



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

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

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3 **The personal benefits of musicking for people living with dementia: a thematic synthesis**
4 **of the qualitative literature**
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6
7 **Abstract**
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10 **Background:** This review aimed to explore the psychological, social and emotional benefits
11 of taking part in music activities for people living with dementia through a systematic review
12 of the qualitative literature. .
13

14 **Methods:** Qualitative and mixed-method studies exploring the use of music for people living
15 with dementia in a number of contexts were identified through a search of Psycinfo,
16 CINAHL, Open Grey, Proquest Theses and Dissertations and Web of Science databases
17

18 **Results:** Eighteen studies were identified that covered a wide range of music programmes for
19 people with dementia, with the majority of programs focusing on active musical participation.
20 A thematic synthesis revealed four key benefits of music engagement for people with
21 dementia, namely: *Taking Part, Being Connected, Affirming Identity* and *Immersion ‘in the*
22 *moment’*.
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26 **Conclusions:** Engaging with music has a number of psychological, social and emotional
27 benefits for people with dementia. However, only seven of 18 studies actively included
28 people with dementia in the research process. Going forward, it would appear essential that
29 people with dementia are encouraged to take a more active role in research exploring musical
30 experiences and that a heightened emphasis is placed upon participatory approaches to
31 knowledge generation.
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34 **Key Words:** Dementia; Music; ‘in the moment’; Participation; Review
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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); ~~Daykin & Joss, 2016~~). 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 ~~and viewing~~ visual art (Camic, Tischler, & Pearman, 2014), theatrical productions (Basting, Towey & Rose, 2016) and improvised music making (Campbell, Ponsillo, Budd & Keady, 2017).

Music is ~~by far~~ 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 ~~excessive walking~~ ~~behavioural disturbances~~ (~~McDermott, Crellin, Ridder & Orrell, 2013~~ ~~Blackburn & Bradshaw, 2014~~), but also as a powerful means of enhancing a person with dementia's sense of wellbeing and agency (Sixsmith & Gibson, 2007). ~~Importantly, Mm~~ 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., Crellin, Ridder, & Orrell,~~ 2013).

~~To date, Within the published literature documenting the use of music in the lives of people with dementia, the focus dominant focus of systematic literature reviews in this area reviews to date~~ 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

~~(or musicking—see next heading below)~~ 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.

~~Moreover, to the best of our knowledge, this is the first time that the qualitative literature exploring the personal benefits of musicking for people with dementia has been presented.~~

Review methods

Definitions: The term *musicking*, ~~first proposed by Christopher Small (1998),~~ shifts/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 ~~an~~ 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-)(~~See Table 2~~). 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 ~~means that~~ allows all levels of engagement with music ~~are to be~~ reported in the review.

Aims and Objectives: 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~~ A secondary key objective aim is to report upon the involvement of people with dementia ~~within~~ the musicking evidence-based 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~~ studies.

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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 ~~where qualitative findings were reported, included, 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 ~~(letters, commentaries and reviews)~~ 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. ~~All records obtained through database searching were imported into Endnote (version X5) for further screening.~~

Hand-searches of relevant journals and reference lists ~~of obtained literature~~ were conducted ~~in order~~ 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.

~~**Study Screening Methods:** First, titles and abstracts of all studies were screened according to the review inclusion/exclusion criteria. If it was not possible to identify whether a study met inclusion criteria through title and abstract review, then they were subject to a full text review. Secondly, the lead author ([author initials removed]) conducted a full text review of all research studies that appeared to meet inclusion criteria. Studies were excluded at this stage if, on closer examination, they did not meet the review inclusion/exclusion criteria. All screening was led by the first author with the involvement of the co-authors.~~

~~**Data extraction:** For the purposes of this review, all published/available data under 'results' or 'findings' sections were considered. Only the qualitative sections of mixed methods research were extracted. All data were exported into a Microsoft Word (2010) document for~~

~~analysis by hand. The details of the included studies were compiled within a data extraction table, detailing year of publication, country, population, number of participants, data collection, methodology, analysis and research questions. All data extraction was led by the [author initials removed] with [author initials removed], [author initials removed], [author initials removed] and [author initials removed] involved in re-reading and confirming the data extraction process.~~

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 ~~ABOUT-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 musicking activities required active participation, with people with dementia taking part in the music making, whether it be through singing or using instruments. There were some examples of passive music engagement, such as shared listening and the use of background music in care situations.~~

The majority of studies chose to explore the impacts of musicking ~~For the most part, the focus of the studies was on exploring the experiences of people with dementia~~ through proxy accounts provided by caregivers; with only seven studies collecting first-hand accounts from people with dementia ~~using through the use of semi-structured interviews~~ (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 ~~ABOUT~~ 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 ~~as~~ 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 ~~cited~~ 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 ~~formal~~ music training. Musicking was enjoyed on an “emotional and sensory level rather than an intellectual level” (Sixsmith & Gibson, 2007, ~~p.~~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

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3 *appeared less aware or disinterested in other people or activities around them.*

4 (McDermott et al., 2014, p.710)

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7 ~~A number of studies indicated that P~~ people with dementia expressed pride and a sense of
8 accomplishment at having taken part in a musicking activity (Camic et al., 2013; Hara, 2013;
9 McCabe et al., 2015; Osman et al., 2016; Tomaino, 2005). Through this encounter, people
10 with dementia were also able to refresh skills that may have been lost over the progression of
11 their condition and ~~to~~ 'learn something new' through exposure to music that may not have
12 been in their personal repertoire (Camic et al., 2013; Hara, 2013; McCabe et al., 2015;
13 McDermott et al., 2014; Unadkat et al., 2016). In turn, this exposure facilitated increased
14 confidence and self-esteem, which was further heightened by the immediate, sensory
15 feedback participants received ~~through~~ from musicking.
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23 Moreover, through ~~taking part in~~ musicking, people with dementia were able to share in the
24 experience as equals to those who did not live with the condition (Gardner, 1999; Götell,
25 Brown, & Ekman, 2009; Hammar, Emami, Engström, & Götell, 2010; Hara, 2013; McCabe
26 et al., 2015; Unadkat et al., 2016). This appeared to draw attention away from 'the dementia'
27 and onto 'the person'. For example, care staff and family carers often appeared surprised that
28 people with dementia were able to engage with music even after their abilities to verbally
29 communicate had been significantly compromised (Gardner, 1999; Hammar et al., 2010,
30 2011b; McDermott et al., 2014; Osman et al., 2014; Sixsmith & Gibson, 2007; Unadkat et al.,
31 2016). ~~Thus, B~~ being perceived as an equal ~~by taking part~~ may have enhanced the person with
32 dementia's sense of identity through the acknowledgement that they were still able to make a
33 meaningful contribution within a shared activity, as in this exchange:
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42 *Spouse: "Well, I can't sing, you always sang didn't you?"*

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44 *Person with dementia: "Yes, I have to teach you! I didn't half laugh at your efforts,*
45 *it's very funny, you are getting better though."* (Unadkat et al., 2016, p.9)
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49 Although musicking was seen as accessible, there were a number of barriers to taking part,
50 with the most frequent being access to music. People with dementia may not have been able
51 to bring to mind their enjoyment of music nor had choice in the way in which they engaged
52 with music. For example, within care home environments, music was often engaged with
53 through media such as the radio or CD players, or, alternatively, via pre-determined activity
54 schedules. People with dementia in these situations had little control over when or how they
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3 engaged with music, or had to rely on others to make the decisions for them, as this
4 illustration suggests:

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7 *“For some people the problem lay in articulating their musical wishes and*
8 *preferences to others. As a result, people with dementia tended to become*
9 *increasingly dependent upon others in order to gain access to music or musical*
10 *activity. Because of limits on their time and personal resources, carers were not*
11 *always able to provide regular access to music.”* (Sixsmith and Gibson, 2007, p:137)
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17 Overall, although this theme highlights that music is universally accessible to everyone in the
18 musicking space, ~~whether they had dementia or not.~~ However, there ~~are~~ appear to be
19 barriers to taking part for people with dementia, especially within care home environments.
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22 **Theme 2: Being Connected**

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24 Musicking facilitated enhanced connection between people with dementia and their spouses,
25 other family members, care staff, musicking facilitators (i.e. music therapists) and the
26 environment in which the activity took place. The majority of studies in the review explored
27 the use of music within a group setting and as a shared activity between people with dementia
28 and their support networks (Camic et al., 2013; Dassa & Amir, 2014; Hara, 2013; McCabe et
29 al., 2013; McDermott et al., 2014; Tuckett, Hodgkinson, Rouillon, Balil-Lozoya & Parker,
30 2015; Unadkat et al., 2016). These music groups were viewed primarily as a social activity in
31 which, over time, a supportive group culture could be developed whatever the encountered
32 environment:
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41 *“When you see one of those care-home rooms with 20-30 chairs in a huge circle –*
42 *generally speaking, I feel that that is the worst sort of setup for any socialising any*
43 *communication anything going on at all. But then this focus of the music, and what*
44 *music enables, changed that.”* Music Therapist (Pavlicevic et al., 2015, p:670)
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49 This group culture, created through musicking, provided people with dementia with a sense
50 of belonging and a sense of security (Camic et al., 2013; Dassa & Amir, 2015; Hammar et al.,
51 2010; Hara, 2013; Osman et al., 2014; Pavlicevic et al., 2015; Tomaino et al., 2015; Unadkat
52 et al., 2016). Moreover, such an initiative, and the shared enjoyment of musicking, also
53 created a sense of togetherness between those with dementia and those supporting them.
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58 Furthermore, musicking provided a space in which the person with dementia was not
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3 dependent on others; in turn, this enhanced the quality of existing relationships with carers
4 and facilitated positive interactions across a number of social and relational networks as these
5 two extracts reveal:
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9 *The caregivers described the elements in the caring situation as uninterrupted and*
10 *this time was described as a nice moment they shared with the [people with*
11 *dementia], which made them feel close to them. (Hammar et al. 2011b, p-105)*
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15 *“Wherever you go and whatever group of people you’re in, singing seems to break*
16 *down barriers and to open up sort of, not only companionship, but a sense of*
17 *belonging, and that’s great”* Person with dementia (Osman et al., 2014, p-5)
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22 This sense of being connected was heightened by musicking as it helped people with
23 dementia to connect with family members, music therapists and care staff on a level that did
24 not require words (Baker et al., 2012; Gardner, 1999; McDermott et al., 2014; Sixsmith &
25 Gibson, 2007; Unadkat et al., 2016). Furthermore, musicking facilitated enhanced eye contact
26 and touch between the person with dementia and others, thus making connections across the
27 musicking space (Gardner, 1999; Hammar et al., 2010, 2011a, 2011b; McDermott et al.,
28 2014; Pavlecevic et al., 2015; Tomaino, 1998). Musicking also promoted non-verbal
29 communication and this created a space in which new ways of meaningful **connecting**
30 communication could be explored, as below:
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38 *“...just being able to be together and enjoy and listen to something we both love is a*
39 *benefit. [...] There were no words or anything...We didn’t need to talk. The music did*
40 *enough.”* Spouse of person living with dementia (Baker et al., 2012, p-14)
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45 Overall, musicking provided an opportunity for people with dementia to connect to others
46 and the environment around them, without the need for words. This **connection** enabled
47 people with dementia to feel part of a group culture, which enhanced a sense of togetherness
48 and a sense of security.
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51 52 53 **Theme 3: Affirming Identity** 54

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56 Within each study in the review, it was evident that each person with dementia had a musical
57 identity and musical history. Personal preferences for certain pieces, or genres, of music were
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3 expressed both verbally and non-verbally, for example by foot tapping, conducting,
4 ~~smiling and smiling and so on~~. Music was also bound to cultural and spiritual identities with
5 many people with dementia connecting to religious music that was significant in their life.
6
7 The expression of musical preferences, in combination with the memories that musicking
8 evoked, resulted in care staff and music therapists actively seeking to understand the life
9 history of the person with dementia (Hara, 2013; Tomaino, 1998). In turn, this enabled people
10 with dementia to strengthen their sense of identity and promoted an understanding of the
11 person that went far beyond a diagnostic label.
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17 This strong affiliation between a person's life history and their musical preferences resulted
18 in the awakening of memories in people with dementia. For example, people with dementia
19 were able to remember past events ~~that were that were to decoupled~~ with music, remember
20 lyrics to songs and, in some cases, develop new memories of the musicking activities from
21 week to week. All but one study (McCabe et al., 2013) drew on biographically relevant songs
22 within group musicking activities. The use of familiar, biographically significant songs was
23 twofold: firstly, people with dementia were able to reminisce about memories associated with
24 these songs and affirm a sense of past-present identity; and secondly, the person's confidence
25 in their abilities was enhanced through an ability to remember lyrics and melodies.
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33 ~~The majority of group based musicking activities utilised music that would have been~~
34 ~~popular when the people with dementia would have been young adults. Accordingly, such~~
35 ~~studies included older people with dementia in their sampling frame (e.g. 65+) so the focus~~
36 ~~was placed on music from the 1940s and 1950s.~~ The shared musical history of many group
37 members allowed people to identify with others who had grown up in the same era.
38 Musicking was therefore able to stimulate memories of times gone by, which people with
39 dementia shared with others in the same space. This ability to reminisce as a group affirmed a
40 collective identity as this quotation attests:
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47 *"...music and singing especially, brings people together, if you are singing then you*
48 *are sharing in something no matter who you are beforehand because you are all*
49 *going for it together."* Person with dementia (Unadkat et al., 2016, p-8)
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53 Furthermore, people with dementia were able to develop new musical tastes throughout the
54 engagement with music activities. This would suggest that although musicking can be used as
55 a tool to reminisce with a person with dementia, it is also important to understand that
56 musical preferences evolve over time. Therefore, as the literature reveals, new musical
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3 experiences should be explored in order to expose the person with dementia to new and
4 interesting musical experiences and consequently a new and changing identity as seen in the
5 illustration below:
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9 *[...] one of the popular waltz tunes, “Irish eyes are smiling” started to be known as*
10 *Arnold’s [person with dementia] favourite song. I observed the process of how it went*
11 *from being ‘a song’ to being ‘Arnold’s Song’ (Hara, 2013, p-155)*
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15 Overall, this theme highlights that music enabled the person to connect with their past
16 through personal musical preferences and a shared musical history with other ~~members of~~
17 ~~the group~~. This enabled shared reminiscence, which affirmed a sense of personal and
18 collective identity, ~~and allowed the person with dementia to join with those with a shared~~
19 ~~musical history~~.
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24 25 **Theme Four: Immersion ‘in the moment’**

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27 People with dementia appeared absorbed in musicking to the extent that they were “lost in its
28 hearing” (Sixsmith and Gibson, 2007, ~~p- 132~~), appearing happier, more ‘alive’ and less
29 agitated. Although these observable changes in wellbeing were described as immediate,
30 doubts were expressed from care staff and family members about the lasting effects of
31 musicking outside of that specific space (McDermott et al., 2014; Sixsmith & Gibson, 2007;
32 Tuckett et al., 2015). However, the positive impact that musicking had on the person with
33 dementia ‘in the moment’ was seen as being as important as any long-term effects on
34 sociability and mood, for example, as these two slices of data attest:
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41 *Many therapists acknowledged they did not know how much staff or family carers*
42 *noticed sustained communicability following music therapy sessions. Therapists*
43 *generally seemed to regard meaningful connection with others and normal*
44 *togetherness that happened during a session more crucial for the well-being of people*
45 *with dementia than potential long-term effects of therapy (McDermott et al., 2014, ~~p-~~*
46 *712)*
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53 *The nature of dementia means that, for those with the condition, the benefit of the*
54 *sessions is somewhat short-lived as the activity is forgotten in some cases; therefore,*
55 *the intrinsic value of the sessions becomes most important (Osman et al., 2014, ~~p-7~~)*
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3 As well as improved mood and communication, music facilitated many embodied reactions
4 which allowed people with dementia to express themselves and take part in the activity
5 without the need for words. This embodied musical participation resulted in people with
6 dementia being able to express musical preferences through their bodily movements, such as
7 dancing and/or reaching out for instruments. It also empowered the person with dementia to
8 express their enjoyment of musicking, whether this was expressed outwardly, such as by
9 actively engaging with the music therapist, or more subtly, such as through foot tapping and
10 swaying in time to the music (Gardner, 1999; Götell, Brown & Ekman, 2002; Hammar et al.,
11 2011a; Hara, 2013; Sixsmith & Gibson, 2007; Tomaino, 1998; Tuckett et al., 2015). Such
12 actions enabled the person with dementia to enhance their sense of self and strengthen their
13 relationships with others, as well as to perform embodied memories from the past. Two
14 further examples of the bodily responses by people with dementia to in the moment
15 experiences are shared below:
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26 *There were several sessions when Carmen [person with dementia] was very tired and*
27 *displayed almost no response. On closer observation, however, I could see that her*
28 *breathing was synchronised with the rhythm of the music. (Tomaino, 1998, ~~p.600~~)*
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32 *The memory exercises, through singing familiar songs, were supported by the rhythm*
33 *of the songs [...] these rhythms entrained their bodies, enabling an almost automatic*
34 *participation with others (Hara, 2013, p.223)*
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39 Overall, this theme highlights the benefits of musicking for the person with dementia 'in the
40 moment'. ~~Musicking also allowed space for the person living with dementia to experience~~
41 ~~music in whatever way they wished, immersing themselves in~~ allowing for a multi-sensory
42 experience that enabled an exploration of sound and self.
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46 47 Discussion

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49 In recent years, there has been a move away from the view that music is a 'curative'
50 intervention for symptoms associated with dementia, and towards a view that music can
51 enhance the wellbeing and quality of life of people with dementia (Sixsmith & Gibson,
52 2007). For this review, we conducted a comprehensive search of the qualitative literature
53 surrounding the use of musicking with people with dementia, ~~in order to understand the~~
54 ~~personal benefits of musicking.~~ Overall, 18 ~~qualitative or mixed method~~ studies were
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3 identified and a thematic synthesis of the qualitative findings literature revealed a number of
4 emotional, psychological and social benefits for the person with dementia when engaged
5 with music. These personal benefits were presented under four themes: *Taking Part*, *Being*
6 *Connected*, *Affirming Identity* and *Immersion 'in the moment'*.
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10 The first theme, *Taking Part*, was a common thread running through the literature,
11 emphasising that musicking ~~is accessible, allowing~~enables people with dementia to take part
12 without having to rely solely on cognitive and/or linguistic capabilities. The accessibility of
13 music also enabled people with dementia to take part in an activity that was failure-free,
14 meaning they were viewed as equals within the musical space. This democratisation of the
15 musicking space enabled the stigma associated with dementia to be challenged, with others
16 involved in the activity able to see beyond the diagnostic 'label' of dementia and to the
17 person living with the condition (Batsch & Mittelman, 2012).
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22 ~~With a diagnosis of dementia often comes a change in close familial and non-familial~~
23 ~~relationships from that of being equal partners, to a relationship in which one partner~~
24 ~~becomes more dependent on the other (Patterson, Clarke, Wolverson, & Moniz-Cook, 2017).~~
25 ~~This role change may lead to a loss of autonomy for the person with dementia, leading to a~~
26 ~~loss in confidence and self-esteem (Vernooij-Dassen, Derksen, Scheltens, & Moniz-Cook,~~
27 ~~2006). Musicking, however, provided a space in which people with dementia were viewed as~~
28 ~~equal, rather than 'other'.~~
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37 This theme also highlighted a number of barriers to musicking, such as control over when and
38 how musicking was engaged with by the person with dementia. Many people with dementia,
39 particularly when they enter a care home setting, may not have control over when and how
40 they engage with music or other arts activities. Such activities may be viewed predominantly
41 as entertainment, with care staff and residents anticipating scheduled activities at a set time
42 on a certain day of the week (Basting et al., 2016). Perhaps thinking beyond music as a
43 scheduled activity, and beginning to explore how musicking can become an integral part of
44 people with dementia's day-to-day lives and linked to the person's biography, the barriers to
45 taking part in musicking can be reduced. Seeking the views of people of dementia in the
46 design of products which enhance access to music would further enhance the usability and
47 acceptability of such technology (Brankaert, 2016).
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50 The second theme *Being Connected* highlighted that musicking provided a space for the
51 person with dementia to be connected: both to themselves, to other people and to the sensory
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3 environment. This sense of being connected enabled the person with dementia to feel a sense
4 of security and a sense of belonging, thus providing an opportunity for them to feel part of a
5 community through the meaningful social interactions that musicking afforded (Nolan,
6 Brown, Davies, Nolan, & Keady, 2006). As everyone was able to take part as equals, this
7 enabled the person living with dementia to “connect with themselves, to music and then,
8 perhaps...to another person” (Pavlicevic et al., 2015, p-668).
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13 The third theme, *Affirming Identity*, explored the idea that musicking strengthened the sense
14 of identity held by a person with dementia. People with dementia were able to express
15 musical preferences, either verbally or non-verbally, but also developed new musical tastes
16 and preferences across time. The singing of biographically significant music acted as a
17 catalyst for memories for the person with dementia, allowing them to remember key life
18 events that were interwoven with different pieces, or genres, of music. However, it was the
19 sense of strengthening a sense of identity and creating a meaningful connection with others
20 that appeared more important than the remembrance of particular life events.
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28 The fourth theme, *Immersion ‘in the moment’*, highlights the value of embodied musical
29 experiences within the present moment. Although the personal benefits of musicking may not
30 have lasted outside of the musicking space, the immersive, multisensory experience of the
31 moment was still valued greatly by family members, care staff and music therapists. In
32 recent years, there has been a growing body of work that is seeking to understand the benefits
33 of meaningful activity for people with dementia ‘in the moment’ (Gridley, Brooks, Birks,
34 Baxter & Parker, 2016; ~~Treadaway, Prytherch, Kenning & Fennell, 2016~~). Understanding of
35 ‘in the moment’ experiences, specifically ‘flow’, are also closely linked to the Positive
36 Psychology movement (Csikszentmihalyi, 1997; Nakamura & Csikszentmihalyi, 2014) in
37 which emphasis is placed not only past experiences, but also on the present moment and the
38 future (Hefferon & Boniwell, 2011).
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47 By placing the ~~dominant~~ focus on music for reminiscence purposes alone, the importance of
48 embodied, ‘in the moment’ responses, can be overlooked (~~DeNora, 2000; Killick, 2016~~) ~~with~~
49 ~~the latter relying significantly on a subjective understanding of experience (Phinney, Hydén,~~
50 ~~Lindemann, & Brockmeier, 2014)~~. Musicking can, therefore be seen as a platform for
51 ‘embodied selfhood’ enabling the person with dementia to strengthen their sense of identity
52 through their bodily agency (Kontos, Hydén, Brockmeier, & Lindemann, 2014). Only by
53 shifting the focus of enquiry towards understanding ‘in the moment’ experiences can we
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3 begin to understand the possibilities for music outside the remit of cognitive enhancement or
4 as ‘symptom’ reduction. Through further exploration of the musical bodies of people with
5 dementia, we can begin to learn more about how music enables a person living with dementia
6 to connect with those around them, and to interact with, the world around them (Phinney,
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8 [Hydén, Lindemann, & Brockmeier, 2014](#)~~Phinney et al., 2014~~)
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12 This review has revealed that many music engagement programmes for people with dementia
13 place a significant emphasis on the shared musical histories of people with dementia, but
14 there are very few instances of the creation of new music *with* people with dementia. Of 18
15 studies, only McCabe et al. (2013) explored the composition of a new piece of music with
16 people with dementia. Although reminiscence-based singing groups appear very beneficial, it
17 is also important to consider how gaining creative control over a musicking project may
18 facilitate enhanced engagement and a sense of agency for people with dementia. As one
19 person with dementia in Unadkat et al’s (2016) study expressed:
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26 *“all that looking back, it can be a bit mindless maybe, possibly if we were being active*
27 *and creating something it would be more beneficial, like a sort of new learning for us.”*
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33 Going forward it would seem necessary that, in practice, it is important to explore the use of
34 music beyond simply being a tool for reminiscence purposes. By shifting the focus away
35 from reminiscence and towards the ‘in the moment’ experiences and the creative musical
36 output of people with dementia, we may begin to understand the benefits of musicking
37 further. Highlighting the importance of ‘in the moment’ creative engagement to those
38 funding, facilitating and taking part in musicking programmes may also lead to more nuanced
39 and participatory approaches to evaluation.
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46 The secondary objective of this review was to understand the involvement of people with
47 dementia in the research surrounding their musicking experiences. Within the identified
48 studies there were relatively few examples of active participation in research by people with
49 dementia. Many of the studies relied on observation, or reports from family members, care
50 staff, and music therapists meaning the voices of people with dementia are largely absent
51 from this research arena. The drive to involve people with dementia in research has
52 significantly increased in recent years, with it no longer seen as being acceptable to rely on
53 proxy accounts (McKeown, Clarke, Ingleton, & Repper, 2010). ~~Recently, there has been~~
54 ~~some innovative work that actively includes people with dementia as research participants or~~
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3 ~~co-researchers (Swarbrick, Open Doors, EDUCATE, Davis, & Keady, 2016; Ward, Howorth,~~
4 ~~Wilkinson, Campbell, & Keady, 2012).~~ The qualitative literature surrounding the use of
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6 musicking in dementia studies needs to make a similar move towards enhanced inclusion of
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8 people with dementia in the conduct and presentation of future research (Gridley et al., 2016).
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10 Conclusion

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

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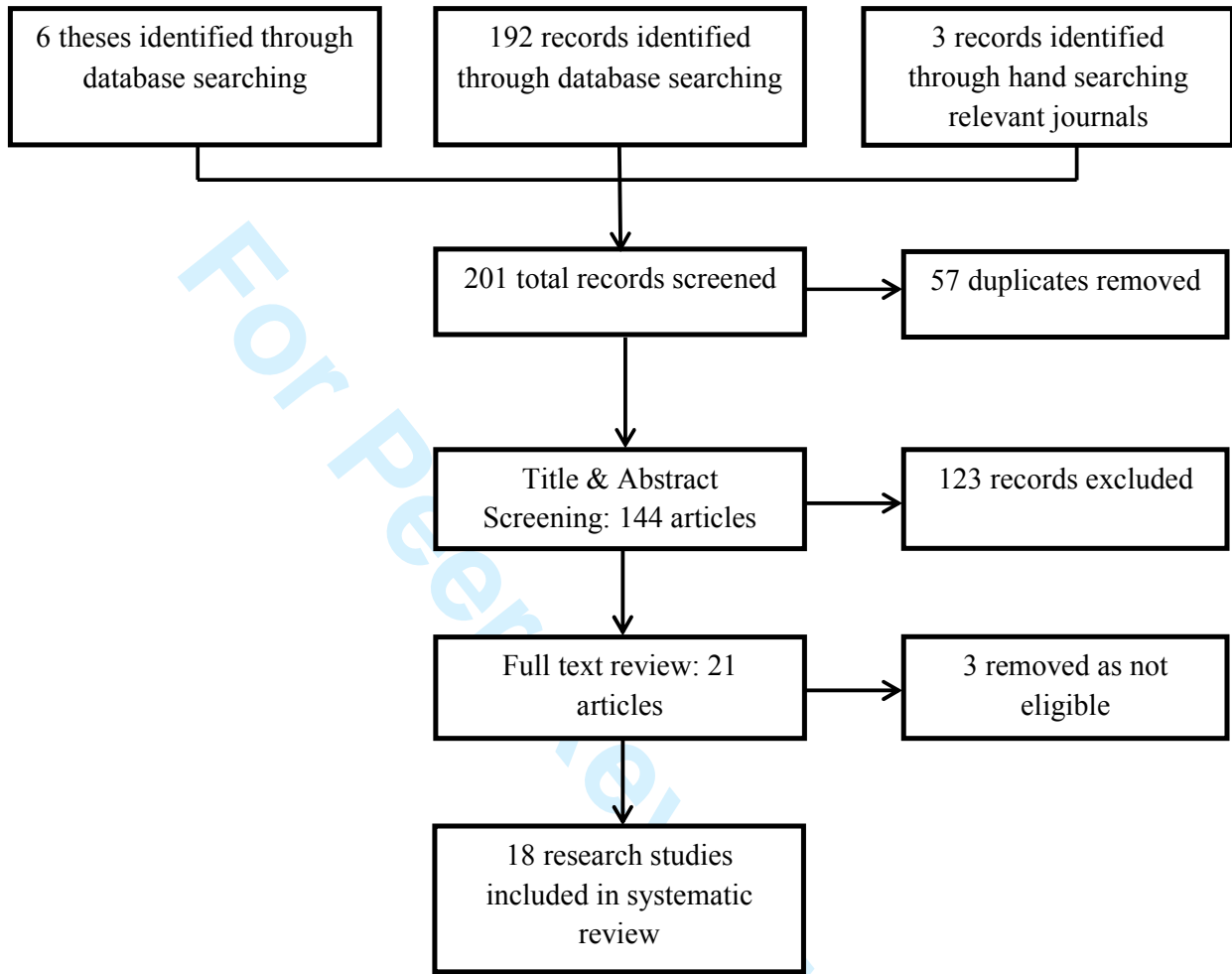
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For Peer Review Only

Figure 1: Flow diagram of database and grey literature searching



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Table 1: Search Terms

Population	Intervention	Methodology/Methods
<i>dementia OR Alzheimer's</i>	<i>music OR musicking OR music therapy* OR singing OR preferred listening</i>	<i>qualitative OR mixed method* OR interview OR focus group OR observation</i>

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Table 2: Identified studies examining the impacts of music on people with dementia

First Author (Year)	Country	Participants	Musicking Activity	Level of Engagement	Methodology	Data collection methods	Analysis	Research questions
Baker (2012)	Australia	5 spousal caregivers	Listening to pre-recorded music	Passive	Mixed-method	Semi-structured interviews Diary entries	Thematic Analysis	To understand the benefits of music on the wellbeing of the person with dementia, from the perspective of the spousal caregiver.
Camic (2013)	UK	10 people with dementia 10 family caregivers	Group singing	Active	Mixed-method	Semi-structured interviews with people with dementia and family carers	Thematic Analysis	To examine whether participation in group singing impacted on the quality of life of both people with dementia and their family caregivers.
Dassa (2014)	Israel	6 people with dementia	Group listening to pre-recorded music	Active	Qualitative	Observation	Qualitative content analysis	To explore the role of music in stimulating communication in people with dementia
Gardner* (1999)	USA	2 people with dementia 2 family caregivers	Individual music therapy	Combined	Qualitative	Interviews with family carers Observation	“Inductive data analysis” (p.21)	To explore the impacts of long-term music therapy on the relationships between the person with dementia, their family caregiver and the music therapist.
Götell (2002)	Sweden	9 people with dementia 5 nurse caregivers	Caregiver singing Background pre-recorded music	Passive	Qualitative	Interviews with staff carers Observation	Phenomenologic-Hemeneutic method	To explore the use of background music versus caregiver singing during caregiving activities.

Götell (2009)	Sweden	9 people with dementia 5 nurse caregivers	Caregiver singing Background music	Passive	Qualitative	Observation	Qualitative content analysis	To examine the effects of background music versus caregiver singing on the emotions and moods of people with severe dementia.
Hammar (2010)	Sweden	6 staff caregivers	Music Therapeutic Caregiving	Passive	Qualitative	Group interviews	Qualitative content analysis	To explore the reaction of people with dementia to Music Therapeutic Caregiving during morning care situations.
Hammar (2011a)	Sweden	10 people with dementia 6 staff caregivers	Music Therapeutic Caregiving	Passive	Qualitative	Video observation	Qualitative content analysis	To explore verbal and non-verbal communication of people with dementia during morning care routines with Music Therapeutic Caregiving.
Hammar (2011b)	Sweden	6 staff caregivers	Music Therapeutic Caregiving	Passive	Qualitative	Group interviews	Qualitative content analysis	To explore the differences in staff caregiver experiences with and without Music Therapeutic Caregiving during morning care situations
Hara* (2013)	UK	10 people with dementia** 10 and their carers** 10 volunteers** 1 singer group facilitator	Group singing	Active	Qualitative	Interviews Observations	Grounded Theory analysis	To use ethnographic study to explore how musicking benefits people with dementia and their caregivers.
McCabe (2013)	UK	9 people with dementia	Creative musical	Active	Qualitative	Semi-structured interviews	Thematic analysis	To explore the experiences of people with dementia involved

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		3 family caregivers	project					in a creative music project, and how the benefits of involvement evolve over time.
McDermott (2014)	UK	15 people with dementia 15 family carers 14 staff carers 8 music therapists	Group music therapy	Active	Qualitative	Focus groups Interviews	General inductive approach	To understand the meaning and value of music for people living with dementia
Osman (2014)	UK	10 people with dementia 10 family carers	Singing for the Brain (Alzheimer's Society)	Active	Qualitative	Semi-structured interviews	Thematic Analysis	To explore the experiences of people with dementia and their carers attending a group singing activity.
Pavlecevic (2015)	UK	6 music therapists	Music Therapy	Active	Qualitative	Focus group	Interpretative Phenomenological Analysis	To reflect on the experiences of music therapists using music for the therapeutic benefit of people with dementia within care home settings
Sixsmith (2010)	UK	26 people with dementia Family/staff caregivers**	Music in everyday life	Combined	Qualitative	Semi-structured interviews	Analysis guided by "conceptual model of wellbeing" (p.129) template	To explore the role of music and music-related activities in the everyday lives of people with dementia
Tomaino* (1998)	USA	4 people with dementia	Individual music therapy	Passive	Qualitative	Video observation Reflexive	Not reported	To explore the experiences of people with dementia when they engage with familiar music.

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Tuckett (2015)	Australia	7 family caregivers 23 staff caregivers	Group music therapy	Active	Qualitative	Focus groups	Qualitative content analysis	To examine the benefit of music in reducing 'behaviours that challenge'
Unadkat (2016)	UK	17 people with dementia 17 family caregivers	Singing group	Active	Qualitative	Couple interviews	Grounded Theory Analysis	To understand the benefits of group singing for people with dementia.