Witnesses to transformation: Family member experiences providing individualized music to their relatives with dementia

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Abstract: Content analysis of 35 family members stories found that sharing individualized music enhanced memory, mood and provided interactive opportunities, where family members connected and communicated with relatives who had dementia. Technology supports a positive new role for family members, who often use MP3 players (e.g. iPods), headphones, splitters, and other technical devices to share preferred, culturally relevant, and digitized music with relatives with dementia. Family members, who provided individualized music described new positive memories and transformed beliefs about the disease and their loved one. Educational leaders in general and music educators specifically, have an opportunity to add renewed emphasis to the culture and value of music as a lifelong resource. Music appreciation courses that include technological skills for creating playlists could support a lifetime of access to individualized music for young and older students, who are also prepared to address needs of those with neurological disorders, such as Alzheimer’s disease.

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The authors have scholarly and practitioner backgrounds in fine arts, music, education, leadership, psychology, and gerontology. We are educators, who are interested in the arts as a support for learning at every stage of life. Elizabeth Johnston is a research fellow at Center for Educational and Instructional Technology University of Phoenix (UOP) holds EdD in Educational Leadership (Loyola of Chicago), MA in Special Education and Fine Arts, and BA in Fine Arts and Psychology (Michigan State). Xeno Rasmusson is an associate professor at California State University East Bay, Department of Human Development, holds PhD in Biopsychology (University of Georgia), BA in Psychology (Augustana College), and Research Fellowships in Neuropsychology of Aging and Dementia at Johns Hopkins School of Medicine and National Institute on Aging. Barbara Foyil is a faculty at UOP holds PhD in Adult Education (Capella University), MA in Educational Technology/Leadership (Pepperdine University), and BS in Human Development (Hope International). Patricia Shopland is a faculty at UOP holds BS in Education (Concordia University), MA in Music and Music Education, EdD in Instructional leadership (Columbia University Teacher’s College), and MEd in Instructional Technology (Lesley University).

PUBLIC INTEREST STATEMENT
Substantial and persuasive research indicated the power of familiar music to calm and engage persons with dementia. Less is known about the responses to music by family members, who provide 90% of the care and sometimes choose culturally and personally familiar music to share with their relative with dementia. As researchers, we found family members treasured the moments when listening or making familiar music was a means to connect, communicate, and engage relatives with dementia. Sharing music allowed the family members to assume new roles and form positive memories with relatives. The role of providing music contrasted sharply with other caretaking tasks that were described as difficult or troublesome. Understanding the value of music at the end of life offers new possibilities for music educators and lovers. Educators could emphasize the value and culture of music and prepare students to enjoy culturally relevant music throughout life.
1. Introduction

Family members provide palliative care for 90% of persons with dementia (PWD) (Kongsuwan & Chaipetch, 2011) or end of life illnesses (Epiphaniou, et al., 2012) and report low levels of support for their caregiving from health teams, other family members, or society in general (Reigada, Pais-Ribeiro, Novellas, & Gonçalves, 2015). Family members of persons with dementia face personal and social challenges as the relationship transforms due to cognitive declines in the PWD (Beard, Knauss, & Moyer, 2009). Despite strategies to support the social relationship, family members of PWDs often report depression, grief, and anxiety (Pinquart & Sörensen, 2003) and experience physical, psychological, or social consequences (Cotel, Rodriguez, Perez, Iglesias, & Logo, 2016). With no effective cure and limited treatments, the primary goal of care for PWDs is improving quality-of-life (Prince, Prina, & Guerchet, 2013) and family members assume multiple new roles to insure the PWD receives personal care, medical services, and psycho-emotional and psychosocial care (Reigada et al., 2015) often performing tasks perceived as troublesome or difficult (Ono, Kanayama, Iwata, & Yabuwaki, 2014).

During caretaking roles, family members engage in a close relationship of common physical, emotional, and intentional experience (Ono et al., 2014), in which emotional states may be mirrored, potentially leading to escalating negative responses (Schulz & Martire, 2004). Elder, Johnson, and Crosnoe (2003) posited lives are lived interdependently and social, historic, and cultural influences are expressed through a shared relational network of family and friends. Transitions, such as end of life, or the experience of dementia represent a set of quantitative and qualitative changes in life course; and, both the individual with dementia and others, who are close in relationship experience transitions.

2. Family member quality-of-life

The principle of interdependent lives (Elder et al., 2003) speaks to the importance of dementia, such as Alzheimer’s disease and other forms of cognitive impairment, as a change agent in the lives of all who are closely linked to the PWD. Individualized music has been identified as an intervention that enhances communication with and relieves anxiety thus, improving quality-of-life for PWD (Gerdner, 2015; Hulme, Wright, Crocker, Oluboyede, & House, 2010) and may provide support for family members (Sarkamo et al., 2014; Snyder et al., 2016) as they take on different roles, while caring for and relating to family members with dementia (Reigada et al., 2015). Schulz and Martire (2004) concluded that family members provide great value to PWD and society in general at great personal cost.

Listening to familiar music has emerged as a promising source of support for persons with dementia (Gerdner, 2015; Sarkamo, et al., 2014). Music reminds listeners of earlier times (Sarkamo et al., 2014), while unifying the relational network in a social experience (Creech et al., 2014). Music and making music is characterized as an innately human activity that brings quality to life and social interactions with others. Creech et al. (2014) and can be supported by those without professional credentials (Clair, Mathews, & Kosloski, 2005). Gerdner (2015) in particular, has reported that culturally significant and personally meaningful music is especially, important for benefits to PWD and family members are in the best position to assemble the individualized music playlists.

3. Formulating the problem

One striking aspect of dementia is the loss of identity and the resultant disturbances for family members who experience losing a loved one to the disease over months or years. Elder et al. (2003) postulated in life course transitions that radical changes, such as dementia influence the entire social system surrounding the affected individual. In family groups or small communities, losing one member resonates throughout the relational network, changing the quality and nature of
relationships. New identities will emerge in older adults experiencing life transitions and in individual members of their social networks (Elder et al., 2003), engaging in music provides an opportunity to develop positive, alternative visions of self (Creech et al., 2014).

Listening and making music has been shown to have a positive effect on older individuals (Creech et al., 2014); and to have a positive effect on both persons with dementia (PWDs) and family members (Saarikallio, 2011; Sarkamo et al., 2014); further, Gerdner (2015) indicated the importance of individually preferred, culturally or ethnically congruent music as a way to communicate with and in calming agitation for PWD as compared to music in general. Family members will take on challenges (Ono et al., 2014) in assuming multiple new roles to insure a relative with dementia receives personal care, medical services, and psycho-emotional and psychosocial care (Reigada et al., 2015). However, the role of providing and sharing individualized music for relatives with dementia is different from other family roles described in literature as troublesome or difficult (Reigada et al., 2015) and less understood.

As researchers we were interested in how family members experienced providing music for a relative who was changing due to dementia. Many family members of PWDs may not be aware of the potential value listening to and actively engaging in music throughout life (Creech et al., 2014; Saarikallio, 2011; Sarkamo et al., 2014), thus, missing an opportunity to improve personal quality-of-life, while continuing to support and engage with a related PWD. Exploratory research was needed on how family members construct meaning about the roles they play when successfully developing, sharing, and experiencing familiar music with relatives who are PWDs in instances, where listening and making individualized music led to positive outcomes.

4. Research questions
To assist in resolving the problem, the following research questions were asked: What experiences do family members of people with dementia share about use of music?

SRQ1: How do the family members describe developing a personal playlist for the PWD? Otherwise, how did they provide music to their loved one?
SRQ2: How do family members describe PWD response to individualized music or music listening in general?
SRQ 3: How do family members characterize individualized music listening as a shared activity with PWDs? In particular, is there narrative evidence that music listening increased or improved social interaction among the PWD and family members of the PWD?

The current qualitative content analysis explored how family members characterized their experience with individualized music in online remarks and testimonials. In particular, 35 family member self-reports shared at the Alive Inside Foundation web site provided a purposive sample to answer the research question and related sub-research questions.

5. Method
The qualitative, conventional content analysis approach used here, allowed researchers to explore the construction of personal meaning (Hsiu-Fang & Shannon, 2005) and develop explanations without pre-existing codes (Kim & Gillham, 2013). New technologies enable public sharing of personal experience and afford researchers a wealth of narrative data for qualitative content analysis. Such data exists in online blogs, email interviews, instant messaging interviews, Skype-enabled interviews, and live conference software that supports live interviews (Wilson, Kenny, & Dickson-Swift, 2015). Content analysis is preferred to explore poorly understood contexts or phenomenon, where little previous research has been published (Denzin & Lincoln, 1994). The content analysis design is appropriate to unobtrusively gather content that has been generated without considerations of researcher interests or influences.
Previous research has established the positive effect of music and music-making for individuals with dementia and caregivers when provided by family caregivers rather than professional care staff (Sarkamo et al., 2014). The purpose of this qualitative content analysis research was to explore the experiences of family members who had provided care and support to relatives with dementia and reported positive outcomes. One goal of the study was to explore how to support family members role as individualized music provider as part of their caregiving functions for the PWD. Accordingly, as researchers, we intentionally focused on stories of individuals, who described positive experience with their PWD family members favorite individualized music.

5.1. The sample

Criteria for this purposive sample of stories were that family members had reported in their own words direct and recent positive experience either providing music to or observing individualized music played for a family member with dementia. Content consisted of 35 stories gathered from The Alive Inside Foundation website (https://www.aliveinside.org). The foundation has made public family members’ stories about positive personal experiences with music and their loved one with dementia as part of the Community Outreach project. Some stories are from the film Alive Inside and were posted during the time frame of 2014–2016 (https://www.aliveinside.org/outreach/). Family member comments were sharply focused on the individualized music experience in the context of the open-ended opportunity to “share your story”. The website established the hashtag #aliveinside-stories for this purpose and their staff have to date uploaded 35 such stories.

Five men and 30 women shared stories about their family members with dementia and nearly all contained personal experiences providing music. The word count averaged 149 words per story (total 5,519), ranging from six to 623 words. Relatives were daughters (19), granddaughters (7), sons (4), a daughter-in-law (1), and a grandson (1) and non-specified (2). The stories identified six as caregivers, 11 non-caregivers but most (n = 22) did not specify. Seventeen of the PWDs were described as having a form of dementia (specifically, Alzheimer’s, n = 15), and the remaining did not specify whether dementia was present or not (n = 18). Given the context and mission of the Alive Inside film and foundation, a safe assumption is the majority of the #aliveinside-stories refer to family members with some form of dementia.

5.2. Procedures

5.2.1. Content gathering

Once the content was identified, the text was downloaded from website and placed into a word processing document. In the first step, the four-member research team cleaned the data and protected the identities of contributors by removing any last names. Cleaning the data included checking for duplication and correcting inappropriate punctuation, and normalizing all the text to read as first person accounts, whereas some stories at the website were introduced, and the family members’ contribution appeared within quotes. All text from the family member remained intact. Data cleaning was conducted individually and then collectively easily reaching consensus.

5.2.2. Data analysis

The pattern of reading separately and then together to adjudicate the findings was followed in the first step and throughout the analysis. The first phase of analysis was categorical and used to describe the sample demographically. The qualitative, descriptive analysis began by identifying “who” and “what” kind of contribution was made. The stories included clear descriptions of who told the story, and as researchers, we provided a word count of each story and the nature of the comments (detailed narrative, simple endorsement or a combination; and some stories were considered to be “off topic” for the present purposes).

We used a conventional content analysis, which is most appropriate when theoretical understanding of a specific phenomenon is limited (Hsiu-Fang & Shannon, 2005) as is the case in the current study. Ziegler, Paulus and Woodside (2006) described the inductive process using a hermeneutic circle.
approach, which we employed. Steps in the process, included (a) developing a holistic understanding, (b) comparing impressions with other team members, (c) identifying units of meaning, individually and then collaboratively, (d) synthesizing findings. In the synthesizing step, the research team developed tentative models that explain the experience after agreeing on the meaning units and aspects of the experience. The research team worked individually and collectively to identify codes and themes in the responses identified as related to the specific research questions. Complete phrases were identified that could be used to generate codes or briefer phrases that helped to categorize or characterize family member contributions. In the first steps, we used four different colored markers to identify text related to research questions. In later phases of thematic analysis, team members also returned to the original text free form coding in the original context to ensure no instances of the final thematic categories had been missed as well as ensuring no new thematic categories were required. Tables in the results section include themes, codes and related comments from the analysis. Research sub-questions are presented first and the overarching question is used to summarize findings in the discussion.

6. Results

6.1. SRQ1: How do family members describe developing a personal playlist for the PWD?

We identified 25 responses that related specifically to family members providing music for their loved one. Two themes emerged: (a) Selection/choosing music for the family member and (b) How music was provided in practice? Table 1 shows codes and family comments on choosing music from memories of favorite specific music or artists (n = 9) or genres (n = 17) beloved by the PWD.

A second theme indicated how music was provided. Two codes emerged in the analysis: (a) Listen: Family members generally reported playing recorded music for the PWD, often specifying CD format or digital music and/or devices and (b) Sing: Some family members reported singing to or giving a live music performance to their loved one with dementia. Eight participants did not provide any details on how the music was provided.

| Table 1. Selecting favorite music for PWDs |
|------------------------------------------|
| **Theme: Selection**                     |
| Codes were favorite specific songs or musical works (9 responses) |
| P1. I knew she loved Diana Ross and the Supremes “I Hear A Symphony” |
| P2. “Fiddler on the Roof” and Sinatra and the music of his youth and happy times with my mom |
| P3. His favorite show-tunes and stuff, or you’d sing a song like “Take Me Out to the Ballgame” |
| P4. She likes Charlie Pride, she likes Merl Haggard, she likes The Sound of Music, Frank Sinatra, etc. So we’re going to get all of my mother’s music |
| P5. And P6. She sings, “Pio pio pio, dicen los politos,” she loves that one |
| P11. We found that she loves to hear music especially some of her favorites like Marc Antony and Bette Midler |
| P15. Some of her favorites are “Brown girl in the ring”; “Amazing Grace”, “The Rose” and “Love lifts us up where we belong” |
| P29. Playlist of our lives! Matt Munro singing “Walk Away,” “Barn Free,” “For the Good Times” |
| P35. Operas in which she participated when she worked at the Grand Opera House in Lodz |
| Codes were favorite artist or genre (8 responses) |
| P2. We’d play “Fiddler on the Roof” and Sinatra and the music of his youth |
| P8. Hymns and Christmas carols |
| P10. Lawrence Welk or polka music |
| P3. I’m lying in bed with him, I’m holding his hand, and we put on Fiddler on the Roof, “Sunrise, Sunset” |
| P18. We began to sing Christmas carols to her |
| P22. Singing familiar songs to her |
| P23. My mom loved music. She sang in the choir at church and loved the old hymns |
| P35. All operas I could think of |
6.1.1. Listen using digital technology
In total seven family members described the specific player technology used to provide recorded music; CD players were named by three, and four named a portable electronic device, with one each naming an iPad, iPod, MP3 player, and smartphone with a bluetooth speaker. Headphones were named in four cases and only one family member specifically mentioned using a splitter for listening to music together with two sets of headphones. Eight family members mentioned singing or performing music.

6.2. SRQ2: How do family members describe PWD response to individualized music or music listening in general?
Two themes emerged in the analysis of the family members descriptions of PWD responses to music (specifically observed behaviors and inferred emotions).

Table 3 includes the codes and family member responses that indicated specific observed behaviors. Sixteen family members provided responses that related to PWD response to individualized music.
6.3. SRQ 3: How do family members characterize individualized music listening as a shared activity with PWDs? In particular, is there narrative evidence that music listening increased or improved social interaction among the PWD and family members or others?

Two major themes emerged in response to SRQ3. These themes were (a) benefits to the PWD and relationships with family members and (b) benefits to family members.

Table 3. PWD responses to individualized music

| Theme: Observed Behaviors | Code: Facial expression (3 responses) |
|---------------------------|--------------------------------------|
|                           | P10. Smiles as she listened           |
|                           | P11. A fun beat makes her smile       |
|                           | P18. She clapped, smiled              |

| Code: Sing along (7 responses) |
|-------------------------------|
| P1. My sister sat up, started to sing along, even doing all the Supremes hand-motions! |
| P3. He’s trying to hum along, like he knew that. All of a sudden he knew all the words |
|     He’d hum with my wife, who sings opera, she has a good voice, and it was beautiful |
| P9. Mom who had been pretty much out of it began to sing “Edelweiss” |
| P18. She was able to sing along to each of the carols and hymns |
| P24. What was a blank stare before becomes a smile and tapping feet. Laughter and constant mumbling |
| P27. Within minutes she started to nod with recognition and tears began to stream down her cheeks |

| Code: Hold hands, tap feet, move (4 responses) |
| P11. She even sometimes tries to move and dance |
| P28. Bounces her head and waves her hand to the beat. Laughs and jokes |
| P34. Would perk up. Often, they would smile, tap toes or air conduct |

| Code: Verbal reply (3 responses) |
| P1. When the song ended, Delia turned to Jeff, her husband, gave him a little shove on the arm, and told him what a funny guy he was |
| P15. When I am in her presence I sing, dance, walk, laugh and hold her hands. I sing her favorite songs and my favorite songs. Some of her favorites are “Brown girl in the ring”; “Amazing Grace”, “The Rose” and “Love lifts us up where we belong. After spending a little time together and if asked, who am I? She will say,” My daughter? |
| P23. She (PWD) said, “I love you” |

| Theme: Inferred emotions |
| Code: Animated (3 responses) |
| P2. We’d play “Fiddler on the Roof” and Sinatra and the music of his youth and happy times with my Mom and it moved him so much. It was the most animated he was |
| P14. He just lights up … I can see it in his eyes |
| P35. She came to life. Her eyes opened wide and guided by my singing, she joined me throughout the piece, looking like she’s experiencing some great joy and pleasure |
| P18. By chance, we began to sing Christmas carols to her and all of the sudden she opened up in a way that we hadn’t seen for years |
Sixteen family members provided responses that related to PWD response to individualized music.

The second theme, which is displayed in Table 5 was family member benefits. Ten family members provided comments about personal benefits.

**Table 5. Family member benefits**

**Theme: Family member benefits**

**Code: New positive memories (6 responses)**

P3. He died in our arms. It was so beautiful. We held him and we released him. It was gorgeous. It was so incredibly beautiful. We just held him and when he was leaving we were just like, “Go Harold, go, you go!”

P9. One of the fondest memories I have is when Mom’s former recreational therapist Martha, came to visit her while she was on hospice. Martha brought along her guitar and played for my Mom and some of the other residents of the nursing home.

P23. She looked me square in the eye “Said, ‘I love you.’” I hadn’t heard her speak other than sounds or nonsensical words for months. That moment will stay with me forever.

P24. What was a silent room becomes full of laughter and constant mumbling. They might not be full sentences or even words, but for just a moment in time he is there with us. Those few minutes mean the world to me.
7. Discussion
A number of themes emerged in response to the overarching research question: What experiences do family members of people with dementia share about use of music? These themes are described in Tables 1–5 and summarized here. We found that family members constructed new positive memories when they found a connection with or saw the PWD engage in the music (Table 5). An emotional relationship or connection, was restored, even if briefly. Transformative moments came when family members reframed self-identities as they listened or made music with PWD. Family members described new roles of great meaning, such as becoming allies, guides, supporters, or conduits to an end of life experience. These positive new roles contrasted sharply with the roles described as difficult and troublesome when providing care and support to a PWD (Ono et al., 2014). In family member stories, listening to or making music was characterized as a powerful aid to adjusting and transitioning to changing conditions within the family network.

Family members in the current study reported social, personal, and a relational benefit when making or listening to music became a shared event. Creech et al. (2014) indicated that music allowed older individuals to experience “purpose, autonomy/control/ and social affirmation” (p. 36) and become communicators and allies who reframed the experience through transformative insights. In the present study, family members described positive, active roles when facing the onset of dementia in a relative, where connections, communications, and interactions were momentarily restored through music interventions. Schulz and Martire (2004) suggested five strategies to support family members of PWD. The present qualitative, exploratory study clarified music as a support for family members in as many as three of the aspects. These were that (1) individualized music is an intervention that alters the environment; (2) that may be therapeutic to the caregiver; and (3) that individualized music experiences are an intervention that reduces the caregiver burden.

An intervention that alters environment: Sarkamo et al. (2014) reported that listening to music enhanced quality-of-life for both caregivers and family members. Creech, Hallam, McQueen, and Varvarigou (2013) found making music with others strengthens social networks and diminishes depression. In the present study, family members described connecting, communicating, sharing, interacting, engaging, improving relationships, and social sharing when they listened to or sang familiar music with PWDs (see Table 4).

Therapeutic for the caretaker: Choosing individualized music was important to the family members in this study (Table 3) and consistent with other research findings that PWD’s favorite music selections resulted in the greatest positive changes in behaviors (Garland, Beer, Eppingstall, & O’Connor, 2007; Hicks-Moore & Robinson, 2008). Ridder, Wigram, and Ottesen (2009) described...
singing as a way to engage PWDs in communicative interactions. Sarkamo et al. (2014) established that listening or singing music could evoke memories or other episodic memories from a past when the PWD had a wider range of cognition. Improved mood for both family members and PWD was also indicated as an effect of listening to or making music on a regular basis.

Reduces caretaker burden: Family members described occasional unexpected speech; the PWD would respond verbally after periods of muteness or greatly reduced verbal communication (Tables 3 and 4). Consistent with similar incidents as illustrated in the film Alive Inside (Rossato-Bennell, 2014), family members in the present study prized these moments as a restorative change to the PWD who seemed like their “old self”. The elements of familiar music (Table 1), such as rhythm, pitch, melody, harmony, and beat, may resonate with PWDs because of the historical and social context of previous life stage progressions. Gerdner (2015) suggested the organized and familiar elements of music served to organize an internal, chaotic PWD experience and calmed anxiety.

In the present study, family members characterized specifically observed behaviors and inferred emotions as PWD responses to music (Table 3). Family members indicated that facial expressions such as smiling or animation could show memories about the present and past experiences of joy in music. The PWD appeared engaged, animated, sometimes smiling and making eye contact and connecting in ways that did not happen without music. These findings are consistent with Gotell, Brown, and Ekman (2003) who reported that PWDs were smiling and able to make eye contact when the caregiver was singing. In a qualitative study, listening and singing were both found as helpful for self-control of emotions (Saarikallio, 2011). Creech et al. (2013) described multiple social, affective, and other benefits for older adults from actively making music.

Conclusions: Family members described positive responses to individualized music (Table 3). Gerdner (2015) indicated individually preferred music lessened anxiety and stimulated memory in PWD; further, ethnicity was identified as an important element in selecting individualized music. One implication of the present study is that music educators could provide a new emphasis on the value and culture of music and prepare students enjoy culturally relevant music throughout life and that could have a positive impact on their memory, emotional state, sense of identify and relationships during later life.

A new learner-centered approach to teaching culturally relevant music is emerging in UK schools (Evans, Beauchamp, & John, 2015). Musical futures engages learners in popular and community-centered music. We suggest that in a learner-centered approach, music educators could introduce learners of any age to the concept of a personal playlist, teach them to use a variety of digital technologies to store and play their personal playlists and how to maintain their playlist throughout their life course. Including the concept, function and development of a personal playlist in the K-12 music curriculum could also be helpful. A further suggestion is that music educators could support and teach the value of music for aged individuals and their families by encouraging individuals of any age to listen to and create music, develop the skill of constructing an individualized play list, and include developing individualized playlists in informal music curriculums.

Limitations: The understandings gained in the present study are limited by the scope and qualitative nature of the analysis and cannot be generalized to larger populations. A second limitation is that we did not develop the interview questions; having conducted this analysis, we would consider a second study where we shape inquiry. However, as researchers, we experienced some transformative insights about music in our lives. We are committed to learning to manage technology, music choices, and our social network to develop a rich and meaningful experience centered on music for ourselves as we transition later life.
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References
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References
Beard, R., Knauss, J., & Moyer, D. (2009). Managing disability and enjoyable life: How we reframe dementia through personal narratives. Journal of Aging Studies, 23, 223–235. doi:10.1016/j.jaging.2008.01.00
Clair, A. A., Mathews, R. M., & Kosiakko, K. (2005). Assessment of active music participation as an indication of subsequent music making engagement for persons with midstage dementia. American Journal of Alzheimer’s Disease & Other Dementias; 20, 37–40. https://doi.org/10.1177/153331750502001005
Cotel, N. V., Rodriguez, N. F. A., Perez, J. A. F., Iglesias, J. C. A., & Logo, M. R. (2016). Burden and associated pathologies in family caregivers of Alzheimer’s disease patients: A comparative study in Spain. Journal of Neurological Neurophysiology, 7(Suppl.), 2.
Creeth, A., Hallam, S., McQueen, H., & Varvarigou, M. (2013). The power of music in the lives of older adults. Research Studies in Music Education, 35, 87–102. https://doi.org/10.17711/1321103X13478862
Creeth, A., Hallam, S., Varvarigou, M., Gaunt, H., McQueen, H., & Pinacs, A. (2014). The role of musical possible selves in supporting subjective well-being in later life. Music Education Research, 16, 32–49. doi:10.1080/14613808.2013.878143
Denzin, N. K., & Lincoln, Y. S. (1994). Handbook of qualitative research (2nd ed.). Thousand Oaks, CA: Sage.
Elder, G., Johnson, M., & Crosse, R. (2003). The emergence and development of life course theory. In J. T. Mortimer & M. J. Shanahan (Eds.), Handbook of the life course (pp. 3–19). New York, NY: Plenum Press. https://doi.org/10.1007/b100507
Epiphaniou, E., Hamilton, D., Bridge, S., Robinson, V., Rob, G., Beynon, T., & Harding, R. (2012). Adjusting to the caregiving role: The importance of coping and support. International Journal of Palliative Nursing, 18, 541–545.
Evans, E., Beauchamp, G., & John, V. (2015). Learners’ experience and perceptions of informal learning in Key Stage 3 music: A collective case study, exploring the implementation of Musical Futures in three secondary schools in Wales. Music Education Research, 17(1), 1–16. doi:10.1080/14613808.2014.950212
Garland, K., Beer, E., Eppingstall, B., & O’Connor, D. W. (2007). A comparison of two treatments of agitated behavior in nursing home residents with dementia: simulated family presence and preferred music. The American Journal of Geriatric Psychiatry, 15, 514–521. https://doi.org/10.1097/01.JGP.0000249388.37080.b4
Gerdes, L. (2015). Ethnicity Is an inherent criterion for assessment of individualized music for persons with Alzheimer’s disease. Clinical Gerontologist, 38, 179–186. doi:10.1080/07317115.2014.988900
Gotell, E., Brown, S., & Ekman, S. L. (2009). Influence of caregiver singing and background music on posture, movement, and sensory awareness in dementia care. International Psychogeriatrics, 15, 411–430. https://doi.org/10.1017/S1471301209900657
Hicks-Moore, S. L., & Robinson, B. A. (2008). Favorite music and hand massage: Two interventions to decrease agitation in residents with dementia. Dementia, 7, 95–108. https://doi.org/10.1177/14713012070785369
Hsiu-Fang, H., & Shannon, S. (2005). Three approaches to qualitative content analysis. Qualitative Health Research, 15, 1277–1288. doi:10.1177/10497323050376687
Hulme, C., Wright, J., Cracker, T., Ouliboysye, Y., & House, A. (2010). Non-pharmacological approaches for dementia that informal carers might try to access: A systematic review. International Journal of Geriatric Psychiatry, 25, 756–763.
Kim, B., & Gilham, D. (2013). The experience of young adult cancer patients described through online narratives. Cancer Nursing, 36. doi:10.1097/NCC.0b013e318291b4e9
Kongsuwan, W., & Chiapetch, O. (2011). Thai Buddhists’ experiences caring for family members who died a peaceful death in intensive care. International Journal of Palliative Nursing, 17, 329–336. https://doi.org/10.12968/ijnj.2011.17.7.329
Ono, K., Kanaizuma, Y., Iwata, M., & Yabuikawi, K. (2014). Views on co-occupation between elderly persons with Dementia and family. Journal of Gerontology and Geriatric Research, 3, 185. doi:10.4172/2167-7182.1000185
Pinquart, M., & Sörensen, S. (2003). Associations of stressors and uplifts with caregiver burden and depressive mood: A meta-analysis. The Journals of Gerontology: Series B, 58, P112–P128. https://doi.org/10.1093/geronb/58.2.P112
Prince, M., Prina, M., & Guruchet, M. (2013). International Alzheimer Report 2013: Journey of caring: An analysis of long-term care for dementia. Global Observatory for Ageing and Dementia Care. London: Kings College. Retrieved from https://www.alz.org.uk/research/world-report-2013
Reigada, C., Pais-Ribeiro, J. L., Novellas, A., & Gonçalves, E. (2015). The caregiver role in palliative care: A systematic review of the literature. Health Care Current Reviews, 3, 143–xxx. doi:10.4172/2375-4273.1000143
Ridder, H., Wigram, T., & Ottesen, A. (2009). A pilot study on the effects of music therapy on frontotemporal dementia-developing a research protocol. Nordic Journal of Music Therapy, 18, 103–132. doi:10.1080/08098113090362371
Rossa-Bennell, M. (2014). Alive inside, film, projector media. Retrieved from www.aliveinside.com
Saarikallio, S. (2011). Music as emotional self-regulation throughout adulthood. Psychology of Music, 39, 307–327. doi:10.1177/0305735610374894
Sarkamo, T., Tervaniemi, M., Laitinen, S., Numminen, A., Kurki, M., Johnson, J. K., & Rantanen, P. (2014). Cognitive, emotional, and social benefits of regular musical activities in early dementia: Randomized controlled study. The Gerontologist, 54, 634–650. https://doi.org/10.1093/geront/gnt100
Schulz, R., & Martire, L. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. The American Journal of Geriatric Psychiatry, 12, 240–249.

Snyder, M., Lee, A., Jenson, C., Gomez, G., Overath, T., White, H., & Germain, C. (2016). Personalized Music in Adults with Dementia: Effects on Caregivers. Journal of American Medical Directors Association, 17(2), B 28. doi:10.1016/j.jamda.2015.12.086

Wilson, E., Kenny, A., & Dickson-Swift, V. (2015). Using blogs as a qualitative health research tool: A scoping review. Journal of Qualitative Methods, 1–12.

Ziegler, M., Paulus, T., & Woodside, M. (2006). Creating a climate of engagement in a blended learning environment. Journal of Interactive Learning Research, 17(3), 302.