

Effects of Personalized Music on Caregivers of Older Adults With Dementia in the Community

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ABSTRACT

Introduction: Music is a relatively low-cost and low-risk approach to managing the behavioral and psychological symptoms of dementia.

Objective: This exploratory study provided personalized music for 3 months to 25 older adults with dementia living in their homes with a caregiver and measured how the intervention affected the caregivers, including their perception of distress.

Methods: Caregivers completed the Caregiving Distress Scale (CDS) at pre- and postintervention and also participated in semistructured, in-depth, qualitative interviews.

Results: Quantitative data were analyzed using SPSS; qualitative data were analyzed using NVivo. Paired t-tests revealed a decrease in total CDS scores ($P < 0.01$).

Conclusion: Overall, caregivers believed that personalized music supported them and reduced stress.

INTRODUCTION

Approximately 5.7 million Americans are living with Alzheimer disease and related dementias.¹ In Wisconsin, approximately 115,000 people have dementia, with that number expected to increase to 242,000 by 2040.² As the number of people affected by dementia grows, it is important to develop and expand effective strategies for meeting their needs, as well as the needs of their caregivers.² One strategy involves the use of personalized music, and one such program is Music & Memory.³ The documentary *Alive Inside: A Story of Music and Memory* highlights the benefits of personalized music playlists and the work of the Music and

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Memory organization.⁴ The documentary shows how personalized music, which is a selection of music tailored for each individual, connects people with their specific histories, restores emotions, and awakens even long-lost memories. Since music engages the brain (especially areas that correspond to pleasure, movement, and memory) more fully than any other type of stimulus, people who were previously unresponsive were able connect to themselves and others. Music is a relatively low-cost and low-risk approach to managing the behavioral and psychological symptoms of dementia.^{5,6} Dementia has a significant impact on patients, families, and caregivers and can affect quality of life.⁷ As the number of people with dementia increases, family caregivers take on an increasing burden of care, along with the personal costs that entails.

Demanding and difficult behavioral disturbances of a person with dementia and their management frequently induce stress and increase caregiver burden.⁸⁻¹⁰ Often, these behaviors are more challenging to prevent, reduce, or manage than the cognitive decline of the disease.¹¹ Caregivers of those with dementia suffer from higher rates of depression, and the physical and emotional impact of this caregiving is estimated to total billions of dollars in the United States.^{8,11}

While the majority of people with dementia live at home and rely on a family member as a caregiver,¹¹⁻¹² previous research concentrated primarily on Music and Memory programs in institutional settings. The purpose of this exploratory study was to bring the Music and Memory program to older adults with dementia living in their homes with a caregiver in Northwest Wisconsin, and to measure how this 3-month intervention affected the caregivers, including their perception of distress.

METHODS

This study received approval from the University of Wisconsin-Eau Claire Institutional Review Board. The approach for the study was based on the Alzheimer Society of Toronto Music and Memory: iPod Project;⁵ and the authors' county Aging and Disability Resource Center (ADRC) assisted with participant recruitment.

There were 25 pairs of participants. Each pair included a person with dementia living at home and their caregiver. Caregivers provided consent, and participants with dementia either gave consent or assent. Each participating pair received a free iPod Shuffle, free over-the-ear headphones, and a free \$50 iTunes Store gift card to access music of their choice; and caregivers were asked to have the person with dementia listen to personalized music for a minimum of 60 minutes per day.

The researchers made a minimum of 3 home visits, each lasting approximately 1 hour. At the first home visit, consent forms were explained and signed, the Caregiving Distress Scale (CDS) was administered (Time 1), and the researcher asked both the caregiver and the person with dementia about music preferences. Researchers noted specific songs, artists, and genres. After the first visit, they downloaded the preferred music from iTunes into a digital library on a desktop computer, then downloaded the music onto the iPod. Each participant received \$50 worth of music downloads; the researcher used the \$50 iTunes Store gift cards to purchase the music. Each iPod had several hours of music on it.

During the second home visit approximately 1 to 2 weeks later, the researchers trained the caregiver how to use the iPod. Several weeks after the second home visit, the researchers called the caregiver to ask how their loved one liked the music, whether there was any music they wanted to add or remove, and if they had any questions about how to use the iPod. If there were no changes or questions, the researcher called the caregiver again several weeks later to check in. If changes were needed to the music and/or the caregiver had questions on how to use the iPod, another home visit was made. At the final home visit, researchers administered the posttest CDS and asked qualitative interview questions.

Pretest data was collected via the 17-question CDS,¹³ which addressed caregivers' feelings of emotional burden, relationship distress, care receiver demands, social impact, and personal cost (Table 1). Caregivers completed the assessment by rating their perceptions of their relationship with the care recipient on a 5-point Likert-like scale, from zero as "strongly disagree" to 4 as "strongly agree." The maximum possible score was 68 points; the higher the score, the greater the caregiver distress. In addition, demographic information regarding sex, age, ethnicity, language, severity of dementia, and relationship of the caregiver to the person with dementia was collected prior to beginning the music intervention.

When the intervention concluded after approximately 3 months, the CDS was re-administered (Time 2) with a qualitative

Table 1. Caregiver Distress Scale and Subscales

Instructions: Specific aspects of family life are affected by the demands of caregiving. With respect to your current situation as caregiver for _____, please indicate whether YOU personally disagree or agree with the following statements using the 5-point scale below.

0-strongly disagree 1-disagree 2-neutral 3-agree 4-strongly agree

- ____ 1. I take part in organized activities less
- ____ 2. I visit my family/friends less
- ____ 3. I take part in other social activities less
- ____ 4. I feel frustrated with caring for _____
- ____ 5. My relationship with _____ depresses me
- ____ 6. I feel pressured between giving to _____ and others in the family
- ____ 7. I feel that my own health has suffered because of _____
- ____ 8. My relationship with _____ is strained
- ____ 9. Caring for _____ has made me nervous
- ____ 10. I feel _____ can only depend on me
- ____ 11. I feel resentful towards _____
- ____ 12. I feel helpless in caring for _____
- ____ 13. My relationship with _____ no longer gives me pleasure
- ____ 14. _____ tries to manipulate me
- ____ 15. I feel overwhelmed by caring for _____
- ____ 16. _____ makes more requests than necessary
- ____ 17. I feel that my personal life has suffered because of _____

Score range for the overall scale is 0-68.

Emotional burden subscale: sum of items 4, 9, 12, 15 (0-16 points).

Relationship distress subscale: sum of items 5, 8, 11, 13 (0-16 points).

Care-receiver demands subscale: sum of items 6, 14, 16 (0-12 points).

Social impact subscale: sum of items 1, 2, 3 (0-12 points).

Personal cost subscale: sum of items 7, 10, 17 (0-12 points).

Table 2. Participant Demographics (N=22)

	Mean Age	Relationship to Care Receiver		
Caregivers	70.12	Wife 14	Daughter 5	Husband 3
Care Receivers	75.48	Husband 14	Parent 5	Wife 3

interview that included semistructured questions such as: (1) How do you and the person you care for use the iPod? (2) How has the iPod Project affected you and the person for whom you care? (3) To what degree has personalized music brought more pleasure to the patient/client/person? (4) To what degree does providing personalized music for the person help you in caring for her/him? (5) How likely are you to recommend this program to other caregivers? (6) How has this approach affected your quality of life? (7) What else would you like to share about this experience?

SPSS was used to analyze the quantitative data. The researchers only analyzed data from participants who completed the CDS twice (Time 1 and Time 2). A paired t-test was conducted to compare scores for each of the 5 subscales and for the overall CDS score. NVivo was used to code the qualitative data. Data from the open-ended questionnaires were transcribed verbatim into Word and then entered into NVivo for analysis. Data were analyzed using the constant comparative method¹⁴ whereby each

Table 3. Descriptive Statistics and *t*-test Results for Mean Differences of Caregiver Distress Scale (CDS) and Subscales

Scale/Subscale	Time 1	Time 2	Change in Mean	SD	<i>t</i>	df	<i>P</i> -value
Overall CDS	29.19	22.74	-6.45	9.61	3.08	21	.006*
Emotional burden	6.70	3.34	-3.36	3.80	4.15	21	.000*
Relationship distress	5.70	2.87	-2.20	3.01	3.44	21	.002*
Caregiver demands	2.42	2.18	.24	2.3	.47	21	.640
Social impact	3.56	3.11	.45	3.47	.614	21	.546
Personal cost	3.31	2.45	.86	2.34	1.73	21	.098

**P* < .01

word, phrase, and sentence was reviewed to decide what codes fit the concepts suggested by the data. Each code was constantly compared to all other codes to identify similarities, differences, and general patterns. An inductive approach was used, where codes, categories, or theme were drawn directly from the data. Although the categories generally flowed from the questions asked, all data were coded throughout the document relevant to the topic of interest, allowing the themes to emerge freely from the data.

RESULTS

The music protocol was designed to reduce distress and enhance satisfaction with caregiving, while offering the person with dementia the potential to improve mood and psychological state. Twenty-five participants started the 3-month program; 22 participants finished. One was sent to a nursing home facility out of the area, one moved out of the area with a different caregiver and did not return emails, and another declined to participate in the post intervention evaluations. (See Table 2 for participant demographics.)

Paired *t*-tests revealed a decrease in total CDS scores and the subcategories of emotional burden and relationship distress among participants. There was no statistical significance for difference in scores in the subscales for caregiver demand, social cost, and personal cost (Table 3).

Four common themes emerged from the caregiver narratives (Table 4). Overall, results indicated that the caregivers believed that personalized music brought more pleasure to the person with dementia and also helped support the caregivers and reduce their stress. There was wide variation in how often and when they used the music, and no clear associations were found between caregiver distress and frequency and/or timing of the music intervention.

DISCUSSION

Personalized music for long-term care residents with dementia has been shown to reduce agitation¹⁵⁻¹⁶ and anxiety; decrease the use of antipsychotic and anxiolytic medications to control behaviors that challenge staff and family members;¹⁵ increase socialization, broad cooperation, and verbalization; improve behavior;

and elevate mood.¹⁶ These findings were also evident in our results and connected to the themes of better quality of life and improved relationship between care receiver and caregiver. However, despite substantial literature concerning the therapeutic effects of music, surprisingly few rigorous empirical evaluations have been conducted,¹⁷ and the interventions were not well-defined and variable.

Dementia symptoms are usually distressing for both the person with dementia and the caregiver; it is essential to consider caregivers in planning interventions to improve daily functioning.¹⁸ Personalized music has the benefit of allowing the caregiver and care receiver to both participate—together or apart—and can be done in a home setting.

In response to this growing trend supported by the literature, we sought to expand the personalized music intervention into the community, where most people with dementia live with a family member. There are many facets of dementia and caregiving, and health care workers are especially suited to approach health care holistically and integrate diverse interventions to assist clients and their families. Since the stress and burden of providing care increase with the progression of dementia, interventions that bolster the caregiving relationship over time are essential.

There are some limitations to this study. Since recruitment was done through the ADRC, the study's subset of caregivers may differ from those who do not seek out services, eg, possibly being more motivated or having a higher caregiver burden at baseline. We recommend that future research be completed on a larger scale, and we would do at least 3 things differently: provide external speakers to all participants so they could listen to music with their care recipient (without having to purchase their own speakers), provide a larger iPod because the buttons on the iPod Shuffle were too small for many participants, and have caregivers keep more detailed logs of their close observations and how and when they use the music.

Myriad health care professionals could utilize and/or suggest this intervention when working with patients with dementia and their caregivers; volunteers also could be trained to provide this resource and teach it to caregivers. Since it may help people with dementia to be more verbal and engaged, it could facilitate their interactions.

CONCLUSION

Although more evidence for the efficacy is needed, personalized music has the potential to have a high impact with a low cost. We suggest that this intervention be further implemented with home care patients and hospice patients, and in other settings, including hospice facilities, assisted living facilities, and community centers. The goal of eventually making personalized music a

standard of care seems both valuable and possible.

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Table 4. Common Themes and Selected Quotes From Caregiver Narratives

Theme 1. Psychological symptoms improved

- A. For caregiver
- Decreased anxiety
 - Decreased stress
 - Decreased depression
 - Increased happiness
"It improved my mood at times."
"It made me feel less nervous."
"I felt less helpless."
"It makes me happy to see her enjoying the music."
- B. For person with dementia
- Decreased anxiety
 - Decreased stress
 - Decreased depression
 - Increased happiness
 - More relaxed and calm
"It makes him happy to listen to the music."
"It gave him joy and made his life better when he used it."
"She was more relaxed and calm."
"He was enjoying directing the band one day!"

Theme 2. Behaviors

- A. Verbal – increased desired behaviors and decreased undesired ones
- B. Physical - increased desired behaviors and decreased undesired ones
- C. Kept the person with dementia occupied
- D. Helped the person with dementia sleep better at night
- E. Kept the person with dementia occupied
- F. Person with dementia was livelier and more engaged
"The music kept him occupied."
"There were fewer difficult behaviors."
"It was easier to do caregiving tasks."
"It helped her sleep better at night."
"He was livelier and more engaged."
"He had fewer outbursts."

Theme 3. Quality of life

- A. Improved quality of life in person with dementia
- B. Improved quality of life in caregiver
"Music and Memory is definitely a positive program. I appreciate we are a part of it. It is good for both of us. Life is a little better and easier."
"For such a small thing it does give a respite for both of us and improves our quality of life."
"It helps me. I'm able to do things while he listens to the iPod."
"It gives her something to do and keeps her from getting bored."
"It's nice to see him doing something he enjoys."
"I love to watch him with the iPod on. It is pleasant to know he is listening to music he used to like and enjoy and that he still has those memories. It has allowed him to reconnect with songs and that area of his life."
"We enjoy music with the iPod concept that provides pleasure for many hours."

Theme 4. Improved relationship between caregiver and person with dementia

- A. Danced together
- B. Sang together
- C. Shared memories
- D. More engaged
- E. Listened to music together
"It is wonderful to listen to the music together."
"We enjoy listening to the music together while dancing and singing together."
"It allows us to connect and share memories."
"We're both more engaged and more motivated."
"The music helps both of us to interact with a better attitude."

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