia. Many of the studies relied on observation, or reports from family members, care staff, and music therapists meaning the voices of people with dementia are largely absent from this research arena. The drive to involve people with dementia in research has significantly increased in recent years, with it no longer seen as being acceptable to rely on proxy accounts (McKeown, Clarke, Ingleton, & Repper, 2010). The qualitative literature surrounding the use of musicking in dementia studies needs to make a similar move towards enhanced inclusion of people with dementia in the conduct and presentation of future research (Gridley et al., 2016).

Conclusion

This review of the qualitative literature surrounding the personal benefits of musicking for people with the lived experience of dementia has provided an opportunity to examine the subjective emotional, psychological and social benefits. Whilst there are some good news stories in the review, it is perhaps fair to say that there is some distance to go to ensure the active participation of people with dementia in understanding, and translating, their own lived experiences. However, going forward, it is important to be able to communicate the 'in the moment' experiences of people with dementia, and view the personal benefits of taking part in musicking as having impacts that extend to multiple stakeholders, and environments, at different points in time and in different ways. Measuring such impacts remains a significant challenge and a research agenda for the future.

Acknowledgements

We would like to acknowledge the Economic and Social Research Council and Manchester Camerata for funding the study. Thanks also to Linda Welch, The University of Manchester, for her help in preparing this manuscript for submission.

References

- Baker, F. A. (2012). Connecting through music: A study of a spousal caregiver-directed music intervention designed to prolong fulfilling relationships in couples where one person has dementia. *The Australian Journal of Music Therapy*, 23, 4-19.
- Basting, A., Towey, M., & Rose, E. (2016). *The Penelope Project: An Arts-Based Odyssey to Change Elder Care*: University of Iowa Press.
- Batsch, N. L., & Mittelman, M. S. (2012). World Alzheimer Report 2012: Overcoming the stigma of dementia. London, UK: Alzheimer's Disease International.
- Beard, R. L. (2012). Art therapies and dementia care: A systematic review. *Dementia*, 11, 633-656. doi: 10.1177/1471301211421090
- Brankaert, R. (2016). Design for dementia: a design-driven living lab approach to involve people with dementia and their context Eindhoven: Technische Universiteit Eindhoven
- Camic, P. M., Tischler, V., & Pearman, C. H. (2014). Viewing and making art together: A multi-session art-gallery-based intervention for people with dementia and their carers. *Aging & Mental Health*, *18*, 161-168. doi: 10.1080/13607863.2013.818101
- Camic, P. M., Williams, C. M., & Meeten, F. (2013). Does a 'Singing Together Group'improve the quality of life of people with a dementia and their carers? A pilot evaluation study. *Dementia*, 12, 157-176. doi: 10.1177/1471301211422761
- Campbell, S., Ponsillo, N., Budd, P., & Keady, J. (2017). "Music in Mind" and Manchester Camerata: an exploratory qualitative evaluation of engagement in one care home in Northwest England. *Quality in Ageing and Older Adults*, 18, 69-80. doi: 10.1108/QAOA-01-2016-0001
- Cayton, H. (2007). Report of the review of Arts and Health Working Group *Department of Health for England*. London.
- Clift, S. (2012). Creative arts as a public health resource: moving from practice-based research to evidence-based practice. *Perspectives in Public Health*, *132*, 120-127. doi: 10.1177/1757913912442269
- Csikszentmihalyi, M. (1997). Finding flow: The psychology of engagement with everyday life. New York, USA: Basic Books.
- Dassa, A., & Amir, D. (2014). The role of singing familiar songs in encouraging conversation among people with middle to late stage Alzheimer's disease. *Journal of music therapy*, 51, 131-153. doi: 10.1093/jmt/thu007
- De Medeiros, K., & Basting, A. (2014). "Shall I compare thee to a dose of donepezil?": Cultural arts interventions in dementia care research. *The Gerontologist*, *54*, 344-353. doi: 10.1093/geront/gnt055
- Gardner, C. I. (1999). Music therapy: Enhancing communication between family caregivers and their loved ones with dementia. New York University, School of Education.
- Götell, E., Brown, S., & Ekman, S.-L. (2002). Caregiver singing and background music in dementia care. *Western Journal of Nursing Research*, 24, 195-216. doi: 10.1177/019394590202400208

- Götell, E., Brown, S., & Ekman, S.-L. (2009). The influence of caregiver singing and background music on vocally expressed emotions and moods in dementia care. *International journal of nursing studies*, *46*, 422-430. doi: 10.1016/j.ijnurstu.2007.11.001
- Gridley, K., Brooks, J., Birks, Y., Baxter, K., & Parker, G. (2016). Improving care for people with dementia: development and initial feasibility study for evaluation of life story work in dementia care. *Health Services and Delivery Research*, 4. doi: 10.3310/hsdr04230
- Guetin, S., Charras, K., Berard, A., Arbus, C., Berthelon, P., Blanc, F., Blayac, J-P., Bonte, F., Bouceffa, J-P., Clement, S., Ducourneau, F., Laeng, N., Lecourt, E., Ledoux, S., Platel, H., Thomas-Anterion, C., Touchon, J., Vrait, F-X., & Leger, J-M. (2013). An overview of the use of music therapy in the context of Alzheimer's disease: A report of a French expert group. *Dementia*, *12*, 619-634. doi: https://doi.org/10.1177/1471301212438290
- Hammar, L. M., Emami, A., Engström, G., & Götell, E. (2010). Reactions of persons with dementia to caregivers singing in morning care situations. *The open nursing journal*, *4*, 35-41. doi: 10.2174/1874434601004010035
- Hammar, L. M., Emami, A., Engström, G., & Götell, E. (2011a). Communicating through caregiver singing during morning care situations in dementia care. *Scandinavian Journal of Caring Sciences*, 25, 160-168. doi:10.1111/j.1471-6712.2010.00806.x
- Hammar, L. M., Emami, A., Engström, G., & Götell, E. (2011b). Finding the key to communion-Caregivers' experience of 'music therapeutic caregiving' in dementia care: A qualitative analysis. *Dementia*, 10, 98-111. doi: 10.1177/1471301210392994
- Hara, M. (2013). We'll Meet Again: Music in Dementia Care. University of Exeter.
- Hefferon, K., & Boniwell, I. (2011). *Positive psychology: Theory, research and applications*. New York, USA: McGraw-Hill Education
- Killick, J. (2016). Creativity and Dementia. In C. Clarke & E. Wolverson (Eds.), *Positive Psychology Approaches to Dementia* (pp. 175-195). London, UK: Jessica Kingsley Publishers.
- Kontos, P., Hydén, L., Brockmeier, J., & Lindemann, H. (2014). Musical embodiment, selfhood, and dementia. In L. Hydén, H. Lindemann & J. Brockmeier (Eds.), *Beyond loss. Dementia, identity, personhood* (pp. 107-119). Oxford, UK: Oxford University Press.
- McCabe, L., Greasley-Adams, C., & Goodson, K. (2015). 'What I want to do is get half a dozen of them and go and see Simon Cowell': Reflecting on participation and outcomes for people with dementia taking part in a creative musical project. *Dementia*, 14, 734-750. doi: 10.1177/1471301213508128
- McDermott, O., Crellin, N., Ridder, H. M., & Orrell, M. (2013). Music therapy in dementia: a narrative synthesis systematic review. *International journal of geriatric psychiatry*, 28, 781-794. doi: 10.1002/gps.3895
- McDermott, O., Orrell, M., & Ridder, H. M. (2014). The importance of music for people with dementia: the perspectives of people with dementia, family carers, staff and music therapists. *Aging & Mental Health*, *18*, 706-716. doi:10.1080/13607863.2013.875124
- McKeown, J., Clarke, A., Ingleton, C., & Repper, J. (2010). Actively involving people with dementia in qualitative research. *Journal of Clinical Nursing*, *19*, 1935-1943. doi: 10.1111/j.1365-2702.2009.03136.x
- Nakamura, J., & Csikszentmihalyi, M. (2014). The concept of flow. In M. Csikszentmihalyi (Ed.), Flow and the foundations of positive psychology (pp. 239-263). London, UK: Springer.

- Nolan, M., Brown, J., Davies, S., Nolan, J., & Keady, J. (2006). The Senses Framework: improving care for older people through a relationship-centred approach. *Getting Research into Practice (GRiP) Report No 2*: University of Sheffield.
- Osman, S. E., Tischler, V., & Schneider, J. (2016). 'Singing for the Brain': A qualitative study exploring the health and well-being benefits of singing for people with dementia and their carers. *Dementia*, 15, 1326-1339. doi: 10.1177/1471301214556291
- Pavlicevic, M., Tsiris, G., Wood, S., Powell, H., Graham, J., Sanderson, R., . . . Gibson, J. (2015). The 'ripple effect': Towards researching improvisational music therapy in dementia care homes. *Dementia*, *14*(5), 659-679. doi: https://doi.org/10.1177/1471301213514419
- Phinney, A., Hydén, L., Lindemann, H., & Brockmeier, J. (2014). As the body speaks: Creative expression in dementia. In L. Hydén, H. Lindemann & J. Brockmeier (Eds.), *Beyond loss. Dementia, identity, personhood* (pp. 120-134). Oxford, UK: Oxford University Press.
- Raglio, A., Bellandi, D., Baiardi, P., Gianotti, M., Ubezio, M. C., Zanacchi, E., . . . Stramba-Badiale, M. (2015). Effect of active music therapy and individualized listening to music on dementia: a multicenter randomized controlled trial. *Journal of the American Geriatrics Society*, 63, 1534-1539. doi: 10.1111/jgs.13558
- Sakamoto, M., Ando, H., & Tsutou, A. (2013). Comparing the effects of different individualized music interventions for elderly individuals with severe dementia. *International Psychogeriatrics*, 25, 775-784. doi: 10.1017/S1041610212002256
- Särkämö, T., Tervaniemi, M., Laitinen, S., Numminen, A., Kurki, M., Johnson, J. K., & Rantanen, P. (2014). Cognitive, emotional, and social benefits of regular musical activities in early dementia: randomized controlled study. *The Gerontologist*, *54*, 634-650. doi: 10.1093/geront/gnt100
- Sixsmith, A., & Gibson, G. (2007). Music and the wellbeing of people with dementia. *Ageing and Society*, 27, 127-145. doi: 10.1017/S0144686X06005228
- Small, C. (2011). *Musicking: The meanings of performing and listening*: Wesleyan University Press.
- Stickley, T., Parr, H., Atkinson, S., Daykin, N., Clift, S., De Nora, T., Hacking, S., Camic, p., Joss, T., & White, M. (2017). Arts, health & wellbeing: reflections on a national seminar series and building a UK research network. *Arts & Health*, *9*, 14-25. doi: 10.1080/17533015.2016.1166142
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8, 45. doi: 10.1186/1471-2288-8-45
- Tomaino, C. M. (2005). Music on their minds: A qualitative study of the effects of using familiar music to stimulate preserved memory function in persons with dementia. New York University.
- Tuckett, A. G., Hodgkinson, B., Rouillon, L., Balil-Lozoya, T., & Parker, D. (2015). What carers and family said about music therapy on behaviours of older people with dementia in residential aged care. *International journal of older people nursing*, 10, 146-157. doi: 10.1111/opn.12071
- Unadkat, S., Camic, P. M., & Vella-Burrows, T. (2016). Understanding the experience of group singing for couples where one partner has a diagnosis of dementia. *The Gerontologist*, Advanced publication online. doi: 10.1093/geront/gnv698