

\*\*\*WHITE PAPER\*\*\*

Personalized Music for Persons with Dementia and their Life Quality:  
Report on a Pilot Study of In-Home Use

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Wisconsin's Music & Memory Program has enabled persons living with Alzheimer's disease and other forms of dementia in over 250 long-term care residences to enjoy their favorite music by listening to iPod shuffles either through headphones or speakers. Staff members at these residences have received certification from Dan Cohen's National MUSIC AND MEMORY<sup>SM</sup> program by participating in training webinars meant to help them understand the purpose of the program and how to introduce it into their facilities. They continue to hone their skills and trade insights on the use of Music & Memory through monthly webinars organized by the Wisconsin Department of Health Services.

In Wisconsin, researchers are examining how personalized music for long-term care residents with dementia may help to reduce agitation and anxiety as well as the use of psychotropic drugs to control behavioral and psychological challenges often associated with dementia. Other state research programs are investigating the effects of the Music & Memory programs in residential care facilities on staff job satisfaction and retention. The Wisconsin Department of Health Services asked us to investigate the delivery of personalized music via iPod shuffles to persons living with various forms of dementia in their own homes.

In this report, we begin by reviewing the literature on personalized music for people with dementia, most of which describes studies conducted in long-term care residences. Next, we describe how we recruited participants and conducted our study using two points of data collection about three months apart. We report the results of our surveys and interviews, evaluate the limitations of our study, and offer insights into challenges and opportunities for programs like Music & Memory that provide personalized music in people's homes.

## Why is Music Important to People with Dementia?

One could answer the question of why music is important to people with dementia by simply stating that making and enjoying music is a significant, meaningful aspect of being human. The renowned neurologist Oliver Sacks often described how music affected his patients with various neurological disorders. Sacks is best known for his observations about music in his book *Musicophilia* (2007), but in an earlier book chapter, he wrote that music “can affect us as nothing else can, and at every level of the body and mind” (1998, p. 1).

Sacks wrote about how his patients with dementia could experience “organization and orientation and calm” (1998, p. 11) when listening to music. He also noted that while memory loss may appear to degrade personal identity, identity is “so deeply ingrained in the nervous system that it is never wholly lost” (p. 11). The identity formation process is intimately entwined with familiar, preferred music from childhood through early adulthood, as research on the so-called “reminiscence bump” (Holmes & Conway, 1999) has demonstrated. Sacks observed that in persons with quite advanced dementia, there is a “continuing possibility of being affected by music” (p. 11).

According to Sacks, familiar music—what the Music & Memory program calls “personalized music”—acts as a kind of mnemonic, or memory aid, to give people access to emotions and memories once thought lost. Anyone who has watched the film *Alive Inside* about the National MUSIC AND MEMORY<sup>SM</sup> program can see this in Henry’s response to putting on headphones and listening to well-loved, well-learned music. Henry, who rarely spoke, began to talk about the music. He communicated his pleasure not just with words, but also with rhythmic gestures.

Researchers are just beginning to understand the way the brain is organized such that people who appear to have lost so much ability to remember can still recognize their favorite music from the past. Petr Janata, of the Center for Mind and Brain at the University of California Davis, has been trying to understand the connection between music and memory through a series of research studies. In one study, Janata examined the content of undergraduates’ “music-evoked autobiographical memories” (MEAMs) and found that their memories were predominantly of personal experiences, positive emotions, and nostalgia for the past (Janata, Tomic, & Rakowski, 2007). In another study using functional magnetic resonance imaging (fMRI), Janata found that autobiographical memory, familiar music, and positive emotions are all associated with activation of the dorsal region of the medial prefrontal cortex (MPFC; Janata, 2009). While speculative at this point, Janata believes that the MPFC remains intact longer as Alzheimer’s disease progresses.

Family members and professionals who work with individuals with dementia know that even those with severe cognitive deficits can often sing multiple verses and choruses of favorite songs. Like Henry in *Alive Inside*, they also demonstrate MEAMs after listening to well-learned music. Neuroscientists studying music are beginning to understand the importance of the MPFC in processing music and

associating it with emotion and memory. They are also identifying many other parts of the brain involved with recognizing and moving to the rhythms of music. In their extensive review of this research and its relation to dementia, Särkämö et al. (2012) stated that “this large-scale activation and modification of the brain, especially the emotional and memory circuits, in response to musical experience may partly explain the power of music to stimulate emotional and cognitive functions in dementia” (p. 155).

If music can evoke positive mood states, it may also reduce negative states associated with anxiety and agitation (Gerdner, 1997; Sung, Chang, & Lee, 2009). This has been the focus of considerable research, primarily in the area of music therapy practice (e.g., Raglio et al., 2013; McDermott, Crellin, Ridder, & Orrell, 2012; Sakamoto, Ando, & Tsutou, 2013). Music therapy involves direct, personal contact with a professionally trained therapist. Using a variation on music therapy, Janata (2012) conducted research on what he called “music medicine.” Music medicine means that people (particularly those in hospitals or long-term care residences) have the opportunity to hear music through the day. In this study, Janata asked music therapists to identify the music preferences of nursing home residents with dementia and when they might enjoy listening to music. He then arranged for the music to be played in their rooms for three hours a day, seven days a week for 12 weeks. Janata found the strongest effect for reducing agitated behaviors in the mornings. Interestingly, he also found that residents in the control group (who had no music their rooms) often wandered into the residents’ rooms where music was playing. This observation supports an earlier research finding that people with dementia who participated in music activities with a music therapist showed an increase in their social behavior (Pollack & Namazi, 1992).

A meta-analysis of nineteen studies concluded that music interventions can increase quality of life for people with dementia by producing short-term improvements in cognitive abilities such as attention and autobiographical memory and in physiological measures (e.g., heart rate, breathing rate, blood pressure) (Vasionytè & Madison, 2013). However, there were mixed findings about music’s role in reducing anxiety and agitation, perhaps due to how the music was presented, the type of music, and the individuality of the persons with dementia (e.g., some become over-stimulated by certain sounds).

As many of the papers reviewed in the meta-analysis noted, one of the challenges with this research is that it fails to meet the scientific standards applied to other types of “interventions” for persons with dementia. The research tends to lack randomized assignment to treatment and control groups, has small numbers of persons enrolled in the studies, and varies in the presentations of the music and the outcome measures which makes comparing studies difficult. It is particularly challenging to draw conclusions about any long-term benefits of engagement with music given the fact that dementia is a progressive condition.

These critiques have been applied not only to various types of music programs, but also to other ways of engaging people with dementia with the arts. In a brilliantly titled paper called “Shall I compare three to a dose of donepezil?”, de

Medeiros and Basting (2013) acknowledged these critiques but argued that the same standards should not be applied to cultural arts programs as to trials of new medications. Music and other art forms can help develop individual and social meaning systems, something pharmacology does not do. Moreover, people vary in what is meaningful to them as is demonstrated by the studies that find various ways of presenting music affect people differently. An important point made by these authors is that cultural arts involve a social network of staff, other residents, and family members. This social aspect is highly significant due to the fact that dementia can be a “disease of exclusion” (Corner & Bond, 2004, p. 153).

Feelings of exclusion can be particularly acute for persons living with dementia in their homes who are cared for by a spouse or adult child. Friends may drift away because they no longer know how to interact with a person with memory loss and other cognitive, behavioral, and emotional challenges of dementia. These challenges are most directly felt by care partners. This is one reason why we wanted to investigate the use of personalized music in people’s homes since there has been some indication from studies in long-term care residences that it can be effective in addressing problems like depression, anxiety, anxiety, and depression. These are often labeled as “behavioral and psychological symptoms of dementia” (BPSDs), although we prefer the designation suggested by the Dementia Action Alliance: “bio-psycho-social distress” (also BPSD). This term refers to the multiple, interacting sources of distress rather than implying that the distress is an outcome of dementia alone (e.g., a symptom) (Dementia Action Alliance, 2016).

### **Personalized Music in Private Homes**

Most research on personalized music for people with dementia has been conducted in long-term care settings. We know of only one published paper about research conducted in people’s homes. It described research that did not use the approach of the national MUSIC AND MEMORY<sup>SM</sup> program with playlists of favorite music loaded onto iPod shuffles. Rather, the researchers learned about 15 participants’ favorite music and gave their care partners CDs to play for 30 minutes prior to the time they had identified as peak agitation periods. This occurred twice a week for two weeks, followed by two weeks when care partners did not play the CDs. The results showed that agitation after listening to the music was lower than before listening, but the reduction of agitation did not generalize to the two week period when there was no music listening. In other words, it was a short-term effect, much like what has been observed in the national MUSIC AND MEMORY<sup>SM</sup> program research in long-term care.

An unpublished study by the Alzheimer Society of Toronto iPod Project examined family caregiver distress, caregiver confidence about providing care, and depression in the person with dementia (Williams, Peckham, Rudoler, Tam, & Watkins, 2014). Some cared for relatives at home, while others visited loved ones in residential long-term care settings. This study used the technique of the national MUSIC AND MEMORY<sup>SM</sup> program in both settings and compared findings about care partners and cared-for persons at the beginning of the study and three months later. The researchers reported a number of benefits of participation, including greater

enjoyment of interactions with other people, most likely due to greater calm. Although measured caregiver distress declined, the difference between Time 1 and Time 2 was not significant. However, the decline in negative feelings about the impact on personal life and health was significant. The caregivers also felt significantly greater ability to engage socially with others.

The study concluded that the personalized music may have had a greater impact on individuals living in residential care and their caregivers because residents experienced more agitation, anxiety, and depression. Nevertheless, Williams et al. (2014) argued for continued use of personalized music loaded on iPods regardless of where the individual with dementia lives. It should be noted that in addition to providing the iPods, the Alzheimer's Society of Toronto also offered other services to participants like support groups, creative therapy groups, one-on-one counseling, and educational workshops. Being surrounded by all of this support could have potentiated the positive results of regular use of the iPods loaded with favorite music.

### **A Pilot Study of Music & Memory in Private Homes**

#### **Participants**

A grant from Bader Philanthropies of Milwaukee, WI, enabled us purchase equipment for 24 persons with dementia and their care partners. Participants included 10 women and 14 men with dementia; all had spousal care partners except for one man and one woman whose daughters were their care partners.

Participants and care partners were recruited through announcements at local Memory Cafés and on the recommendation of the community care coordinator at a local memory assessment center. Letters were sent to individuals' homes and were followed up with telephone calls.

#### **Materials and Procedure**

Initial interviews with participant pairs in their homes determined music preferences. The researchers adapted the Music Assessment Questionnaire and the Music Genre/Artist Preference Matrix (both supplied by the national MUSIC AND MEMORY<sup>SM</sup> program) to gather information about the kind of music participants wanted on the iPods. In some cases, care partners supplied favorite CDs. We purchased music from iTunes and also had a large CD library loaned by staff at a local long-term care residence.

As soon as the music was organized into three playlists loaded on iPod shuffles for each individual, the researchers made appointments to return to participants' homes to show them how to use the equipment. Each pair of participants and care partners received the iPod shuffle, headphones, small speaker, charger, plastic box to hold the equipment, printed instructions about iPod use and charging, and suggestions for socially interactive activities when the speakers were used. In addition to demonstrating the equipment during the second visit, we answered questions about the Music & Memory program, administered the Bath Assessment of Quality of Life in Dementia (BASQID; Trigg, Skevington, & Jones,

2007) to the participants and left scales for the participants and care partners to complete and return to us within a week of our visit.

Approximately three months later, we made appointments to return. During these visits, we re-administered the BASQID, interviewed the participants and care partners about their experiences with the Music & Memory program, and left scales for them to complete and return to us.

The BASQID consists of 17 questions organized into three groups measured on 5-point Likert scales: ratings of quality of life, health, and memory (1=*very poor*; 5= *very good*); satisfaction with health, ability to look after self, level of energy, enthusiasm for doing things, usual way of spending the day, level of independence, personal relationships, and ability to talk to other people (1=*not at all satisfied*; 5= *extremely satisfied*); ratings of extent to which the individual can move around the local community, do all the activities he/she wants to do, do things he/she enjoys, has choice about things he/she wants to do, feels useful, and feels happy (1= *not at all*; 5=*a great deal*). The interviewer showed the question printed in large font and held up the corresponding scale to which the participants could point or reply verbally. The administration of the BASQID was recorded on a digital recorder and later transcribed. Occasionally the care partner assisted the participant in answering the questions and these responses were also recorded.

Participants completed the Oshkosh Music Listening Experience Scale (OMLES) approximately one week after receiving the iPods and again at the end of the study. The scale was developed for this study and consists of nine items which participants answer on a 5-point Likert scale (0=*not at all*; 4=*completely*). Examples of items are “I had total concentration,” “I found the experience rewarding,” and “I want to listen to more music.”

Care partners completed three scales at the beginning and end of the study. For the Revised Memory and Behavior Problems Checklist (Teri, Truax, Logsdon, Umomoto, Zarit, & Bitaliano, 1992), care partners rated the frequency of 24 behaviors in the previous week such as “asking the same question over and over” and “appears sad or depressed” on a 5 point Likert scale (0=*not at all*; 4=*daily or more often*). They also rated how much the 24 behaviors bothered them (0=*not at all*; 4=*extremely*).

The Gain in Alzheimer Care Instrument (GAIN; Yap, Luo, Ng, Chionh, Lim, & Goh, 2009) asks care partners to use a 5-point Likert scale (1=*disagree a lot*; 5=*agree a lot*) to indicate agreement with 10 items about whether providing care has, for example, “helped to increase my patience and be a more understanding person,” and “helped to bond my family closer.”

The final scale completed by care partners at the beginning and end of the study was the Caregiving Distress Scale as adapted by the Toronto Alzheimer’s Society (CDS: Williams et al., 2014). For this scale, care partners rate their caregiving experiences on a 5-point Likert scale (1=*strongly disagree*; 5=*strongly agree*). Sample items are “I take part in organized activities less” and “Caring for \_\_\_ has made me nervous.”

A semi-structured interview was conducted during the Time 2 visit to inquire about experiences with the Music & Memory program. Participants and care partners answered questions about frequency of use, duration, time of day, responses to the personalized music, effects on the participant and care partner's relationship, and technical issues related to the use of the iPod.

## **Results**

Letters and phone calls resulted in 12 pairs of participants and care partners agreeing to another in-home visit about three months after beginning the Music & Memory program. Unfortunately, only 10 pairs returned the second round of scales. Reasons for not participating at Time 2 included various life stressors such as an injury sustained by one participant. Transcripts of the interviews revealed that several care partners had noted declines in cognitive abilities between Time 1 and Time 2. We surmise that the individuals who chose not to participate in the Time 2 data collection may have also experienced similar challenges. In addition, although we explicitly stated in our letters and phone calls that it did not matter if they had decided not to use the iPod shuffle, we think some people may have been embarrassed to let us know that.

Because of the low return rate for the scales, we could do no statistical analyses of the data. However, we did observe trends in the mean scores that showed an increase in participants' positive responses to the music (OMLES), but a decrease in their life quality (BASQID). Similarly, we observed a drop in mean scores on the GAIN scale, but an increase in care partner distress as measured by the Revised Memory and Behavior Problems Checklist and the CDS. The interviews gave us some insights into why this may have occurred.

**Themes from interviews.** After transcribing the interviews conducted at Time 2 about the Music & Memory program and the comments made during the administration of the BASQID at Time 2, we applied the method of interpretive phenomenological analysis (IPA; Quinn & Clare, 2008) to describe and interpret the findings. We read each transcript several times, made margin notes about what participants and care partners said, and grouped the notes into themes. These themes lined up with the two components of the Time 2 discussions. Some themes related directly to the discussion about the Music & Memory program, and others became apparent when we read the discussions that occurred during administration of the BASQID to ascertain participants' quality of life.

**Themes about Music & Memory.** We identified four themes related to the responses of persons with dementia to the personalized music. Participants and care partners talked about music's calming effect, positive feelings associated with listening to favorite music, physical engagement with the music, and the way music can focus attention on other activities.

*"It's good for relaxation."* The calming effect of listening to familiar music was a common theme. Both participants and care partners noted this. One participant has tinnitus and his care partner commented, "when he says his head bothers him, this becomes something soothing that fills that space." This type of response is one

of the reasons the National MUSIC AND MEMORY<sup>SM</sup> program has become so popular in long-term care residences. Understanding how agitated behaviors among persons with dementia might be mitigated through listening to favorite music has been a major research focus for many years.

*"I enjoy it."* In addition to the reduction of arousal, the positive emotions associated with listening to preferred music have also been a major focus of research. Both participants and care partners described the enjoyment elicited by music, enjoyment that could in some cases divert attention from negative emotions. For example, one care partner stated, "When I feel his frustration at not being able to talk, we use this and can just see him relax."

*"The beat is what she got into."* In a paper on music and the brain, neurologist Oliver Sacks described the propulsive powers of music "to elicit, to drive, and to regulate movement" (1998, p. 4). One care partner observed how her husband tapped his foot in time to the music. Other forms of engagement included humming along with the music as the vocal system engaged with the rhythm and melody of songs.

*"She gets one of her projects going and puts the music on and she'll stay with it."* Some participants and their care partners indicated that listening to the music helped maintain attention when engaged in other activities. Although we did not specifically inquire about this, it is possible that before the onset of dementia symptoms, some participants always liked music playing in the background of activities like studying for an exam, doing woodworking, cooking, etc. In our interviews, we heard about people doing puzzles, sewing, and going for walks with the iPod playing favorite music. The latter was especially noted for one individual with Parkinson's disease, an observation corroborated by Sacks (1998).

Two themes emerged from care partners' comments about their perceptions of participants' responses to listening to the iPods. In addition to noting the themes just described, they also described how using the personalized music helped them to cope with their care duties. A second theme concerned their decision-making about using the iPods in terms of how Music & Memory fit within their daily lives.

*"It keeps her occupied."* By having the participants be occupied with the personalized music, care partners could accomplish various tasks in the home. Sometimes keeping the individual occupied helped the care partner "not go bonkers." When the daughter of a man evidencing various forms of "bio-psychosocial distress" felt close to the state she described as "bonkers," she put the headphones on her father and had him listen to music. Sometimes, being occupied was an alternative to lack of focus and attention. One wife offered the iPod as an alternative activity when "he's maybe just not engaged in something else." Finally, one daughter stated that beyond keeping her mother occupied, "I am trying to do anything I can to help my mother live a better life." All of these statements can be seen as expressions of the ways care partners coped through using the Music & Memory program.

*"We kind of got out of it."* This quote came from a spouse who ruefully admitted that they were not using the iPod shuffle for listening to favorite music. She said, "Things have been busy here." Another care partner stated, "The iPod is one of the first things to go off course." In other words, they realized that there was only so much they could do in the course of a day, and it was not always possible to pause and produce the iPod and headphones or speaker. Similarly, a care partner told us, "We've got things going on all the time." Finally, another simply said, "Now I have to do everything" and tending to the demands of everyday life interfered with her ability to maintain the iPod, which needed regular charging. This situation results not only from the multiple complex demands of daily life, but also from the loss of executive function persons with dementia often experience. In other words, they can no longer formulate goals and take initiative to meet them (e.g., express the desire to listen to favorite music or ask for the iPod).

The last set of Music & Memory themes depicts issues care partners and participants had when using the iPod equipment and the negative responses of some participants to the music selection. The latter problem may be due to the limited number of musical genres, artists, and groups on the list we presented participants and the difficulty many people have naming performers or songs, even well-loved ones.

*"A few times it's disappeared."* The iPod shuffles are very small so it is not surprising that they were easily misplaced. A related problem with the size was that with the exception of the few adult children serving as care partners, all the other care partners and participants were older. Some had visual challenges; others complained that their "big fingers" could not manage the tiny buttons. Although we provided plastic boxes for the equipment, sometimes the various pieces got lost. Searching for the equipment, or remembering to charge it, seemed like a burden.

*"We don't have a big enough playlist."* Even though we tried to match music preferences identified in the initial interview with the music we loaded onto the three playlists of the iPod shuffle, we did not always succeed in pleasing participants. We returned to pick up the iPods and load different music for several participants who were unhappy with the music selections. For example, one person decided he wanted some bluegrass and another commented that some of the music was "too old." Another told us, "There are a couple of sections that are really blah to me." The most alarming report came from the daughter of a participant who described how upset her mother became when listening to some Johnny Cash songs because they mentioned guns. She became convinced there were guns in her house. We could not have predicted this since in the initial interview, she noted that she liked Johnny Cash's music. These observations lead us to conclude how important it is to realize that music preferences are just that: preferences that can be quite strong. People can like one song by an artist, but strongly dislike another song by the same artist. Care must be taken in selecting the music and flexibility must be maintained in willingness to revise the playlists.

***Themes about dementia life quality.*** We believe it is important to place our findings about the Music & Memory in-home pilot study within the larger context of

the lives of our participants and care partners. The transcripts from the administration of the BASQID gave us a glimpse into some of the challenges they were living with. This appreciation of the complexity of their lives helps us understand the mixed results we obtained from the scales and also the reluctance of some persons to continue in the study by participating at Time 2.

Four themes emerged from the IPA process: (1) participants are aware of their memory difficulties and grieve the losses that accompany them, (2) participants are grateful for their care partners and are aware that their need for care results from the difficulties dementia has introduced into their lives, (3) participants are aware of the constrictions imposed on their lives due to lost functions like driving and deteriorating communication abilities, and (4) despite all this, many participants state they can still enjoy life. Research by Linda Clare and her colleagues confirms our findings. One study found that people with dementia living in care homes retain awareness about their situation in three domains: self, relationship, and the environmental context (Clare, Rowlands, Bruce, Surr, & Downs, 2008). They defined awareness as “an accurate appraisal of a given aspect of one’s situation, functioning, or performance, or of the resulting implications” (p. 2367). In another study of awareness among persons still living in their homes, Clare and her colleagues noted the interaction of awareness of the changes taking place in their lives due to dementia and their coping styles. Similar to our findings, some of their participants coped by adjusting in various ways to the changes wrought by dementia, while others coped with a self-maintaining style that explained changes as due not to memory loss but to other issues like age or a history of trouble remembering things (Clare, Roth, & Pratt, 2005).

*“Because of a lack of memory, it just...it just drains happiness.”* One of the first items in the administration of the BASQID asked participants to rate their memory. They were given a strip of paper with the possible responses ranging from “very poor” to “very good.” Most pointed to somewhere between “poor” and “very poor” though they elaborated in interesting ways by noting affective responses to memory loss as in the quote above and in describing variations in memory ability related to the type of memory or the circumstances.

For example, one man said, “I got selective memory” and went on to say that if you told him he had a “bottle of booze down the stairs” he would remember that, although he also said he quit drinking booze. Another woman differentiated between “memories” and “memory” by saying “they’re pretty good memories but I could plunk out, too.” One participant differentiated long-term memory from recently encoded memories by saying, “I can’t remember current things but I can remember things from years ago. So there’s a gap in there.” Another noted how his ability to remember varies: “My memory kind of goes up and down.”

The theme of memory returned as we moved through the items on the BASQID. For example, a woman laughed when we posed the memory item for her and said, “Oh, I don’t have memory. I can’t remember anything. It’s almost terrible.” A bit later when we asked if she is satisfied with how things are in her life, she said, “I would say a little satisfied because I got a real good mother and I can talk to my

mother...oh, no. She's dead now." Her daughter interjected, "That's exactly right. There's a memory" to which the woman replied, "My poor mother is dead, too bad." This exchange is also an example of how persons with dementia rely on care partners to assist with remembering. Many have evolved a form of collaborative cognition, which points to the second theme we noted about relationality.

*"She's my GPS."* In response to several of the items on the BASQID, participants mentioned their care partners. The man who talked about his wife as his GPS was responding to the item that asked about his ability to do things he enjoys. For another item that inquired about his satisfaction with his level of independence, he stated, "My independence. If I was alone it would be a minus, not at all. With her help, I would say a little satisfied."

Another man responded to the first item that asked him to rate his quality of life by stating, "Pretty good; my wife takes good care of me." Still another participant responded to that item by saying, "I got a good hubby." Replying to an item about his satisfaction with how he usually spends his day, one man said, "Satisfied. I like to stay home and she's got a lot to do with that."

Most of the comments about relationships and life quality referred to the spouse or adult child as care partner. One man was unusual in that he mentioned friends several times. His wife has enlisted several friends who take him to community activities for persons with dementia like Memory Cafés and a singing program. In response to an item about his ability to choose things to do on a daily basis, he said, "I think that if I want to do something, I just tell her I'm going here, or I'm doing that. I've got friends, several that I go places with them and that sort of thing." Earlier in the interview when we asked if he is satisfied with the way he spends his day, he said, "There's two other guys. It's good. Sometimes I think that to get going, to keep me going." This man responded to other items with statements that matched our third theme: awareness of other limitations.

*"I would like to get out a little bit further sometimes."* Several participants, including the woman quoted here, had to stop driving between Time 1 and Time 2. Her answer was in response to the BASQID item that asked about the extent to which she could move around in her community. A man with Parkinson's dementia talked about how he liked to drive but acknowledged, "I know no one is going to let me have it back so I do what I can." Later, when talking about his ability to do things he enjoys, he expressed resignation about his situation by saying, "I want to drive all the time and I can't do any driving. So I take bicycles everywhere. So that's just the way it is with me. Not going to worry about it. I'm not going to fight it." A man with a dual diagnosis of Alzheimer's disease and Lewy Body Dementia responded to an item about his satisfaction with his level of independence by referring to having to stop driving. He said, "No keys, no goal."

In addition to demonstrating awareness of limitations imposed by no longer being able to drive, participants also commented on limitations derived from communication difficulties. For example, one man responded to the item about whether he is satisfied with personal relationships by saying, "I have a hard time

with communication, so probably not at all.” Another stated his frustration with his inability to express his appreciation to people who help him. This came in response to the item that asked the extent to which he feels happy: “There are a lot of people looking after me and working for me and I can’t tell them how much I appreciate.”

Some people situated their communication limitations within the context of the relationship with the other person. In response to the item that asked about satisfaction with the ability to talk to people, a man said, “depends on the people and so forth and what they’re doing and stuff.” In a way, this reflects a robust finding in gerontology regarding the way older people are selective about relationships in the service of emotion regulation (see e.g., Carstensen, Fung, & Charles, 2003).

Socioemotional selectivity appeared in a woman’s response to the same item: “There’s a lot of them I don’t like that I don’t want to be talking. Don’t want to be bothered with.”

*“I really love to do things.”* Despite all their frustrations with memory and the need to rely on others, as well as the limitations on their lives, many of our participants stated that they can still enjoy life even though as one woman put it, “Getting older you don’t have the oompa you had.” She went on to respond to our last item about whether she is happy by saying, “I feel if I’m not happy, I better change a few things.” Another man who stated with a laugh, “I don’t remember but I miss a lot of stuff” ended the interview by replying to the happiness item by saying, “Most of the time I’m fine.” Similarly, a woman commented, “As I’ve gotten older and older, I can’t do any more,” but then she said about happiness, “I really think that I enjoy my life.” We heard many replies like these indicating awareness of the dramatic, irreversible changes in their lives as a result of their dementia, but at the same time, most people expressed resilience. We could offer other similar quotes from our participants, but will end with a one-word statement from a woman in response to the happiness item. Using the BASQID, we asked, “To what extent do you feel happy?” She answered, “Blessed.”

### **Summary and Conclusions**

Our study of the in-home Music and Memory program produced varied results. On the one hand, we were disappointed by our inability to persuade half of our participants to allow us to return to talk with them three months after they enrolled in the Music & Memory program. Moreover, from the limited quantitative data we obtained, we observed declines in our measure of participant life quality and increases in care partner distress. However, our interviews revealed a far more nuanced portrait of these individuals’ lives. Some appreciated and frequently used iPod shuffles loaded with their favorite music and that was reflected in an overall increase in scores on the Oshkosh Music Listening Experience Scale. We learned how participants and care partners used the iPods and some reasons why they did not use them. A number of care partners felt maintaining the iPods and being responsible for having participants use them was a burden, while others saw benefits in helping them cope with the many tasks they needed to accomplish every day.

Our efforts to measure participants' life quality could not be statistically analyzed due to the low number of responses. However, the transcriptions of discussions conducted during administration of the life quality instrument were informative, showing high levels of awareness of limitations of memory, reliance on care partners, and frustration from giving up signifiers of independence. However, many individuals also communicated a sense of resilience and continued appreciation and enjoyment of life.

Our conclusions are limited not only by the small number of respondents at Time 2, but also by the fact that we do not know how much music they listened to prior to enrollment in the Music & Memory program. We also did not request information about medication use which might have affected daily rhythms, including agitation and anxiety, as well as pleasure. We had no matched control group that did not receive personalized music. Finally, we did not conduct drop-out research to learn why half of our original participants and care partners declined the Time 2 interview. In other words, there may be a selection bias operating in the persons who did agree to the Time 2 interview.

Music & Memory is a popular program and word about it is spreading among care partners of individuals with dementia. Despite the limitations of our study, our experience leads us to make several recommendations for further implementation and study of in-home Music & Memory programs:

- The playlists should be carefully constructed, using an expanded list of possible suggestions.
- Participants and care partners should receive a printout of the playlist before the songs are loaded in order to avoid the problem we had with some individuals rejecting the song selections.
- Some individuals may have Bluetooth capabilities in their homes and could subscribe to free Pandora stations for listening either with headphones or speakers.
- Alternatives to the tiny iPod shuffles should be considered, especially for older people who are not used to this type of technology.
- We did not want to add further burden to care partners by asking them to record when the iPods were used (both in terms of time, and in terms of the situation and the participant's mood) but this would be useful information to researchers.

The fact that dementia is a progressive condition affects researchers' ability to study the effect of arts programs like Music & Memory over time. Nevertheless, we believe it is important to continue to study the role of music in the lives of people with dementia and to expand the focus beyond listening to personalized music on an iPod. One alternative comes from Finland where researchers used a Picture Gramophone to deliver music that participants could select by touching a screen. It showed the artist, gave the name of the song, and then showed lyrics as the song played (much like a karaoke machine). Staff in facilities using this machine reported an increase in social interaction among residents and an increase in positive mood

(Topo et al., 2004). Similar programs likely could be loaded onto tablet computers for use in people's homes.

We gave our participants and care partners small speakers because we wanted to offer the option of shared music listening. Some research has examined the presentation of music with a stronger social element than the Music & Memory program delivered via iPods and headphones. For example, Sherratt, Thornton, and Hatton (2004) found the greatest effect on well-being in persons with dementia from listening to live music. It produced more meaningful engagement than when recorded music was played. Live music is inherently social because at least one other person is present to sing and/or play an instrument.

A Swedish research study's methods could be applied to caregiving within private homes. Daily care tasks were conducted in a nursing home without music, with background music playing, or with the caregiver singing to or with the resident. The singing produced a "joint sense of vitality" (Götell, Brown, & Ekman, 2009, p. 422), more positive emotions, and a reduction in aggressive behaviors. Another Finnish study coached care partners in their homes to sing with and to the persons they were caring for; they also regularly listened to music together. The researchers stated, "Regular musical activities can have an important role in maintaining cognitive ability, enhancing mood and QOL [quality of life], and promoting the well-being of family members in mild/moderate dementia" (Särkämö et al., 2013, p. 648).

To conclude, we return to the wisdom and expertise of Oliver Sacks who, throughout his career as a neurologist treating people with various types of debilitating neurological disorders, repeatedly referred to the transformative power of music. Musical memory is preserved in Alzheimer's disease and other forms of dementia. Music in dementia "can still be perceived, enjoyed, and responded to. Where there is human consciousness, there can be a response to music" (Sacks, 1998, p. 13). The future holds much promise for collaboration among researchers who study the effects of arts programs like Music & Memory on quality of life in persons living with dementia, practitioners who enact and support these programs, and policy makers who allocate money to underwrite these programs.

## References

- Carstensen, L. L., Fung, H. H., & Charles, S. T. (2003). Socioemotional selectivity theory and the regulation of emotion in the second half of life. *Motivation and Emotion, 27*, 103-123).
- Clare, L., Roth, I., & Pratt, R., (2005). Perceptions of change over time in early-stage Alzheimer's disease: Implications for understanding awareness and coping style. *Dementia, 4*, 487-520.
- Clare, L., Rowlands, J., Bruce, E., Surr, C., & Downs, M. (2008). "I don't do like I used to do": a grounded theory approach to conceptualizing awareness in people

- with moderate to severe dementia living in long-term care. *Social Science & Medicine*, 66, 2366-2377.
- Corner, L., & Bond, J. (2004). Being at risk of dementia: Fears and anxieties of older adults. *Journal of Aging Studies*, 18, 143-155.
- De Medeiros, K., & Basting, A. (2013). "Shall I compare thee to a dose of donepezil?": Cultural arts interventions in dementia care research. *The Gerontologist*, 54, 344-353.
- Dementia Action Alliance (2016). Living with dementia: Changing the status quo. Retrieved from [http://daanow.org/wp-content/uploads/2016/04/Living\\_Fully\\_With\\_Dementia\\_White-Paper\\_040316.pdf](http://daanow.org/wp-content/uploads/2016/04/Living_Fully_With_Dementia_White-Paper_040316.pdf).
- Gerdner, L. A. (1997). An individualized music intervention for agitation. *Journal of the American Psychiatric Nurses Association*, 3, 177-184.
- Götell, E., Brown, S., & Ekman, S-L. (2009). The influence of caregiver singing and background music on vocally expressed emotions and moods in dementia care: A qualitative analysis. *International Journal of Nursing Studies*, 46, 422-430.
- Holmes, A., & Conway, M. A. (1999). Generation identity and the reminiscence bump: Memory for public and private events. *Journal of Adult Development*, 6, 21-34.
- Janata, P. (2009). The neural architecture of music-evoked autobiographical memories. *Cerebral Cortex*, 19, 2579-2594.
- Janata, P. (2012). Effects of widespread and frequent personalized music programming on agitation and depression in assisted living facility residents with Alzheimer-type dementia. *Music and Medicine*, 4, 8-15.
- Janata, P., Tomic, S. T., & Rakowski, S. K. (2007). Characterisation of music-evoked autobiographical memories. *Memory*, 15, 845-860.
- McDermott, O., Crellin, N., Ridder, H. M., & Orrell, M. (2012). Music therapy in dementia: A narrative synthesis systematic review. *International Journal of Geriatric Psychiatry*, 28, 781-794.
- Pollack, N. J., & Namazi, K. H. (1992). The effect of music participation on the social behavior of Alzheimer's disease patients. *Journal of Music Therapy*, 29, 54-67.
- Quinn, C., & Clare, L. (2008). Interpretive phenomenological analysis. In R. Watson, H. McKenna, S. Cowman, & J. Keady (Eds.), *Nursing research: Designs and methods* (pp. 375-384). London: Churchill Livingstone.
- Raglio, A., Bellandi, D., Baiardi, P., Gianotti, M., & Granieri, E. (2013). Listening to music and active music therapy in behavioral disturbances in dementia: A crossover study. *Journal of the American Geriatrics Society*, 61, 645-647.
- Sacks, O. (1998). Music and the brain. In C. M. Tomaino (Ed.), *Clinical applications of music and neurologic rehabilitation* (pp. 1-18). St. Louis, MO: MMB Music.

- Sacks, O. (2007). *Musicophilia: Tales of music and the brain*. New York, NY: A. A. Knopf.
- Sakamoto, M., Ando, H., & Tsutou, A. (2013). Comparing the effects of different individualized music interventions for elderly individuals with severe dementia. *International Psychogeriatrics*, *25*, 775-784.
- Särkämö, T., Laitinen, S., Tervaniemi, M., Numminen, A., Kurki, M., & Rantanen, P. (2012). Music, emotion, and dementia: Insight from neuroscientific and clinical research. *Music and Medicine*, *4*, 153-162.
- Särkämö, T., Tervaniemi, M., Laitinen, S., Numminen, A., Kurki, M., Johnson, J. K., & Rantanen, P. (2013). Cognitive, emotional, and social benefits of regular musical activities in early dementia: Randomized controlled study. *The Gerontologist*, *54*, 634-650.
- Sherratt, K., Thornton, A., & Hatton, C. (2004). Emotional and behavioral responses to music in people with dementia: An observational study. *Aging & Mental Health*, *8*, 233-241.
- Sung, H-C., Chang, A. M., & Lee, W-L. (2009). A preferred music listening intervention to reduce anxiety in older adults with dementia in nursing homes. *Journal of Clinical Nursing*, *19*, 1056-1064.
- Teri, L., Truax, P., Logsdon, R., Uomoto, J., Zarit, S., & Vitaliano, P. P. (1998). Assessment of behavioral problems in dementia: The Revised Memory and Behavior Problems Checklist. *Psychology and Aging*, *7*, 622-631.
- Topo, P., Mäki, O., Saarikalle, K., Clarke, N., Begley, E., Cahill, S....Gilliard, J. (2004). Assessment of a music-based multimedia program for people with dementia. *Dementia*, *3*, 331-350.
- Trigg, R., Skevington, S. M., & Jones, R. W. (2007). How can we best assess the quality of life of people with dementia? The Bath Assessment of Subjective Quality of Life in Dementia (BASQID). *The Gerontologist*, *47*, 789-797.
- Vasionytè, I., & Madison, G. (2013). Musical intervention for patients with dementia: A meta-analysis. *Journal of Clinical Nursing*, *22*, 1203-1216.
- Yap, P., Luo, N., Ng, W. Y., Chionh, H. L., Lim, J., & Goh, J. (2009). Gain in Alzheimer Care Instrument—A new scale to measure caregiving gains in dementia. *American Journal of Geriatric Psychiatry*, *18*, 68-76.
- Williams, A. P., Peckham, A., Rudoler, D., Tam, T., & Watkins, J. (2014). Evaluation of the Alzheimer Society of Toronto iPod project. Retrieved from <http://alz.to/wp-content/uploads/2014/12/IPod-Project-Evaluation-Final-Report-April-2-2014-FINAL-REV.pdf>.