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Implementation of personalized music listening for assisted living residents with dementia

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Abstract

Personalized music listening (PML) has been touted as a safe and inexpensive means of improving the quality of life, mood, and behavior of persons with dementia. A PML program was implemented in an assisted living facility and evaluated across the five dimensions of the RE-AIM framework: reach, effectiveness, adoption, implementation, and maintenance. The first 17 residents invited to participate were enrolled and followed over eight months. Effectiveness was evident in staff-reported mood improvement in 62% of encounters. Adoption was evident in qualitative feedback collected from medication technicians. Implementation was facilitated by low costs, engagement of external volunteers, highlighting outcomes that are relevant to staff, and attention to playlists over time. Maintenance required continued engagement of volunteers, ongoing fundraising, attention to facility staff engagement, and iterative adjustments to the program framework as staffing changes occurred. PML was found to be a meaningful intervention that is possible at a reasonable cost.

Keywords

Dementia; Personalized music listening; Assisted living; Music; Memory; Alzheimer's

Introduction

An estimated 5.4 million Americans carry a diagnosis of Alzheimer's disease or related dementias (ADRD), and the prevalence is projected to increase to 13.8 million by mid-century with the aging of our population.¹ Symptoms of ADRD including agitation, anxiety, apathy, and depression reduce a person's quality of life and increase caregiver burden. Specifically in assisted living facilities (ALF), persons with ADRD can create increased workload for staff with mood changes manifesting as resisting necessary care, verbal outbursts, attempts to leave the facility, or physical aggression.² Research suggests agitation and anxiety each affect 9% of persons with dementia, while apathy affects 50%; such numbers increase institutionalization and healthcare costs as therapies must address these comorbid

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behavioral and mood changes.³ In 2010, the global costs of dementia were estimated at \$604 billion.⁴

While new pharmacologic therapies for ADRD remain a distant hope, the current standard of medical care remains symptomatic management. Approved drugs have limited effectiveness, and off-label use of antidepressants and antipsychotics is expensive and carries significant adverse effects. Multiple studies indicate that behavioral and sensory interventions such as family presence, recreation, redirection, and art therapy are more effective methods of dealing with problematic behaviors.^{5–10}

Over many years, music listening has been explored as a safe and inexpensive treatment for mood changes in persons with dementia.^{11–22} Greater efficacy is achieved when music is personalized to an individual's past experiences [i.e. *personalized* music listening (PML)], and further when the timing and mode of administration of music are also specific (i.e. individualized music).^{23–29} Personalization is theorized to provide autobiographical context that connects the listener to remote memories, emotions, and verbal abilities preserved despite the neurocognitive decline.²³ In these interventions, music is often delivered with headphones to create an immersive environment that minimizes sensory distractions to the recipient and also decreases negative reactions from nearby persons who may have different preferences.³⁰

Individualized music was pioneered by Linda Gerdner to combat anxiety and agitation,²⁷ and has since been carefully delineated in an evidence-based guideline, now in its fifth edition.²⁶ In contrast, PML has been largely driven by Music & Memory, a non-profit organization founded by Dan Cohen, which has gained substantial renown through the award-winning 2014 documentary *Alive Inside*. A recent analysis of the national Minimum Data Set for nursing home residents found that facilities with Music & Memory as compared to those without tended to have decreased antipsychotic and anxiolytic use as well as decreased behavioral problems.³¹

While individualized music programs have been successfully run by trained staff and family in the past,³² the resources of many ALFs and their residents' families are not amenable to the investment required to develop and sustain a music delivery program. In addition, limited financial resources preclude some facilities from undergoing the full-certification process of the Music & Memory organization. Here, the implementation of a student volunteer-driven PML program, now in its fourth year, that combines elements from both models at an ALF that serves many residents with limited financial and social resources is described. This program is evaluated using the five dimensions of the RE-AIM framework: reach, effectiveness, adoption, implementation and maintenance.³³ Throughout this description, emphasis is placed on the importance of external partnership, simplicity, and flexibility when implementing such a program in an environment where staffing and monetary resources are limited.

Methods

Setting and population

This quality improvement project was exempt from research review by the Duke University Medical Center Institutional Review Board. An ALF was selected on the recommendation of the county ombudsman based on her knowledge of the facility's limited resources and desire for a music program. She made the initial introduction of medical students and faculty sponsor to the administrator. Despite its distance of 8 miles from the medical school, the facility was an ideal site due to its needs and willingness to collaborate. Specific residents within the ALF were selected for the program by the facility's administrator, the only person in the planning group with personal relationships with resident families and access to medical records. The administrator was not a medical professional, but was asked to include residents who had been diagnosed per chart review with dementia including those with problematic behaviors. The administrator explained the program to residents and family members and asked for their cooperation and permission to participate. Residents were enrolled gradually, and the first 17 residents enrolled in the program were tracked for response to PML over a period of 8 months.

Intervention

Each participant was assigned an iPod Shuffle®, which was chosen for its compact design, perceived durability, the presence of a clip for placement on resident clothing, and ease of programming multiple devices to one central music library. Over-the-ear headphones were also purchased for the participants as hearing aids made ear buds unusable.

Two medical student volunteers visited the ALF weekly over the 8 months. Initial playlists were developed through interviews with residents and their family members guided by a simple music preference form. Personal CDs belonging to residents or family members were used to develop individual playlists. All other music was purchased and stored on a secure music account. Playlists were adjusted based on resident response to music on a bi-monthly basis. The computer utilized for playlist development was transported to the ALF during visits and stored within a locked room at other times. The iTunes® account belongs to the program, is not linked with any individual volunteer, and is only used for volunteer activities.

In discussion with the facility administrator, medication technicians (MTs) were selected to distribute music as they were deeply familiar with residents through assisting with activities of daily living and administering medications. An orientation was provided for ALF staff, with an emphasis on the MT's role in passing out and collecting the iPods®. MTs were trained to introduce the music by clipping the devices to the back or front of the participant's shirt, depending on individual comfort and level of dementia. Some participants could skip or pause songs and this was encouraged if they were capable. The MTs were shown how to store the devices, and recommended to distribute music at least twice a week for at least 30 minutes each time. Medical students continued to distribute iPods during their visits and the administrator encouraged MTs to use the iPods on a regular basis primarily after the morning medication pass. They were also encouraged to try the music to mitigate difficult

behaviors. MTs were given the autonomy to decide music timing and frequency. The duration of each individual session was not recorded.

Assessment

A simple three tier rating scale for initial mood and change in mood for the participants after PML was used to monitor program effectiveness. MTs used their overall impression of the resident to determine a gestalt initial mood (normal, agitated, or withdrawn), and a change in mood (no change, improvement, or worsening). The MTs recorded the name, date, time, initial mood, change in mood, and qualitative comments on one line of a form developed to monitor compliance and effectiveness. They were instructed to make these recordings at the beginning and end of listening periods.

Students implementing the program made qualitative notes regarding aspects of the implementation process, resident reactions, and MT suggestions. Feedback was solicited individually or in small groups from MTs at least once a month using three questions: How have residents benefited from the personalized music? What keeps you from using the devices? What could be done to improve the PML program? Responses were used to guide program development and also to encourage MT adoption of the program.

Data analysis

Definitions used to evaluate each of the five RE-AIM measures are described in Table 1. Reach was defined as the number of individuals who participated out of those who were asked. Effectiveness was assessed by the percentage of encounters in which a resident's mood was considered improved by the medication technicians. Adoption of the music program was explored through pattern graphs of initial mood and responses for three participants who received the intervention frequently throughout their participation. Implementation is assessed by describing key aspects of the program that facilitated delivery within the setting. Maintenance was assessed by describing the costs involved in maintaining the program and the barriers encountered and tackled over the first four years.

Results

Reach

The ALF housed approximately 75 residents with ADRD at any given time. Throughout the past four years, approximately 35 different residents and families have been asked to participate in the program, and all have agreed to join. Turnover of residents in the facility from death or discharge was high, but a steady state of 20 actively enrolled residents has been maintained.

Effectiveness

Over the initial 8-month period, a total of 822 encounters were logged by the MTs for an average of 48 per resident. The frequency of MT administration varied widely from 2–3 times per week to once a month. Of these, initial mood was recorded as normal in 575 encounters (70%), depressed/withdrawn in 76 encounters (9%), and anxious/agitated in 91 encounters (11%) (Fig. 1a.). PML was refused in 80 cases (10%). As shown in Fig. 1b.

excluding refusals, resident response showed an improved mood 461 times (62%), no change 255 times (34%) and worsened mood response only 26 times (4%).

Qualitative notes about the residents recorded by MTs revealed a general increase in emotional expression and goal-directed activity during PML. Specific activities noted by MTs in normally sedentary residents included the following: singing, dancing, smiling, gesturing, foot tapping, and engaging with visitors. Some minimally verbal residents started singing along to songs, telling the volunteers “turn it up!” or “I love it, I appreciate it”. Some residents reminisced about their past, saying “It’s real pretty, but you know, I’m old...I can’t play like that anymore.” Discussions with residents’ family members also revealed a deep sense of gratitude for the program.

Adoption

By the end of the initial 8 months, all MTs working in the facility were actively participating in the PML program. Pattern graphs generated of responses over time helped to understand how staff adopted this intervention (Fig. 1c). Three graphs are used to illustrate staff persistence in offering music and the evolution of attempting use during periods of withdrawn or agitated mood. In the pattern graphs of Fig. 1c, participant A seemed to have initial normal mood for most administrations early in participation but more frequent anxious/agitated mood (−1 on the scale) as time went on, and only two occurrences of depressed/withdrawn mood (−2). Nevertheless, this participant’s mood was often observed to improve as a result of the music as illustrated by elevation above the horizontal line in the response graph. Participant B had many administrations when mood was normal with positive or no change in response. However, when music was provided during mood disturbances the response to the music was variable and judged as worse on 5 occasions. Participant C received the music frequently; when an initial mood disturbance was recorded it was primarily depressed/withdrawn and the response was rarely negative (once). Staff persisted with offering music even when they did not always note a positive response for this participant.

Implementation

Major expenses when first establishing the program included iPods, headphones, storage devices, and music (Table 2). The medical student volunteers identified four key elements that facilitated PML program delivery: (1) mission; (2) program champions; (3) choosing and maintaining the music delivery mechanism; and (4) carefully titrating playlists.

With regard to mission, although many residents would have enjoyed and wanted to participate in the program, targeting residents with dementia helped staff and residents to accept the program. The focus helped to avoid seeing the program simply as another activity, but rather as a key intervention to allay behavioral issues and improve quality of life. Internal champions emerged at the level of the administrative leadership among the MTs and were maintained through regular interaction with student volunteers. The choice of listening devices and plan for storage and charging had a major impact on implementation. The colorful shuffles that were not internet connected did not disappear very often. Two devices were lost when they were in use and never properly returned to storage at the end of the day

during the initial 8 months and loss has not exceeded 2 per year. Storage of devices required a balance of security and availability. Devices were placed in a designated location within a locked medication storage room. In the second year, at the request of frontline staff, an iHome speaker was purchased for free field music playing during mealtimes in the facility. Staff reported smoother mealtimes with the device, but song selection was no longer personalized and needed to be relatively broad (e.g. holiday music). Playlist titration emerged in importance when some residents did not respond favorably to music recommended by family members, so students spent time trying songs and watching responses. Some residents who have been with the program for longer periods became less responsive to the same music. In these cases, playlists were changed to include different songs from the same artists, genre, or time period.

Maintenance

Since the initial investment, annual budgets have primarily had to account for broken or lost device replacement, new music purchases, and staff training. Approximately two devices out of twenty total need to be replaced annually.

The ALF proudly advertises the PML program on its website. Each year 2–4 new medical student volunteers have been identified in the incoming class to adopt the program. Senior student volunteers mentor incoming volunteers regarding the importance of maintaining relationships with facility leadership and frontline staff champions, cultivating engagement through their visits, and providing in-service education. Incoming volunteers have latitude to continuously improve the program.

An important challenge this program faced during its fourth year was an entire administrative turnover at the ALF. Navigating the transition while also ensuring continued delivery of music to participants in the program required increased volunteer time spent at the facility and renegotiating program logistics. Flexibility was key in changing from a program driven by individual MTs to one where an Activities Director became the primary champion and has assumed music device distribution. This has also impacted procedures for music device storage. One activities director agreed to a prominent display in the activities room which prompted more routine utilization. The activities directors have emphasized scheduled time for PML while as needed usage has declined except for those residents who are able to ask for the device.

Discussion

Many lessons were learned over the four-year implementation of this program. Most importantly, focusing on the mission was critical in sizing the program for the resources and capabilities of the setting. Similar to residents, staff turnover relatively frequently at the ALF. Recognizing the funding constraints and time constraints of both student volunteers and staff, only a fraction of all residents with ADRD are enrolled at any time. Others planning to implement a similar program must objectively evaluate resources necessary for implementation, expansion and dissemination.

Committed facility leadership and frontline caregiver champions played a critical role in the success of the PML program. The ALF administrator was contacted several weeks before implementation, which was an important first step in establishing a trusting relationship that enabled program initiation. While an initial goal of the student volunteers was to work with residents with milder disease still capable of vocally expressing particular music preferences, the administrator prioritized enrollment of residents with the most severe cognitive impairment and behavioral symptoms. This addressed the facility's greatest needs, and helped ensure buy-in. In addition, several MTs, nursing assistants, and activities directors became program champions, which created ownership within the facility. While other programs have included family members as part of a joint PML team,³² family members capable of engaging at this level with the program have not been found.

Education was an important component of developing champions. During the initial in-service orientation for ALF staff, basic information on dementia care was included and PML's role as an integral part of a resident's care plan was stressed. The orientation was limited to 30 minutes to respect constraints on staff time. The simplicity of the program and the time spent in documenting the response were highlighted. Aside from the formal in-service training, frequent informal interactions with the staff participating daily in PML allowed for reinforcement of these concepts. Ideally in-service training should occur annually, if not biannually, in order to account for high levels of direct-care worker turnover¹ and iterative improvement of the program.³⁴

One of the greatest barriers to adoption of the program was the perception of music as entertainment rather than as an effective and essential dementia care tool. However, the simple form used to record mood and response to PML created an opportunity for each MT to reflect on the impact of the intervention, which led to widespread adoption. When the program first began, MTs acknowledged the program saying, "that's a real great idea you guys have," but would not prioritize PML. However, several months into the program, MTs began telling volunteers that "the iPods have been a huge help in calming residents during our busiest times." In particular, MTs were particularly impressed by the calming effect PML had on one participant who was "usually ready to break out." MTs were observed to begin personalizing music timing to prophylactically target participants who were known to be agitated at certain times of day, a core tenet of individualized music. While the impact of PML on ALF personnel was not objectively evaluated, participating MTs endorsed feeling an ease in their work-flow and improved satisfaction with their work, which is similar to other reports.³⁵ In this ALF, incentives or mandates handed down by facility leadership were not utilized to encourage adoption.

Although initial data collection by MTs during the first 8 months of implementation proved to be important in facilitating staff adoption of the program and demonstrating efficacy, continuing data collection was not sustainable long-term. MTs recognized the importance of tracking use of PML, but would sometimes forget and try to "back-fill" entries from memory. Although a paper form was used, integration into electronic care tracking systems could help increase compliance and perhaps allow for summarized feedback that would reinforce sustained implementation and data collection. The impact of this program on need

for pharmacologic interventions was not measured, however, this type of data could further facilitate staff adoption.

It is difficult to fully separate the positive effects of interaction with students and staff from the positive impact of the personalized music. The attention from MTs and volunteers might account for some of the positive changes seen in the PML program participants. However, based on the literature and our experiences, the physical activity and socialization was not the primary factor.^{10,36} For most participant encounters, time spent listening to music was individual and did not include sustained staff or student contact. Interactions from staff and volunteers were primarily reactionary (e.g. holding the arm of a resident once they decide to start walking or dancing with headphones on) as opposed to intentional (e.g. getting the resident up and walking and then also applying the music device).

Several MTs were concerned about increased fall risk in residents who walked or danced in response to PML. Importantly, most studies have not shown a connection between music listening and a change in fall incidence.³⁷ Music devices were observed to be left safely on the resident for extended periods of time as the staff performed required daily duties in the vicinity. Observing many participants receiving the intervention in a common area or while awaiting meal service are ways to manage fall risk.

Another challenge was that residents who required more attention from staff – to keep headphones in place or to prevent falls from increased desire to stand – were less frequently provided PML. Similarly, the predictable “responders” ended up receiving the intervention more frequently, whereas quiet, less responsive listeners received it less. Interestingly, the MT-reported data showed that even residents with an initially normal or withdrawn mood still showed improvement after PML. This underscores PML’s utility not only in reducing negative behaviors, but also as a means of improving day-to-day quality of life through increasing positive actions such as socialization or movement. In addition, several participants who initially refused music eventually enjoyed PML after consistent exposure. Refusals were often a result of poor initial selection of music, and highlight the importance of personalization. Improvement was only achieved after careful titration and exploration of the participant’s past musical taste. Carefully adjusting playlists and discussing these residents in-person with MTs are ways to promote more equitable music distribution.

In the third year of operation, another group of medical students inspired by the impact of this program obtained funding for a PML program in a long-term care facility at a Veterans Affairs Community Living Center. Key elements of implementation were shared with the second group and helped to translate personalized music to a new setting. At the VA, the students limited their program to veterans with cognitive impairment with a similar mission to enhance quality of life and allay behavioral issues. Their work began with two champions, a physician and nursing supervisor. The student group at the VA chose to use MP3 players. In brief, MP3 players offer the advantage of a lower cost and a screen on the music device to more easily recognize the song being played. Potential disadvantages include less durability and the need to use non-iTunes software for the music library. It is critical for individual PML programs to evaluate the setting as well as the technological aptitude of local facility project champions in selecting a device. Programs should account for the possibility of lost

or stolen devices, and implement protocols to avoid such incidences. Although iPod Shuffles and MP3 players are small and can be lost, the lack of internet connectivity mean that they do not pose a high risk of theft. Now that iPod Shuffles are no longer available, iPod Nanos® will be used moving forward in this program in order to continue with the established iTunes library. Although the Nanos are more expensive than the older Shuffles, the new devices provide a screen and the ability to have multiple playlists on one device. Although medical students implemented the interventions both at our ALF and at the VA, volunteers in high school and college would be appropriate to engage when provided with introductory information about dementia care, appropriate advisors, and collaborative facility staff.

Conclusions

In less affluent living communities, a music listening program is feasible with volunteer support. Expensive certifications may not be necessary, and simple monitoring schemes such as a gestalt mood measure may help to facilitate adoption. Key activities when developing a program include targeting a particular population (in this case those with dementia), identifying project champions, choosing technology that can be easily supported, titrating playlists carefully, and continuously improving protocols. Effective and sustainable PML programs also require attention to music personalization, patience in allowing residents to adjust to using the device, and incorporation of device use into daily routines.

PML programs are ideal opportunities for community engagement with the residents and staff of ALFs. Volunteers can focus on raising funds, collecting music preferences, and loading/adjusting playlists. Engaging leadership and facility champions early is necessary to promote routine use, charging, and proper storage of the devices to avoid misplacement. Proper staff training and encouragement are also critical to developing buy-in, which comes even more quickly with opportunities to observe positive resident responses. Perhaps community or external engagement will be less critical as a culture is developed where music is a crucial component to enhance quality of life, personalize care, and avoid problematic behavior.

As others have emphasized, the effects of PML depend on repeated and consistent use of music devices.³⁸ Since staff time is limited, PML may be neglected in favor of other seemingly more important duties such as medication administration or assistance with activities of daily living. It is crucial to help staff recognize that embedding PML into daily routine improves resident quality of life, increases potential for greater cooperation with care, and may decrease behavioral problems. In addition, implementations must be system-specific to conform to work flow patterns. Despite the complexity of involving more staff and requiring more effort to sustain the approach with staff rotation and turnover, involving direct care staff conceptualizes music as an intervention and part of a resident's plan of care rather than an activity or pastime.

PML is a meaningful intervention across the dementia spectrum of impairment. Implementation is possible at a reasonable cost with sustained volunteer involvement. Many facilities may be willing to incorporate maintenance costs into their budget, which are

minimized in subsequent years once a music library has been developed, as previously purchased devices can be reprogrammed with new playlists for new residents. Additional research and quality improvement efforts are needed to extend our understanding of the benefits of music for persons with dementia, as well as the processes that will increase access and optimize implementation.

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Abbreviations:

PML	Personalized Music Listening
MT	Medical Technicians
ALF	Assisted Living Facility
ADRD	Alzheimer's Disease and Related Dementias

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Fig. 1.

Initial mood and response to personalized music. (a) Percentages of each mood category prior to music listening in all recorded encounters. (b) Percentages of each response category to music listening with refusals excluded. (c) Experiences were more closely examined for the 3 residents with the most encounters. Initial mood was plotted over time with dips from normal (0) representing periods of agitation (−1) or depression (−2). Response to the intervention was also plotted over time, with values above or below the horizontal axis (0; no change) representing a positive (+1) or negative (−1) response.

Table 1

RE-AIM measure definitions

RE-AIM Analysis	
	Used Definition
Reach	Number of residents participating in the program out of all who were asked
Effectiveness	Change in mood as reported by medication technicians
Adoption	Staff participation- medication technicians, administrators, activities director
Implementation	Key elements of delivery, Cost
Maintenance	Cost to maintain the program, Barriers identified and tackled

The criteria for evaluating each of the five measures of the RE-AIM framework are described.

Table 2

Estimated personalized music listening program budget

Item	Individual Cost	Cost for 20 residents
2 GB Listening Device	\$50	\$1,000
Over-the-head Headphones	\$15	\$300
Music library	\$40	\$500
Replacement Devices	n/a	\$200
Total	\$105 per resident	\$2,000 per 20 residents

Approximate cost of the program for each individual enrolled and for a program of twenty individuals. The estimated music cost depends on overall music preference overlap between residents. The estimated cost of replacement devices accounts for 3 lost/broken per 20 residents.