

Evidence-Based Guideline: Individualized Music in Persons with Dementia (6th Edition)

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Abstract

The 6th edition of the *Evidence-Based Guideline: Individualized Music for Persons with Dementia* (PWD) is available as a free downloadable pdf. Individualized music corresponds to four of the Dementia Care Practice Recommendations of the Alzheimer's Association. This guideline provides the culmination of nearly 30 years of research and clinical implementation as a nonpharmacological intervention for caregiver management of anxiety and agitation in PWD. Understanding potential causes for these behaviors is critical to the safe delivery of care. Timing of the intervention should be individualized along with the selection of music. The intervention has been empirically and clinically tested by scholars in the United States and nine other countries. In addition to reduced anxiety and agitation, PWD have shown positive affect while listening to the music. Family and staff caregivers also report that when played "free field," individualized music is a stimulus for positive social interaction, increased feelings of caregiver satisfaction, as well as perceived improvement in the care recipient's quality of life. The intervention is individualized at multiple levels, and is more than simply playing preferred music for the PWD. It emphasizes personhood, including the cultural and spiritual significance of music in the person's life. Individualized music has been successfully used in home care, adult day care, assisted living, long-term care, post-acute care, and palliative care. The guideline provides a grading schema for the strength and consistency of evidence, with a step-by-step description of the intervention to insure consistency for implementation and evaluation of outcome measures. Because grandchildren can be an important component of family caregiver dynamics, basic principles of the evidence-based guideline have been translated into an illustrated story book for children and their family members. A website provides free resources for professional health care providers, family caregivers, and children.

Keywords: Individualized Music; Dementia; Alzheimer's Disease; Agitation; Person-Centered Care

Introduction

There are currently an estimated 5.7 million Americans living with Alzheimer's disease or a related dementia (ADRD) [1] and nearly 50 million people worldwide living with the disease [2]. Livingston and colleagues [3] conducted a study of 1281 residents living in long-term care facilities (LTCF) and found that 86% had dementia. Of those persons, 40% exhibited "clinically significant" symptoms of agitation with 86% exhibiting "some" symptoms of agitation. Findings showed increased levels of agitation were correlated with a lower quality of life. Beerens and colleagues [4] conducted a systematic review of the literature and similarly found agitation to be a factor related to a lower quality of life in PWD.

As a means of improving quality of care for persons with ADRD, the Alzheimer's Association established the 2018 Dementia Care Practice Recommendations [5,6] that include but are not limited to:

- Evidence-Based Nonpharmacological Practices to Address Behavioral and Psychological Symptoms of Dementia (BPSD).
- Evidence-Based Intervention for Transitions in Care for Individuals Living with Dementia.
- The Fundamentals of Person-Centered Care for Individuals with Dementia.
- Meeting the Informational, Educational, and Psychosocial Support Needs of Persons Living With Dementia and Their Family Caregivers.

The *Evidence-Based Guideline of Individualized Music for Persons with Dementia* is a nonpharmacological intervention that should be considered for the management of behavioral and psychological symptoms of dementia (BPSD) such as agitation (and corresponds to the first recommendation as identified above). The guideline was originally developed in 1996 and is now in its 6th edition [7]. The cumulative efforts by researchers and clinicians in the U.S. and abroad has strengthened the evidence for this guideline over the years. The second and third recommendations listed above are inherent aspects of the theory-based intervention that guides this evidence-based guideline. The author has long been committed to the fourth recommendation by providing free resources to educate and empower staff and family in the use of this intervention. These efforts include diversity of teaching modalities to serve a variety of learning styles and needs. Each of the above recommendations will be discussed in relation to the evidence-based guideline including seminal research

along with more recent studies. For a complete listing and discussion of supporting research please refer to the 6th edition of the guideline [7].

Origin and Development of Individualized Music for Management of BPSD

Gerdner began clinically exploring the use of individualized music in the late 1980s and pioneered a research protocol for use of individualized music as a nonpharmacological intervention for the management of agitation in the early 1990s. This pilot study [8] focused on the dependent variable of agitation as operationalized by a modified version of the Cohen-Mansfield Agitation Inventory [9]. Findings of this preliminary study garnered much attention in the scholarly literature. Shortly thereafter, Gerdner began weighing the strengths and limitations of the preliminary study in preparation for a larger more rigorous study. It became apparent that the timing of the intervention should be individualized to achieve optimum effects when used to alleviate agitation. Her work in this area led to the development of a middle-range theory with testable propositions to guide future research. Roy [10] describes a middle-range theory as a bridge between research and evidence-based practice [10].

Middle Range Theory

The middle-range theory of *Individualized Music Intervention for Agitation* (IMIA) [11] guides the implementation of this intervention throughout the transition of care from mild to advanced stages of dementia. Music is a powerful catalyst for memory. Selection of music is based on its meaningfulness to the person prior to the onset of cognitive impairment and promotes the use of preserved abilities such as remote memory. Music may stimulate a wide range of emotions. Therefore, it is important to select music that stimulates positive feelings. As the disease advances it becomes increasingly difficult for the PWD to understand verbal language. However, it is theorized that receptive and expressive musical abilities are preserved long after the diminished ability to process or express verbal language. Experts have written on the hypothesized mechanism by which this occurs [12-14]. Importantly, music may be used as a means of communicating with this population even in the advanced stages of dementia when the person is unable to understand verbal language and has a decreased ability to interpret environmental stimuli.

A middle-range theory is often linked to a conceptual model to provide a greater degree of specificity [15]. IMIA incorporates the Progressively Lowered Stress Threshold

(PLST) Model developed by Hall and Buckwalter [16] to explain potential antecedents of “dysfunctional behavior”, such as anxiety with progression to agitation. This model proposes that cognitive impairment, associated with dementia, results in a progressive lowering of the person’s stress threshold throughout the disease process. Over time lesser amounts of stress are required to meet and exceed the stress threshold, resulting in “dysfunctional behaviors.” Hall and Buckwalter emphasize that all “dysfunctional behavior” (e.g., agitation) has meaning and is indicative of an unmet need [16]. The following factors are identified as contributors to stress in PWD: 1) physical stressors (pain, discomfort, infection); 2) misleading or inappropriate stimuli; 3) change of environment, caregiver or routine; 4) internal or external demands that exceed functional capacity; 5) fatigue; and 6) affective response to perceptions of loss [16-18]. An understanding of the antecedents of agitation are critical to appropriate and safe intervention. For example, if pain is suspected as the underlying cause for “behavioural” disturbances, medical consultation should be sought for appropriate assessment, diagnosis and treatment [19]. Although individualized music may be used to supplement medical care, it should not replace it.

An individualized assessment of temporal patterning of anxiety and agitation in the PWD is important to achieve optimal effectiveness. This skill is acquired over time by learning to identify the subtle changes in behavior that lead to agitation. The intervention should be implemented when signs of anxiety or agitation first begin.

In summary, the middle range theory of IMIA is based on the following propositions [11]:

1. The temporal patterning of agitated behaviors in PWD is often predictable based on the application of the PLST model [16,18].
2. Music evokes an individual emotional response within the listener that is associated with personal memories.
3. Response to personal memory is enhanced when music selection is based on past personal preferences.
4. The presentation of an individualized music intervention alleviates agitation in the PWD.
5. There is a positive relationship between the degree of significance that music had in the person’s life prior to the onset of cognitive impairment and the effectiveness of the intervention.
6. Individualized music intervention is most effective when the intervention is implemented approximately 30 minutes prior to the peak level of agitation.

Testing of Middle Range Theory

Seminal Study

The follow-up study [20] was strengthened by using an experimental repeated measures pretest-posttest crossover design to compare the immediate and residual effects of individualized music to classical “relaxation” music relative to baseline on the frequency of agitated behaviors in PWD. Importantly, the timing of the experimental and comparison intervention was also individualized to maximize the outcome on the dependent variable. A statistically significant reduction in agitation was identified during the presentation of individualized music compared to classical “relaxation” music. In addition, anecdotal data supported a positive response (e.g. smiling, humming, and rhythmic tapping) during the use of individualized music [20]. Case examples were included in both the preliminary study and the seminal study to provide support for clinical significance. Completed research won the International Psychogeriatric Association/Bayer Research Award in 1999. The impact of this study resulted in an invitation for the author to write a follow-up article with a commentary by Nicola T. Lautenschlager [21].

Further Testing of Middle Range Theory

Japanese researchers [22] expanded the evaluation of individualized music by including biophysiological, functional, and behavioral outcome measures. The study included 10 PWD who received preferred music twice per week for 8 weeks (16 sessions). During the corresponding time period, 13 subjects participated in a comparison intervention (games, drawing, pasting pictures). Statistical analysis comparing baseline to one-week post intervention scores showed that subjects in the experimental group had a statistically significant improvement in the “language” subscale of the *Mini Mental State Exam* and a statistically significant reduction in “irritability” as measured by the *Multidimensional Observational Scale*. In addition, there was a statistically significant reduction in salivary chomogranin A (CgA) following session 16. The authors of this study concluded, “the changes in CgA levels supported Gerdner’s mid-range theory (p. 17).” No significant findings occurred in the comparison group across outcome measures.

In 2007, Suzuki and colleagues [23] expanded on this research by incorporating immunoglobulin A (IgA), as well as saliva chromogranin A (CgA) and behavioral outcome measures. The study tested a group intervention, based on the music preferences of eight persons with dementia. One person refused saliva sampling and researchers were unable to obtain saliva sampling from a

second. The experimental group was compared to a control group, over a 3-month period. Findings included a statistically significant reduction in salivary CgA with no significant change in IgA. The researchers once again concluded that this findings support Gerdner's mid-range theory. There is further need to expand upon the important research of Suzuki and colleagues [22,23].

Evidence Based Guideline: Individualized Music for Dementia in Persons with Dementia

The 6th edition of the evidence-based guideline [7] is available as a free downloadable pdf and provides a detailed description of the theory-based intervention, including specific steps for implementation with a grading scheme to determine the strength and consistency of evidence. Two versions of the copyrighted *Assessment of Personal Music Preference* (developed by Linda A. Gerdner, Jane Hartsock & Kathleen C. Buckwalter) are included in the guideline. The first version may be completed by the person directly, if in the early stages of cognitive impairment. If cognitive impairment prevents answering the questions, a family version is also available. The questionnaire views the importance of music from a holistic perspective by assessing the importance of music during the person's life through various activities such as: singing in a church choir, playing a musical instrument, dancing, and/or simply listening to music. Questions also explore the role of ethnic heritage and religion in the selection of music preference. Assessment begins with a general questions and progressively narrows the focus to obtain information on exact performers and song titles. The two versions of this questionnaire have been incorporated into clinical practice and research in both the United States and abroad and found to be helpful (refer to evidence-based guideline for a complete listing of research). The questionnaire may require adaptation and refinement for some cultures and ethnic groups.

The evidence-based guideline for individualized music provides instruction on the most appropriate time to intervene to obtain optimal effects. This is achieved through the individualized assessment of temporal patterning and learning to identify the subtle changes in behavior that lead to agitation.

The technology used to present music should be individualized based on personal needs of the intended listener. The use of headphones and ear buds are appropriate if the selected music is disturbing to others in the environment. However, the older person may not be accustomed to listening to music through headphones or

earbuds. Some may prefer to listen to music "free field" for convenience of sharing the experience with family and friends. Research findings conducted within a "real-life" context provide examples of spontaneous socialization when individualized music is presented "free field" [24].

Importantly, the guideline is comprehensive with an additional section dedicated to evaluation of outcome and process factors. An extensive appendix includes all the tools necessary for implementation of individualized music. This is important for replication in clinical practice and empirical research.

Quick Reference Guide

A quick reference guide [25] is also available as a free resource for professional health care providers, paraprofessionals (e.g. certified nursing assistants) and family members. This document is most appropriate for staff and family who have been trained in the comprehensive guideline but find the summarized version highlighting key points to be helpful in practice. However, the full evidence-based guideline should be accessible due to its comprehensive nature and the inclusion of tools required for assessment, implementation, and evaluation.

Evidence-Based Interventions for Transitions in Care for Individuals Living with Dementia

Individualized music can be used in a variety of settings from early to advanced stages of dementia. Supporting research is presented to discuss its versatility for transitions in care. To reiterate, the research cited in this article is not exhaustive but includes classic research, those with a unique contribution, and those that are more recent. Please refer to the free pdf guideline for a complete listing. Individualized music has been successfully implemented in home care [26,27], adult day care [11], assisted living [28], long-term care [20,24,29-34], post-acute care [33], and palliative care for the advanced stages of dementia [35]. In addition, the use of individualized music for agitation in PWD has been proposed for disaster preparedness [36]. Also a researcher in Australia is exploring the incorporation of individualized music in their occupational therapy "tool kit" [37].

Fundamentals of Person-Centered Care for Individuals with Dementia

The multidimensional aspects, of individualized music for PWD, are aligned with the holistic person-centered approach to care as described in the middle range theory

of IMIA [11]. The intervention focuses on preserved abilities that allow music to serve as a catalyst to unveil the individual's personhood. This intervention is appropriate in the early stages of dementia as well as the advanced stages when processing verbal language becomes increasingly impaired. *Assessment of Personal Music Preference* incorporates the use and meaning of music in the person's life along with its relationship to the person's ethnic heritage and religiosity [20]. The following examples are provided on the use of individualized music within different cultures and countries: France [38]; Iran [39]; Great Britain [40]; Japan [22,23]; Norway [41,42]; Sweden [43]; Spain [44]; and Taiwan [31,32,45]. In addition, individualized music has been tailored to the cultural and ethnic heritage of a number of Americans including: Czech American [11] and Mexican American [46]. An African American woman residing in the southern region of the country, found gospel music sung by Mahalia Jackson especially comforting [24]. Also, the continuing education program developed by Gerdner [47] contains an actual case example (with fictitious identifying information) of an Italian American woman who spoke minimal English and was calmed while listening to the Italian lyrics of songs sung by Dean Martin. A project, currently underway, is assessing the effectiveness and feasibility of using individualized music with a group of Mennonite PWD. Recorded song selections are limited to religious acapella music.

Meeting the Informational, Educational, and Psychosocial Support Needs of Persons Living with Dementia and their Family Caregivers

The purpose of individualized music is to provide a relatively inexpensive approach to the management of agitation in PWD. Agitated behaviors negatively impact quality of life for the PWD as well as the family caregiver. Research findings have shown BPSD in PWD resulted in family caregiver stress as measured by a reduced salivary immunoglobulin A, causing a compromised immune response [48] and depression as measured by the *Geriatric Depression Scale* [49].

Research has supported the effectiveness of individualized music when implementation by trained staff and family under "real life" conditions [24,26-29,32,35,40,50]. Throughout these studies, the recipient's positive response to the music served as a facilitator or motivating factor for implementation.

Free Learning Resources

In keeping with the mission of developing a relatively inexpensive intervention, the author has made extensive efforts for the availability of free online learning resources. The full evidence-based guideline is available through the University of Michigan, School of Nursing, National Nursing Practice Network (NNPN) [7]. A free online learning module, *Individualized Music for Persons with ADRD*, is posted through the Geriatric Education Center at Stanford University [51]. In addition, Sigma Theta Tau International in partnership with the John A. Harford Foundation has posted an online continuing education program on the management of agitation in persons with dementia through the use of individualized music [47]. Free access requires membership to Sigma Theta Tau. Organizations in Australia (Dementia Behaviour Assessment & Management Service, Community Industry Group and Australian Red Cross) have also posted a document entitled, *Individualised Music Intervention: Program Guidelines for Aged Services* [52].

Children and Family Picture Book

Persons with ADRD are often cared for within multigenerational homes. More specifically, 26% of family caregivers have children younger than 18 years of age living with them (National Alliance for Caregiving and the Alzheimer's Association). A U.S. study including 372 dementia caregivers, reported that 4% of children assisted with the care of their grandparents [53].

Very little research has been done regarding the relationship between grandchildren and their corresponding grandparent with dementia. One important study was conducted in Spain by Celdrán, Triadó, and Villar [54]. Findings reported that adolescent grandchildren who had a close relationship with their grandparent prior to the onset of dementia were more likely to identify a decline in this relationship following the onset of dementia. Behavioral disturbances were identified as a primary reason for this decline. Investigators recommended including grandchildren in informational programs about Alzheimer's disease (AD) and addressing issues that are most distressing to them. A recently published book assists in this effort.

Musical Memories is a realistic fiction picture book for children and their family [55]. This genre "portrays the real world in all of its dimensions" [56]. The story provides an honest and respectful depiction of an older person with AD, to promote understanding and compassion. Although targeted for children ages 8 to 12, the underlying message of understanding and compassion transcends to persons of all ages.

The story is unique in that it reflects the current knowledge and understanding of AD, going beyond the issue of short-term memory impairment to address behaviors that may be especially distressing to young people. *Musical Memories* promotes a problem solving approach that models the use of a simple intergenerational activity (listening to music) to stimulate reminiscence, thus promoting communication and understanding to empower a granddaughter in maintaining a relationship with her grandmother who has AD.

The story parallels Gabrielle's love of music and ballet with her Grandmother's love of Frank Sinatra's music and dancing. Gabrielle enjoys coming home from school and listening to music with Grandmother while she shares the stories of her youth. Importantly, the storyline also incorporates information to help children understand the cause of behaviors exhibited by the PWD. Misinterpretation of environmental stimuli can be especially stressful. Early in the story, a scene is presented in which Gabrielle becomes frightened when she misinterprets her own reflection on a dusty mirror in a darkened corner, for that of a stranger. Grandmother experiences a parallel example near the conclusion of the story. By recalling her earlier experience, Gabrielle is able to understand the distress that Grandmother is feeling. However, unlike Gabrielle's experience, no one is able to reason with Grandmother to alleviate her stress. This provides an opportunity for Gabrielle to apply all that she has learned. The family keeps Grandmother safe while Gabrielle plays Grandmother's favorite music, until she is gradually able to relax. *Author Notes* at the back of the book are written to supplement and promote the learning experience of this story.

Musical Memories may also be used as a resource for healthcare professionals and teachers who are working with children or a family caregiver living in a multigenerational home that includes an older person with ADRD.

A website (<https://gerdnerlinda.wixsite.com/musical-memories>) provides free learning resources for Kids, Family and Teachers to enhance the educational value of the book. A link is also available for Health Care Providers that includes a free downloadable pdf of the *Evidence-Based Guideline for Individualized Music in Persons with Dementia* [7].

Assessing Risk Benefit Ratio

The 6th edition of this evidence-based guideline provides a step-by-step approach for the safe use of

individualized music for PWD when implemented by trained health care professionals, staff and family. When making a decision regarding implementation of any intervention it is important to weigh the risks against the benefits. The benefits of individualized music for this population far out weight the risks. However, it is important to read and understand the risks as identified in the guideline and to take the necessary precautions. For example, it is recommended that the person be able to hear a normal speaking voice at a distance of approximately 1-1/2 feet, to benefit from this intervention. Impaired hearing may result in the distortion of sound which in itself may be a source of irritation. In addition, the volume should be set at an appropriate level. A setting that is too loud is likely to cause the person to become agitated.

It is important to closely monitor the person's response to the music when initially presented. If an increase in anxiety or agitation is noted, stop the music and remain with the person to insure their safety until their anxiety is reduced. Review the completed assessment questionnaire for an alternative music selection. Play the new selection at a later date, if the person responds adversely an alternative non-pharmacological intervention should be explored.

When music is played "free field" other residents in the immediate environment should be assessed to insure the music is not disturbing to them. In contrast, one surprising and memorable example occurred during a study in which the intervention was implemented by trained staff and family under "real life" conditions. An elderly woman listened to individualized music in her room on prescribed days and times. Her adult daughter was visiting and turned the music on during the identified time. Two of the women from down the hall came into the room to listen to the music sung by Frank Sinatra. Normally, the woman for which the music was intended was rather quiet and withdrawn. This time all three women were listening to the music and reminiscing about the music and their lives. The daughter was especially pleased in seeing her mother's increased social interaction [24].

Along with a statistically significant reduction in agitated behaviors while listening to individualized music, anecdotal notes and open-ended interviews provide examples of positive affect, expressed satisfaction, meaningful interaction with others and increased social interaction. Overall, staff found the positive response to be a facilitator for implementation of the intervention. When ask to identify barriers a CNA stated, "sometimes we were short staffed - that's about it." Another CNA

stated, “They [family] enjoyed it and they also go along with the music and take over if they see I’m busy” [24].

More recently, empirical evidence has shown positive effects of individualized music in persons with dementia who are living in long-term care facilities as well as those residing in assisted living facilities [28,57]. In addition, the use of individualized music for persons with dementia when implemented by family caregivers has been reported to provide an increase in quality of life for both the caregiver as well as the person with dementia [50]. There is need for additional research on the effects of individualized music on quality of life for persons with dementia.

Discussion

The current evidence-base guideline for Individualized Music is the culmination of nearly 30 years of clinical and empirical testing. The step-by-step approach explained in this guideline is important for the replication of further research to evaluate the effects of individualized music and to guide clinical practice in a safe consistent manner. Findings show this intervention has benefited persons from early onset to advanced stages of dementia. The intervention is individualized on multiple levels and takes a person-centered approach to care. *Assessment of Personal Music Preference* provides a holistic perspective of the importance of music in the person’s life prior to cognitive impairment. There is need for a greater presence of evidence-based practice in long-term care facilities. However, staff often lack a basic understanding of research, translational research and evidence-based practice to achieve this goal [58]. Without this foundation, administration and staff in long-term care become vulnerable to interventions that are driven by marketing strategies, become expensive over time, and lack the scientific rigor of evidence-based guidelines.

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