

# Music Lessons: Exploring the Role and Meaning of Music for Older Adults with Dementia\*

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## RÉSUMÉ

Le vieillissement de la population et l'augmentation de l'incidence des démences font ressortir la nécessité de mettre en place des stratégies alternatives permettant aux personnes de vieillir dans leur communauté. Le but de cette étude de cas multiples est d'explorer, à partir du point de vue d'un initié, le rôle et la signification de la musique dans la vie des personnes atteintes de démence qui vieillissent dans leur communauté. Les méthodes comprennent des entrevues semi-structurées, des observations et des vidéos. L'analyse a révélé que la musique joue un rôle bénéfique, mais complexe, dans la vie de ces personnes. La connexion a été identifiée comme le thème central dans cette étude, et comprend trois types de « connecteurs » en tant que sous-thèmes, soit le moi, le partenaire et la musique. La connexion avec soi-même implique une conscience du moment présent, un accès aux souvenirs et l'expression de soi. La connexion avec le partenaire s'appuie sur la connexion avec soi-même et le temps passé ensemble à écouter de la musique. Enfin, le lien avec la musique se fonde sur les deux sous-thèmes précédents, ainsi que sur le désir de préserver la « normalité » des choses. Cette étude fournit un éclairage nouveau dans le corpus croissant des écrits interdisciplinaires consacrés à la démence, à la musique, au vieillissement dans la communauté et aux pratiques contemplatives, ainsi que sur les conséquences du vieillissement et des soins pour les personnes atteintes de démence.

## ABSTRACT

An aging population and increasing rates of dementia point to the need for alternative strategies that allow individuals to age in place. This multiple case study explored, from an insider's perspective, the role and meaning of music for individuals with dementia who are aging in place. Methods were semi-structured interviews, observations, and videos. The study's central theme is connection, with three types of "connectors" – self, partner, and music – as subthemes. Connection to self involves present moment awareness, accessing memories, and self-expression. Connection to partner builds on self-connection and spending time together with music. Lastly, the connection to music builds on the previous two subthemes as well as the desire to keep things "normal". This study provides insight into the growing body of interdisciplinary literature dedicated to dementia, music, aging in place, and contemplative practices, as well as implications for aging and caring for someone with dementia.

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## Introduction

In Canada, seniors represent the fastest-growing age group. In 2011, an estimated 5 million Canadians were aged 65 years or older, a number that is expected to double in the next 25 years (Statistics Canada, 2011). A significant consequence of population aging in Canada is the increasing rates of elderly targeted illnesses and diseases, including dementia (Alzheimer's Association, 2014). Dementia prevalence is significantly affected, appearing at a record high with 564,000 Canadians currently living with dementia (Alzheimer Society of Canada, 2016), making dementia one of the most significant public health issues of the 21st century (Alzheimer's Association, 2014).

Older adults with dementia reside in long-term care homes, assisted living facilities, hospitals, and at home in the community. The majority (61%) of Canadians with dementia live at home in the community (Canadian Institute for Health Information, 2016) and transition to an institution in the later stages of the illness. Varying factors lead families to this decision of institutionalisation, most prominently the increasing severity of cognitive impairment, a diagnosis of Alzheimer's disease and subsequent worsening of symptoms, increased dependency for daily activities, and increasing behavioral and psychological symptoms (Curtin, 2010). The desire to remain at home is strong among older adults with dementia; a person's home reflects their identity, achievements, independence, competence, and self-esteem, factors which are important to maintaining quality of life, health, and happiness for people with dementia (Gould & Basta, 2013).

Caring for a person with dementia takes a physical and psychological toll: Up to 75 per cent (of both formal and informal caregivers) will develop a psychological illness, 15–32 per cent will experience depression, and all are at an increased risk for obesity and a weakened immune response (World Health Organization, 2015). As the demands of the caregiving role increase, caregivers are often forced to reduce or quit employment and limit social activity, making them vulnerable to social isolation and adding financial stress (Brodaty & Luscombe, 1998; Vitaliano et al., 2005; World Health Organization, 2015). The negative effects of caregiving are well documented in the health literature (Brodaty & Luscombe, 1998; Cooper, Katona, Orrell, & Livingston, 2008; Vitaliano et al., 2005) while the benefits of caregiving are less often discussed.

Research shows that the positive aspects of caregiving are most commonly found in the caring itself, or the dynamic of the relationship between caregiver and care recipient (Lloyd, Patterson, & Muers, 2016). The act of caring is embedded within these intimate personal relationships (Abel, 1990), and thus the feelings of

attachment pre-illness have a strong influence on their present commitment to one another (Cicarelli, 1983; Le Navenec & VonHof, 1996). Some caregivers feel companionship, fulfillment, enjoyment, love, and empathy through the act of caring (Boerner, Schulz, & Horowitz, 2004; Shim, Barroso, & Davis, 2012). In particular regard to dementia, an important precursor to a person finding joy in caring is the acceptance of the changes in their shared life with their loved one (Lloyd et al., 2016; Shim et al., 2012). It has been argued that there is an established need for accessible, cost-effective strategies that support family caregivers in caring for their loved ones at home while maintaining their own health and well-being (Hanser, Butterfield-Whitcomb, Kawata, & Collins, 2011).

A key component of maintaining a high quality of life and care for individuals with dementia is the acknowledgement and understanding of their sense of self. The seminal work of Kitwood (1997) describes how personhood is directly linked to identifying one's self-worth and dignity and how, with a diagnosis of dementia, individuals are often treated and cared for in ways that depersonalise and infantilise. Ultimately, this leads to a loss of personhood that is often associated only with the neuropathology alone, and does not account for the self and agency that remains (Kontos & Naglie, 2007). Pia Kontos' work builds on Kitwood's notion of personhood, and discusses the idea of embodied selfhood as an expression of ourselves based on a notion of agency that "resides below the threshold of cognition, and facilitates meaningful engagement with the world" (Kontos, 2014, p. 112). A study on elder-clowning (a red-nosed clown who specialises in working with older adults through music, dance, and humor), with 23 long-term care residents with dementia showed that residents would initiate as well as respond to verbal and embodied engagement (Kontos, Miller, Mitchell, & Stirling-Twist, 2015). Participants opened their eyes, began smiling, stomped their feet along to the beat that the clowns played on their ukuleles, and joined in on playful teasing between the clowns and residents (Kontos et al., 2015). Embodied engagement and accessing the insiders' perspective (the individual with dementia) is a strategy to account for this selfhood.

Pharmacology is one approach to treating dementia and a common strategy for enabling older adults to remain at home. Drug treatments, however, have been largely unsuccessful and ineffective in alleviating many of the main symptoms of dementia, such as anger, agitation, wandering, psychosis, and/or apathy (Nair, Browne, Marley, & Heim, 2013). In response to the limited success of drug therapies, non-pharmacological interventions, including the use of music, have been emerging since the early 1970s as important approaches to treating dementia (Brotos & Marti, 2003; Chu et al., 2014;

Clair, Tebb, & Bernstein, 1993; Cowles et al., 2003; Gill & Englert, 2013; Hays & Minichiello, 2005; McDermott, Orrell, & Ridder, 2014; Sixsmith & Gibson, 2007). Non-pharmacological interventions aim to address the underlying needs such as lack of sleep, comfort, nutrition, and socialisation that are causing the responsive behaviours instead of masking them with medication, something with the potential to enhance the quality of care and improve communication between the caregiver and person with dementia (Cohen-Mansfield, 2001). Of the many alternative therapies available today, music therapy has been highlighted as one of the interventions that individuals with dementia most often respond to (Davidson & Fedele, 2011; Foster, 2009). Potentially, some have argued, because the parts of the brain required for the processing of musical information remain intact regardless of a dementia diagnosis (Davidson & Fedele, 2011; Foster, 2009). This means it is possible that musical perception, sensibility, emotion, and memory can survive even after other forms of memory have disappeared (Foster, 2009).

The use of music therapy, applied to a wide range of health issues and illnesses, is documented in the literature. Exploring music and health outside of a therapeutic lens, however, has been less prevalent. The majority of research to examine older adults' health and the connection to music is institutionally based and focuses on music as a therapeutic intervention (Fraser et al., 2015). For example, a scoping review in the area of arts and aging found that 58.3 per cent of included studies were intervention based, and only 28.9 per cent of studies explored current personal artistic and creative activities (Fraser et al., 2015). The removal of this medical lens, and the recognition of engagement with music as an everyday common activity for older adults, have positive outcomes (Laukka, 2007). Specifically, a study surveying 500 community-dwelling older adults in Sweden found that 64 per cent of participants listened to music once or several times a day, and the reasons for listening included pleasure, mood regulation, relaxation, feeling of belonging, and connection to their identity (Laukka, 2007).

Persons with dementia want to challenge the idea of leisure as therapy and instead recognise, according to Dupuis et al. (2012), "leisure [as] a space to experience and celebrate life despite dementia ... they want to focus on leisure as a means to live life to the fullest" (p. 245). The informal listening and making of music is shown to improve cognitive (stimulation, memory), social (engagement), and emotional (joy, relaxation, stress relief) well-being (Creech, Hallam, McQueen, & Varvarigou, 2013; Johnston, Rasmusson, Foyil, & Shopland, 2017; Laukka, 2007; Sole, Mercadal-Brotons, Galati, & De Castro, 2014; White, 2016).

## Research: Purpose, Design, and Methods

The majority of research on music and dementia has focused on institutionalised settings and clinical music therapy interventions; hence, much less is known about music among community-dwelling older adults. The purpose of this multiple case study was to explore, from an insider's perspective, the role and meaning of music in the lives of individuals with dementia who are aging in place (i.e., at home). Three questions guided this exploration:

1. What does music mean to someone with dementia and how has this changed over their lifetime?
2. How does music influence the health and well-being of individuals with dementia? (e.g., memory, identity, self-hood, engagement, relationships)
3. How is music integrated into the day-to-day lives of individuals with dementia aging in place? (e.g., played from a personal device, aloud in the house, scheduled use, spontaneous use)

We used a multiple case study methodology for this qualitative exploration. Case study research is defined by Creswell and Poth (2018) as:

A qualitative approach in which the investigator explores a real-life, contemporary bounded system (a case) or multiple bounded systems (cases) over time, through detailed in-depth data collection involving multiple sources of information (e.g., observations, interviews, audiovisual material, and documents and reports). (pp. 96–97)

In this study, the case was the individual with dementia and his partner bounded by time (5 weeks), place (their home in Southern Ontario), and activity (the experience of music) (Creswell & Poth, 2018).

A critical, interpretivist lens and a modified version of the *Psychosocial model of music in dementia* (McDermott et al., 2014) guided the study. Interpretivism assumes that human beings construct meaning as they engage with the world, and then make sense of this interaction based on the historical and social perspective that we have bestowed upon us by our culture (Creswell, 2003). The nature of knowledge under interpretivism is subjective and interactive, which drives the research in this area to reflect understanding and interpretation (Guba & Lincoln, 2005). Interested in the role that music plays in the lives of individuals with dementia who are aging in place in their own homes and communities, the researchers wanted to explore what music *means* to these participants; experience and meaning are the fundamentals of interpretivism (Guba & Lincoln, 2005; Schwandt, 1996).

Critical qualitative research seeks not just to study and understand society, but also to critique and change it (Patton, 2002). A critical qualitative research lens

questions and takes into account received knowledge, underlying assumptions, social forces and interests at play, models of thinking, power relationships, and people and issues that are marginalised in mainstream policy (Andrews, Gillett, & Voros, 2016; Eakin, 2015). The nature of our study originated from the critique that the perspectives of people with dementia are often unconsidered in dementia research. Applying a critical perspective, the study questioned the assumption that alongside a diagnosis of dementia there is a loss of selfhood, and it explored the perspectives of a seldom-studied population – individuals with dementia who are aging in place (i.e., at home). The model that McDermott et al. (2014) had proposed emerged out of a lack of frameworks in the area of music and dementia, and from a lack of understanding about how and why music is an effective therapy. This model highlights the diversity of what music means in the lives of persons with dementia, and consists of three main categories of factors that are influenced by music: *here and now*, *who you are*, and *connectedness*. The principal investigator (author ME of this article) modified this model to better reflect the study and literature on music and dementia and thus provide a framework for music as a meaningful activity that can contribute to overall health and well-being.

#### *Participant Recruitment and Selection*

We recruited participants through established connections with three local Alzheimer societies. The societies advertised the study in their various programs, placed an excerpt about the study in their newsletter, circulated study information on their social media sites, and/or put the principal investigator in direct contact with potential participants. Rolling recruitment was utilised, in that the researcher began data collection upon recruiting the first participant and during this time was recruiting others. The eligibility criteria for participants were (a) having a dementia diagnosis, (b) living alone or with others in the community, (c) using music in their lives in a routine capacity, and (d) lacking enrollment in formal music therapy. Over a 10-month period, these three cases were the only eligible participants that expressed interest in the study.

#### *Research Setting*

The observation, interviews, and video recording occurred at the participants' homes, located in Southern Ontario. The reasons for collecting data in the participants' homes, beyond the fact that the home environment where individuals were aging in place was a key aspect of the study, were first, that individuals with

dementia tend to be more comfortable in environments that are familiar to them, and second, the study aimed to explore the use of music in the day-to-day lives of individuals with dementia.

#### *Data Collection*

Ethics approval was granted from the Brock University Research Ethics Board. The principal investigator visited each of the three couples three times, with one to two weeks between each visit. The initial visit consisted of introductions, consent, and building rapport. The two subsequent visits were for conducting interviews on the topic area and in two cases, filming participants engaging with music. At the first interview, the investigator asked questions such as *What is it about music that you specifically enjoy? What devices do you use to listen to music and why? What does a typical day look like for you and where does music fit into that day? Does music affect your relationship with others?* The second interview was a follow-up, providing the opportunity for: clarification, asking new questions that addressed any gaps (such as *What does music do for you that other things can't? Can we talk and/or listen more about/to some of the music you discussed last time? How does music help you?*), prompting the participant for more information on particular topics, addressing any missed topics or questions, and elaborating on any interesting points. Visits lasted from 30 minutes to 3 hours.

Upon meeting participants and discovering that their sole caregivers were their spouses along with, for most of their lives, their musical partners, and that the spouses wanted to be present during the interview process and were highly engaged in the conversation, we decided to include spouses in the study. Each participant, including spouses, read and signed the consent form. Ongoing verbal consent throughout the study ensured that the participants remained interested in participating and did not feel that they were being taken advantage of in any way.

The principal investigator conducted two open-ended, semi-structured interviews with each of the three couples in their homes. Both the person with dementia and their partner had equal consideration and talking time during the interviews. Direct observation occurred simultaneously with interviews. Field notes concentrated on (a) artifacts in the home that were related to music (e.g., stereos, instruments, cassettes/CDs/records); (b) observable emotion during the talking about, listening to, or making of music; (c) personal identifiers related to music (e.g., clothing); (d) physical movement during the listening or making of music; and (e) notes on the home environment and specifics on how and where music was used.

Videos of each couple were also captured during data collection. The benefits of video as a data collection tool include the fact that it has the potential to capture detail in observations that can be missed in the moment; it can capture a different, visual side of the participant that cannot be expressed in words, in addition to being a stable artifact and, therefore, can be reviewed repeatedly (Pink, 2007; Yin, 2009). Videos have the potential to increase the quality of field observations and their utility by others (Patton, 2002). We selected videos rather than photographs because music, as one of our central research topics, is best captured through the additional, audio aspect of video (Pink, 2006).

With the participants' consent, the principal investigator videotaped them listening to or making music in their home. Participants were offered the additional option of keeping the video camera with them during the time between interviews. This option offered an opportunity to capture more visual data and during a time when the participants may have felt more comfortable, without the researcher's being present. Participants were given a handout listing examples of moments that they could capture with the camera (e.g., listening to music while doing the dishes or relaxing; singing; dancing; playing an instrument), as well as simple instructions on when and how to operate the camera. They were encouraged to use the video camera whenever the opportunity presented itself over the data collection period. Participants could set up and use the video camera themselves, which one couple did; however, if the couple needed assistance with the video camera, the principal investigator was available to film these moments for them; for two of the couples this occurred at the end of the allotted interview time. The amount of visual data captured ranged between two and five videos, lasting from two to 40 minutes for each of the couples.

### *Analysis*

Combining Creswell's (2003) and Stake's (2006) steps for data analysis in qualitative research with Heath, Hindmarsh, and Luff's (2010) steps for video analysis, our study's data analysis was a nine-step iterative process.

#### *Step 1: Organise and Prepare the Data for Analysis*

Upon completion of data collection with each participant, the principal investigator typed up field notes; gathered all video, picture, and audio files into digital, participant-specific folders; and sent audio files to an external transcriber to be transcribed verbatim.

#### *Step 2: Immersion in the Data*

Upon completion of all interviews and receipt of all transcripts, the principal investigator conducted a first read-through and viewing of the data.

#### *Step 3: Coding*

After multiple read-throughs and viewings, some of the memos merged or stood alone to become codes. These categories were labeled with either indigenous or sensitising concepts/codes.

#### *Step 4: Compiling Data*

Master documents (including a personal information chart, important coded sections of the transcript, key field notes, and screen captures from videos or photos) were created for each participant.

#### *Step 5: Meeting with Analysis Team*

At this point, to discuss and clarify codes and preliminary themes, the principal investigator assembled an analysis team that consisted of two other master's level graduate students in health sciences, and a gerontologist with a PhD in public health (author PG of this article).

#### *Step 6: Cross-Case Analysis*

Taking the team's perspective into consideration, the principal investigator reexamined the three master documents as well as the codes and started making some preliminary thematic notes on these areas. Along with the notes, the principal investigator created a similarities and differences chart of the three cases, and a diagram outlining the progression of the participants' Alzheimer's disease as well as the effects it had on the individual and the partner relationship.

#### *Step 7: Identification of the Salient Themes*

The principal investigator narrowed down the themes to six – (a) identity and change over time, (b) connection, (c) complication and challenges, (d) humor, (e) music as a contemplative practice, and (f) transformative nature of qualitative research – and pulled specific examples from the transcripts into separate documents according to each theme.

#### *Step 8: Write Multiple Storylines*

Building on the cross-case analysis, the principal investigator developed three storylines (three different perspectives on the whole story that could be told from the data). The storylines of each story were as follows: (a) there is value in the use of music for and with individuals with dementia (however, this relationship is complicated); (b) the health and well-being of persons with dementia is influenced by music through selfhood, meaning, and relationships (as outlined in the theoretical framework); (c) for all three participants, music acts as a catalyst for connection, both for self-connection in the individual with dementia and connection to their partner.

*Step 9: Interpret and Derive Meaning from the Data*

The principal investigator decided to expand on a combination of storyline 1 and 3 with the main theme of connection, while acknowledging the complicated aspects of music, as this told the truest and most thorough depiction of the data. Storyline 2, outlined by the theoretical framework, influenced the conceptualisation of the final storyline through the use of some of the sensitising concepts (selfhood, meaning, and relationships). This step also involved future research implications, questions, and gaps.

**Findings**

The findings reveal that music plays a beneficial, yet complicated role in the participants' lives. Analysis highlighted "connection" as the central theme of the study with three key "connectors" – self, partner, and music – as subthemes. In the following section, we will present portraits of the participants and each of the key themes supported with evidence.

*The Participants*

Three couples met the inclusion criteria and participated in the study (see Table 1). All three participants used music in an informal way and lived with their partners, who were also their sole, informal caregivers. We assigned each participant a pseudonym. The following are pieces of their musical stories.

*1. George and his love of dance*

George has always loved to dance – solo, with a partner, or in a group. He began dancing when he was 14 years old in the United Kingdom and continued dancing, even when he was deployed to Africa while in the army. When George met Beth, his wife of 68 years, they began dancing as a couple and have continued to do so throughout their lives together. As a result of his dementia diagnosis, they recently stopped dancing at the legion hall, church, and other events but continue to dance in the kitchen.

*2. Tim and his love of singing*

Tim discovered his skill and love for singing late in his life. Tim's family roots are Welsh, and he often speaks to the music engrained in this culture. He began learning to play piano when he was a young boy and continued with tuba and trombone in high school. There was a period of time in his adult life when he did not play music, but this changed when he met his wife Jill. Jill and Tim began singing in various choirs 15 years ago and are still active members today.

*3. Phil and his love of playing instruments and listening to music*

Phil has spent most of his life playing a variety of instruments. Music has always been Phil's favourite hobby; he's played contra in multiple drum corps and continues to appreciate music through listening and watching DVDs of some of his favourite performances. When Phil is not volunteering for a local Alzheimer society, his days are spent with his wife, Susan, sorting sports cards and listening to and reminiscing about music from the past.

*Connection*

The central theme was connection. In all three cases in our study, music acted as a catalyst for connection: (a) *self-connection* within the individual with dementia, (b) *connection to their partner*, and (c) *connection with the music*. For individuals with dementia, staying connected – within the self, to others, and with daily life – becomes increasingly difficult as the illness progresses (Gouveia, 2010). Wayman, author of the book *A Loving Approach to Dementia Care: Making meaningful connections with the person who has Alzheimer's Disease or other dementia or memory loss*, has described individuals with dementia as a jigsaw puzzle, pieces of which the dementia progressively removes, leaving random pieces with which one is left to connect (Olson, 2014). Previous research has shown that familiar music can aid in the preservation of self and evoke memories and associations that offer an opportunity for intra- and interpersonal connection (Foster, 2009).

**Table 1: Participant information**

Participant	George	Tim	Phil
<b>Gender</b>	Male	Male	Male
<b>Age</b>	94	77	65
<b>Ethnicity</b>	British	Welsh	Canadian
<b>Date of dementia diagnosis</b>	2008	2012	2013
<b>Participation in alternative therapies</b>	No	No	No
<b>Partner name</b>	Beth	Jill	Susan
<b>Partner gender</b>	Female	Female	Female
<b>Length of relationship</b>	68 years	20 years	Long-term but years unknown
<b>Musical connection</b>	Dancing partner	Choral singing partner	Drum corps partner

### 1. *Connection to Self*

We observed music as a catalyst for self-connection through the production of present moment awareness, memories, and self-expression. Engaging with music (listening, dancing, singing) acted as an anchor to the present moment that provided participants with moments of self-awareness and thoughtfulness. After engaging with music, participants' thoughts appeared clearer and more focused, allowing them to comment more clearly and explicitly on topics such as their musical performance or their struggle with dementia. For example, after practicing a choral hymn with his partner, Tim turned to the interviewer and said, "You can see I'm having difficulty", referring to losing his spot in the music and needing help from his partner to stay on track. Similarly, Tim, in a state much clearer after the hymn than during his interview, turned to the interviewer and explained, "Yeah, I feel good inside then and after [singing in the choir], okay? And you know, a lot of these things just keep rolling around in your head ..." and "It eases the mind and away you go, you know?" In a similar manner, Phil too was able to organise his thoughts, and subsequently his sports card collection, when music was playing in the background: "Well, I do a lot of stuff with music as far as my collections and things like that, because if I have a TV on I probably wouldn't be halfway near done what I do with the music."

The way in which music enabled the study participants to, at least temporarily, organise their thoughts allowed the purposeful access of music-associated memories. The ability to recall memories from the past connected participants to their selfhood and made them feel proud, which had become increasingly difficult to do. After recalling a past memory on video, Phil exclaimed, "Wow! I like it when I can remember things like that". Tim spoke directly about the connection of music and memory:

Music has that ability to, to bring you to, to a memory that – and an emotion – and it brings you right back to that emotion and whatever it was and uplifted, uplifted by music, sometimes depressed by music [laughter] but not very often ... it just, it makes you feel different emotions – sadness – and that sort of stuff.

Additionally, music fostered self-connection through participants' body movements and expressions. This expression took many forms: hand gestures, mimicking how they would hold and play an instrument, dancing steps to a song, or singing along to music. Expressing themselves through movement was a reminder that a "self" still existed, despite their Alzheimer's diagnosis. Although expressing ourselves through our bodies is not the only way we show our inner "selves", for individuals with dementia it is often one of the lasting

ways they can communicate their selfhood (Kontos, 2014). For example, George, who no longer recognised the faces of some of his family members, was still able to remember the steps to dances he had performed with his wife throughout their life.

Similarly, while listening to music, Phil moved his upper body mimicking that of a conductor from his experience in drum corps. There were many examples of this type of movement in the video data. As the following excerpt from the study investigator's field notes of Phil's self-videotaping indicates, there was considerable connection within himself while listening to music:

The camera is placed on his tabletop, where he sits to sort his sports card collection. We have a close-up view of Phil (only his upper half), and can see stacks of cards and binders on bookshelves in the background. The instrumental music – a string orchestra – is playing quite loudly, and Phil appears to be completely "in the zone". He is inserting cards into a clear file protector and nodding his head along to the music. There is a lull in the music before a new instrument chimes in. In this moment, Phil, without skipping a beat, moves his arm in an upward sweeping motion as if conducting the orchestra himself. As the music continues, so too, does Phil, returning to his sports cards.

Although the ways music benefits self-connection for individuals with dementia were clear from our study observations, music cannot be considered a panacea for solving all problems. Memory is the primary cognitive faculty affected by dementia, and as a society that values cognitive capacity, we often associate this loss of memory with a simultaneous loss of self. Although participants did maintain some sense of self, they, like others with dementia, had to deal with jumbled thoughts and hard-to-access memories that made it more difficult to connect with and feel like themselves. Jill, Tim's partner, described the time when Tim was first starting to show signs of dementia:

There were just things that were happening, you know, like it's – it wasn't so much forgetfulness although yes, there was forgetful – like you have short-term memory things, but it was more getting things mixed up you know ... and then we started to notice when we were away in Florida, that Tim would have a harder time finding his, his way around like you know, like a new place that he didn't know, you know? ... these were signs to me that something was really going on strangely.

### 2. *Connection to Partner*

We found that music also acted as a means to connect individuals with dementia to their partners. All three

participants in this study were married, with their partner serving as primary informal caregiver. Referring to the partners as “caregiver” unduly emphasises caregiving over other aspects of their life, and does not do justice to the relationship’s complexity. Accordingly, we refer to them as *partners* because we believe this depicts the relationship with the study participants more honestly. Music acts as a way to connect the participants and their partners through a musical partnership that co-exists with their respective care recipient and caregiver roles.

This musical partnership connection builds upon the self-connection that participants experienced. It also provides an activity both individuals could mutually share. During and after engaging in music, partners reconnected through recalling memories, heightened self-awareness, and familiar embodiment. Partners seized this as an opportunity to connect with their loved one and share a moment together. With dementia, finding moments to connect becomes increasingly rare; thus, the sharing of the present moment is invaluable. Phil and Susan spend time together in their basement listening to music from their past and reminiscing on moments spent together, “and we play a lot of trivia on ... who the artist might be, you know ... A lot of times we try and figure out what we were doing when we heard this song.”

Participants’ embodied selfhood was recognised by their partner and provided a moment of connection similar to that experienced before the onset of dementia. The principal investigator witnessed these moments of connection on the video data during the engagement with music. For example, after dancing with her loved one to a song from their past, Beth exclaimed, “We haven’t danced like that in years!” The following excerpt from the study’s field notes on the video of Beth and George succinctly conveys their connected relationship:

About 30 seconds into one of their favourite songs from their past, Beth and George make eye contact and smile – they recognise the tune. Beth reaches for George and he responds by embracing Beth in a dancing position, hand in her hand and hand on her waist. Beth’s facial expression shows her surprise as she quickly makes eye contact with me, as if to say “are you seeing this?!” It’s only a moment before her eyes and smile return to George and the two of them begin box stepping around the kitchen. George leads Beth to the beat of the music; they appear to be completely comfortable in each other’s arms – a familiar place. Beth’s smile never leaves her face.

In all three cases, music gave these dyads something to share and engage in together. The dementia meant increased time spent together, as individuals with dementia need help practicing, playing, and operating

musical devices. This situation, while requiring significant changes in the way that music was integrated into their lives, provided an opportunity for the relationships to strengthen and grow. Our analysis highlighted numerous ways the relationships had strengthened. For example, with respect to the Tim and Jill dyad, the couple spoke regarding the change in their relationship, which was evident in their expressions and body language:

I think since Tim’s had more difficulty following music it’s almost as – it’s brought us closer together because we practice together all the time and there’s this community ... again I am back to when we are singing together ... there’s just this feeling that goes between you, it’s hard to describe it, it’s like this string.

This excerpt from the videotape field notes further conveys the couple’s connection:

Tim and Jill are in their kitchen, sitting side by side, at a desk with a computer and file folders of their sheet music, their usual practice space. Both Tim and Jill hold their own booklet of sheet music for this particular choral hymn they are about to sing. Jill sits in front of the computer and pounds on the keys to get the instrumental music to play. The piano music begins and they both start to sing the tenor part in unison. Tim rocks in his chair and they remain very concentrated on the music, practicing hitting every note. Halfway through the song Tim loses his spot in the music, and Jill leans over to help him find the right page in his booklet. They miss only a few beats before they pick it right back up. They end the piece repeating the lyric “a beautiful song”; the piano ends and Tim and Jill turn to each other; they smile and laugh.

The strength and resiliency of these relationships have developed through the struggles and challenges they have encountered post-diagnosis. Dementia, due to the nature of the illness, affects not only the individual but also those closest to them. As their partners take on a caregiving role, the dynamic of the relationship changes. There is tension between holding on to the past and embracing their new circumstances. They can no longer do certain activities or attend events that they once did. Partners, in particular, expressed missing the more social aspect of their lives pre-dementia: “We’ve got no friends anymore”, and, “I do [miss the social aspect of drum corps], I do, I really do. We don’t have dances anymore, I love to dance; Phil loves to dance when he, when he’s not, unbalanced by the noise.”

### 3. Connection to Music

The connection to music for individuals with dementia provided participants with opportunities for feeling like



their old selves, connecting to their loved one, and the continued, enjoyable presence it played in their life. For example, when a participant was asked if he relied on music in any way he replied, "If you are not feeling too good and you go and you lie down, what do you do, you turn on the music, don't you" and "it basically it helps up here [pointing to his head] and calms you, yeah, calms yourself down." Despite challenges, partners remained connected to music for similar reasons, familiar recognition of their loved one, sharing in a moment together, and the consistent, pleasurable role it played in their life. When partners were asked about what music did for them that other things could not, or if they relied on music in any way, they explained:

Well, at the present time it, it lifts me up ... sometimes you get like a little bit of depression because of certain things and, and I'll come on in the kitchen still and put the music on and it lifts my mood up, yeah.

If I think of a world without music or, or a, a life without music I can't even imagine that, I'd have to have music in my life ... I think I rely on music as kind of comfort, as a, as a, a companion almost you know, in your life you know, it's something there and, I hope you know, to always have it; as I said, I can't imagine a world without music.

The connection to music fueled the want, and arguably need, of both the participant and partner to hold on to this piece of their life that still felt "normal" amidst so much change. For example, when talking about their choir involvement, Tim's partner stated, "I would like him to continue as long as he can so I am trying to, you know, play that sort of balancing act". Both participants and partners expressed the importance of music in their life and when asked what life would be like without music they replied, "How would that be – I think we would probably end up, or I would probably end up, getting it somehow or another."

Although providing many benefits, music also proved to be a challenge for the study participants. Participants began to forget, or had already forgotten, how to play their instrument, practice choral singing, read music, and/or use devices for listening to music. They were also losing control over their thoughts and memories, thus losing the ability to feel like themselves. For example, Phil had to leave drum corps:

We left while Phil was having problems physically so we had to, he had to kind of give it up and he, he went back a couple of times but he found he just couldn't do it, and then we tried to go back to the ensemble and he was going to play baritone, but he, he just couldn't figure it out, he got confused.

Partners also felt the struggle of dementia, which required constantly finding new ways to integrate

music into their lives; they faced the challenges of shifting back and forth from being a musical partner to filling a caregiver role, and experienced anxieties about the ever-changing complications they faced daily. Partners wanted to keep things consistent for themselves and their loved one but were struggling to do so. For example, Jill explained:

The choir, as much as I love it, it's becoming more a bit stressful for me because I am worrying about him instead of doing my own practicing but I just – I would like him to continue as long as he can so I am trying to, you know, play that sort of balancing act and it's getting a little difficult.

All of these factors led to a change in the relationship to music, for both the study participant and their partner. Where they once turned to music for enjoyment and an escape from everyday life, there are occasions when they increasingly find themselves frustrated with not being able to perform, practice, or listen as they used to. Tim explained, "It does frustrate you because you know, you, you always have been able to do something and then all of a sudden whoops [laughing] it ain't working." Instead of an escape, in many ways music becomes a reminder of all of the change and loss that dementia has caused.

## Discussion

Evidence for connection to self, partner, and the music challenges the idea that with a diagnosis of dementia there is only loss. In the biomedical literature, the dominant representation of dementia is as a devastating syndrome (Henderson, 2002). Often, the most debilitating and demeaning aspects of a case are discussed, and the tragedy of a diagnosis is emphasised. Of course, it would be misleading to ignore the losses that are experienced by individuals with dementia and those closest to them: loss of shared memories, routines, control, and friendships, to name a few (Mitchell, Dupuis, & Kontos, 2013). However, what our analysis revealed is that despite all of these losses there are aspects of the self that still remain and can be revealed through engagement with music.

This study supports the literature on music and memory, and that through engagement with music individuals with dementia can access memories that are otherwise inaccessible (Cowles et al., 2003; Hays & Minichiello, 2005; Kerer et al., 2013; Vanstone & Cuddy, 2009). Additionally, this study contributes to the connection between dementia and music as a contemplative practice.

The health literature has begun to explore the positive outcomes of contemplative practices. Contemplative

practices aid in “developing capacities for deep concentration and quieting the mind in the midst of the action and distraction that fills everyday life”; they are a “reminder to connect to what we find most meaningful” (The Center for Contemplative Mind in Society, n.d.). Music, however, as a contemplative practice benefitting health, is largely missing from this research. There is literature on music linked to meditation (Sarath, 2015; Vidyarthi & Riecke, 2014) and used in an educational setting (Power, 2013; Shippee, 2010; Westerlund & Väkevä, 2011), but even then, the research is limited.

Our findings suggest that music offers organisation of thoughts, and acts as an anchor to the present moment for individuals with dementia. It is through this clarity that music facilitates intentional mind wandering to past memories (Seli, Carriere, & Smilek, 2015). This is supported by the literature that shows mindfulness meditation enhances working memory, attention, focus, and intelligence for older adults with dementia (Robertson, 2015). Having control and intention in recalling memories has positive effects on an individual with dementia – maintaining identity, strengthening relationships, expressing selfhood, and experiencing feelings of joy. This research supports the literature that emphasises the need for contemplative practices in caring for persons with dementia, as accessing the present moment experience – as with music – is critical for these individuals to manage many of their symptoms (e.g., attention deficits, memory loss, disorientation) (Person & Hanssen, 2015; Robertson, 2015). As one participant said, “there is a magic to the music”.

Music also acts as a catalyst for connection between the person with dementia and their partner, through embodied selfhood. Our findings support the literature on embodied selfhood in those with dementia and further suggest that the participant's embodiment is recognised by and beneficial to their partner, providing a moment of relational presence and thus, connection for the couple. Pia Kontos has discussed embodied selfhood in relation to dementia and in how persons with severe dementia continue to express themselves through their bodies (Kontos, 2005, 2012; Kontos & Naglie, 2007; Kontos & Martin, 2013; Kontos et al., 2015; Mitchell et al., 2013). She speaks specifically to the connection of music and embodied selfhood: “The persistence of musicality despite advanced Alzheimer's disease exemplifies the existential expressiveness of the body that I argue is a fundamental source of selfhood” (Kontos, 2014, p. 114). Research also shows that our embodied selfhood and experience of music is an expression of our relationality with others and as a means for social bonding or familiar recognition to occur (Ahessy, 2017; Kontos, 2014; Mitchell et al., 2013). Combining embodied selfhood and present moment awareness perpetuates relational presence

allowing for the reciprocal nature of engagement (Kontos et al., 2015).

The moments of connection and the increased amount of time the couple were now spending together, post-diagnosis, were shown to strengthen their relationship. This finding is contrary to what has been portrayed in much of the caregiver literature that discusses burnout and depression (Brodady & Luscombe, 1998; Cooper et al., 2008; Vitaliano et al., 2005) and adds to the literature on caregiver benefit. In spousal relationships that are central to the individuals' lives, caregivers find more meaning (Boerner et al., 2004; Fauth et al., 2012). Spousal caregivers often treat caring as an extension of their marital relationship and not as an additional burden (Cheng, Mak, Lau, Ng, & Lam, 2016; Lloyd et al., 2016). Although they may still experience burden, spouses – wives in particular – conceptualise caring as a natural part of their role as a life partner. Specifically, with dementia, some caregivers feel emotionally closer to their care recipient after the diagnosis and the newly increased amount of interaction and time spent together (Fauth et al., 2012), which was also evident in our study findings.

Lastly, our findings support the positive aspects of the experience of music and dementia (enhanced feelings of well-being, increased social interactions, heightened sense of empowerment and control (Johnston et al., 2017; Sixsmith & Gibson, 2007)). However, analysis revealed that music is not a panacea. At times music can increase the frustration of both the person with dementia and their partner, as they struggle with not being able to use/perform music as they used to and are searching for new ways to keep it in their lives. Personalising (meaning customising or selecting to meet individual needs, specifications, or preferences based on life experiences) support strategies is key; it is important to find what is meaningful to them and to explore ways to keep this in their life. Someone who does not enjoy music may not suddenly appreciate and be calmed by it after a diagnosis of dementia. Similarly, the type of music is important for personalisation, as is the implementation strategy.

### Study Limitations

It is possible that our study design and co-production of data means that the participants may have “performed” for the principal investigator during their time spent together; as in other aspects of life, it is common to feel the need to impress when meeting a new person for the first time. However, the principal investigator's response to the interviewer effect and relationship dynamic was to spend time with participants over multiple visits, and to comfort the participants as much as possible during the interview process. The repeated

visits provided more opportunity for building rapport and less pressure on the second, and third visits after having previously met one another.

The three cases interviewed and observed in this study yielded an in-depth view into the role of music and dementia, yet is limited by the small sample. These cases were unique in that all participants lived in the community with their partners, all of whom were their primary informal caregivers. Each couple also had extensive experience with music, most of which they had experienced together as a partnership. The findings are thus limited to these unique cases and this particular context, and cannot be generalised to, for example, individuals who live alone, or to those who have participated in a lifelong meaningful activity that is not music. Findings might have been different had the interviews been conducted individually with each participant and not with their spouses present, as well as if the person with dementia was female and not male unlike the couples interviewed for this study.

### Implications and Directions for Future Research

This study provides insight into the growing body of interdisciplinary literature dedicated to providing specific indicators of music's value in the lives of persons with dementia and their partners. This study supports the research on the benefits of music for memory and further suggests that informal, at home, unstructured music can be beneficial. Beyond music applied as a therapeutic intervention to address behaviour (the main focus of traditional literature), we suggest offering it as a tool that can enrich the lives of persons with dementia and their partners.

Enriching the lives, and strengthening the relationship between the person with dementia and their partner, are positive aspects of the illness that are rarely discussed in the literature. The majority of the caregiver literature discusses burnout and depression, and although these are very meaningful and important aspects of a caregiver role, this study suggests there can be positive aspects to caregiving for someone with dementia.

Contemplative practices that quiet the mind and allow us to connect to ourselves are emerging as an important area for health research. Findings from this study provide insight into how music may be framed as a contemplative practice, important to the lives of individuals with dementia. Being aware and living in the present moment is extremely difficult for these individuals (Person & Hanssen, 2015; Robertson, 2015). However, music seems to help anchor them (at least temporarily) and, as a result, helps these individuals

manage many challenges related to their dementia and connect to their partner.

Practical implications of this research include the personalisation and implementation of music for individuals with dementia and their partners. A significant amount of information recommends the use of iPods for persons with dementia (Rossato-Bennett, 2014; <http://musicandmemory.org>); however, all of our participants listened to music aloud in their homes and not from a personal music device. These devices individualise the music experience, separating the person from their partner and potentially losing the opportunity to connect.

This study illustrated the importance of music and connection, therefore studying other alternative strategies (e.g., visual art, meditation, yoga) for individuals with dementia may provide similarly beneficial, useful, and timely information. Exploring other alternative strategies can help with understanding what or if there is something unique about the music and dementia connection. Research on strategies for improving at-home care and offering opportunities for connection has the potential to impact caregivers and decrease caregiver burnout, another important component to allowing individuals to age in place.

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