



# Evidence-Based Guideline: Individualized Music for Persons with Dementia (7<sup>th</sup> Edition) — Non-Pharmacological Intervention for Agitation

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## Abstract

Individualized music is a non-pharmacological intervention for the management of agitation in persons with dementia. It is supported by the *Middle-Range Theory of Individualized Music Intervention for Agitation (IMIA)*, including testable propositions. The Evidence-Based Guideline: Individualized Music for Persons with Dementia (PWD) was originally published in 1996, has recently been updated and is now in its 7th edition. The current edition is 81 pages in length and includes 144 references. This guideline provides the culmination of over 30 years of research and clinical implementation. 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 in implementation and evaluation of outcome measures. The intervention is individualized at multiple levels, and is more than simply playing preferred music for the PWD. The intervention emphasizes personhood by including the role of music in the person’s life prior to the onset of cognitive impairment. This includes the role of music in the person’s ethnic identity and religious practice. The intervention has been empirically and clinically tested by scholars in an expanding number of countries. Individualized music is versatile and has been successfully used in home care, adult day care, assisted living, long-term care, post-acute care, and palliative care. As with previous editions, the 7<sup>th</sup> edition is available, along with all supporting documents and forms, as a free downloadable pdf.

**Keywords:** Individualized Music; Dementia; Music; Cognitive Impairment: Agitation

**Abbreviations:** IMIA: Individualized Music Intervention for Agitation; ADRD: Alzheimer’s disease or Related Dementias; PWD: Persons with Dementia; NPS: Neuropsychological Symptoms; CBC: Canadian Broadcasting Corporation; PLST: Progressively Lowered Stress Threshold; Cg A: Chromogranin A; IgA: Immunoglobulin A; WHO: World Health Organization.

## Introduction

In 2020, Alzheimer’s Disease International estimated 55 million people living throughout the world with

Alzheimer’s disease or related dementias (ADRD). Dementia is characterized by cognitive impairment, a key antecedent to agitation [1-6].

An early study of community-dwelling persons with Alzheimer’s disease, living in the United States, found 67.5% exhibited agitation [7]. Similarly, a more recent study, analyzed a retrospective U.S. database of community-dwelling individuals with ADRD and found 61.3% exhibited agitation [8].

Agitation, in persons with dementia (PWD) negatively

impacts quality of life by interfering with delivery of care and social interaction [9,10]. In addition, agitation has been correlated with an increased incidence of falls [11], delayed onset of sleep, and disruption of nighttime sleep [12,13]. Nursing staff have identified agitated behaviors as a major stressor [14]. Behavioral and psychological symptoms, such as agitation, has also been associated with family caregiver stress and burden [13,15-17], low secretion rates of immunoglobulin A in saliva with a compromised immune response [18], depression [19,20], and reduced quality of life [19]. A meta-analysis conducted by Cheng [21] found that neuropsychological symptoms (NPS), primarily disruptive behaviors (e.g. agitation) in persons with dementia are the most predictive of caregiver burden and depression.

### Pioneering Work

Gerdner worked for six years in an administrative role in long-term care during the 1980s. During that time, she observed the negative effects of agitation on residents and the associated stress it caused staff and family. She recognized the critical need for an alternative non-pharmacological intervention for the management of agitation in persons with dementia and began exploring the use of music for this purpose. There was need for a cost effective intervention, that could easily be taught and used by nursing staff on an "as needed" basis, 24 hours per day, 7 days per week.

Gerdner matriculated into a top ranked graduate school of nursing, knowing what her focus of scholarship and research would be. She did a thorough literature review with focus on behavioral syndromes, as identified by Cohen-Mansfield and Billig [22] along with additional background information and potential antecedents of agitation as identified by Hall and Buckwalter [4]. This provided a beginning framework for the incorporation of individualized music as an intervention. Individualized music is conceptually defined as music that had been integrated into the person's life and is based on individualized preference prior to the onset of cognitive impairment [23]. The person's favorite recorded music was identified, obtained and served as the intervention for this pilot study to test the effects of individualized music for reducing agitation in persons with dementia [23,24]. Findings were very promising and provided the foundation for a more rigorous study.

### Middle-Range Theory

In preparation for the next phase of the research trajectory, Gerdner [1] developed the *Middle-Range Theory of Individualized Music Intervention for Agitation* (IMIA). This led to a theory based intervention with testable theoretical propositions. Overall she theorizes that music may be used

as a means of communicating, even in the advanced stages of ADRD, when the person has a decreased ability or an inability to understand verbal language and a decreased ability to interpret internal and external environmental stimuli.

Importantly it is believed that receptive and expressive musical abilities are often preserved long after the diminished ability to process or express verbal language. However, experts disagree on the hypothesized mechanism by which this occurs [25-31].

ADRD is usually associated with short-term memory loss; whereas remote memory often remains surprisingly intact. Therefore, it is theorized that the presentation of carefully selected music, based on personal preference, will provide an opportunity to stimulate remote memory. The elicitation of memories associated with positive feelings, such as happiness and love, will have a soothing effect on the person to prevent or alleviate agitation. This changes the focus of attention and provides an interpretable stimulus, overriding stimuli in the environment that is meaningless or confusing [1].

An understanding of agitation in persons with ADRD is important to the identification of potential antecedents. The Middle-Range Theory of IMIA incorporates the Progressively Lowered Stress Threshold (PLST) model as developed by Hall and Buckwalter [4]. This model postulates that a progressive decline in cognition, as associated with dementia, results in a progressive decline in the person's stress threshold. Therefore, over time less and less stressors are required to meet and exceed the person's stress threshold. As stressors accumulate and approach the threshold the person begins exhibiting signs of anxiety. This is the ideal time to intervene with a non-pharmacological intervention, such as individualized music. Without intervention, stressors continue to accumulate and will exceed the stress threshold, resulting in dysfunctional behavior, such as agitation [32].

When a physiological stressor, such as pain or infection is suspected [33,34], medical consultation is warranted. Importantly, individualized music may be used to supplement medical care, but never to replace it.

The evidence-based guideline includes information on the assessment of temporal patterning, in an effort to individualize timing of the intervention. The subtle behaviors of anxiety leading to agitation becomes more apparent as behavioral patterning is observed over time. For example, following training and experience in observing temporal patterning, one certified nursing assistant said, "When she gets anxious she gets confused. When I turn the music on she pretty well gets rid of the anxiety..." [32, p. 28].

## Seminal Study

A more rigorous research design with a larger sample size was used to test the intervention as well as specific propositions for the Middle-Range Theory of IMIA [35]. An experimental repeated measures pretest-posttest cross over design was used to compare the immediate and residual effects of individualized music to classical “relaxation” music, relative to baseline on the frequency of agitated behaviors in elderly persons with ADRD. Thirty-nine subjects with severe cognitive impairment were recruited from six long-term care facilities in Iowa. Baseline data were collected for 3 weeks. Findings from the music preference questionnaire (described later) guided the selection of individualized music. Group A (n=16) received individualized music for 6 weeks followed by a 2-week “washout” period and 6 weeks of classical “relaxation” music. Group B (n=23) received the same protocol but in reverse order. Music interventions were presented for 30 minutes, two times per week. The Modified Cohen-Mansfield Agitation Inventory measured the dependent variable. A repeated measures analysis of variance with Bonferroni post hoc test showed a significant reduction in agitation during and following individualized music compared to classical music.

This research won the International Psychogeriatric Association / Bayer Research Award at the 1999 conference in Vancouver, British Columbia, Canada. This led to a featured interview on Canadian Broadcasting Corporation (CBC) Television Newsworld for the program “As It Happens with B. Budd/S. Cole” on August 17, 1999, and re-aired on August 18, 1999.

Dr. Gerdner's seminal study was published in *International Psychogeriatrics* [36]. This study was identified as the 4th most highly cited research article in this top-tier journal. Ten years later, she was asked to write a follow-up article for publication in *International Psychogeriatrics* to address the current status of her work [37]. This was accompanied by a commentary written by Dr. Nicoa T. Lautenschlager.

Importantly Japanese researchers, Suzuki and colleagues, [38] expanded the evaluation of individualized music on persons with dementia by including biophysiological and functional measures in addition to behavioral outcomes. The experimental group, who received individualized music, 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 chromogranin A (CgA), following session 16. The researchers concluded that “the changes in CgA levels supported Gerdner's mid-

range theory” (p. 17). No significant findings occurred in the control group across outcome measures.

In 2007, Suzuki and colleagues expanded on the previous study by incorporating immunoglobulin A (IgA) as well as saliva chromogranin A (CgA). 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 finding supports Gerdner's mid-range theory.

## Evidence-Based Guideline

An evidence-based guideline for the theory-based intervention of Individualized Music was originally published in 1997 and is now in its 7<sup>th</sup> edition. Overtime, there has been an exerted effort to maintain consistency in the rigorous scholarship of this document. The guideline continues to provide a step-by-step description of the intervention to insure consistency for implementation and evaluation of outcome measures. Each step of the intervention is followed by accompanying citations including the strength of supporting evidence. Grading, ranges from A (evidence from well-designed meta-analysis) to D (evidence from expert opinion or multiple case reports). An appendix includes all of the necessary forms for implementation and evaluation including outcome and process factors.

Importantly, this intervention is *individualized* at multiple levels, and involves more than simply playing preferred music for a person with dementia. Timing of the intervention should also be individualized when used for the purpose of alleviating anxiety and agitation. Assessment of temporal patterning of agitation is incorporated into the assessment phase, to individualize the timing of the intervention. Ideally, the intervention should be started when the person initially shows signs of anxiety.

Individualized music is versatile, allowing the intervention to be implemented in a variety of settings. Research findings often focus on its use in long-term care, but studies have also identified its effectiveness in reducing anxiety and agitation in the home [39], adult day care [1], assisted living [40,41], acute care [42], post-acute care [43], rehabilitation [44], and palliative care [45].

With the reduction of anxiety and agitation, anecdotal data has shown an expanding number of positive outcomes including: positive affect, expressed satisfaction, meaningful interaction with others, reduction in loneliness / isolation, and indicators of increased quality of life.

One study evaluated the effectiveness of individualized

music when implemented “free field” under real life conditions by trained staff and family members. Informants reported that music served as a catalyst for meaningful interactions with co-residents, staff and family. One adult daughter said,

When I turn the music on, the elderly ladies come in Mom's room and they'll set on the bed. Mom doesn't interact a whole lot any more. However, two or three times I've walked in and there was mom's roommate and two or three other little ladies sitting on the bed...and they're actually talking because they are listening to the music. They love Frank Sinatra...so I think that helps her socialization as well [32, p. 28].

Other researchers reported when individualized music was implemented by family caregivers the music seemed to provide an increase in quality of life for both the caregiver, as well as the PWD [46].

The updated guideline reflects the expanding body of research and knowledge related to this intervention. Select revisions, worthy of highlighting include the following: (1) Expansion of the construct of agitation. (2) *Assessment of Individualized (Personal) Music Preference* (2<sup>nd</sup> Edition) (3) Ethnicity an inherent criterion. 4. Mode of delivery.

### Expansion of the Construct of Agitation

Dr. Jiska Cohen-Mansfield pioneered the construct of agitation [22]. Her work provides the operational definition of agitation. As she continues to expand her research in this area, updated references have been added to reflect the current knowledge. To be inclusive, the guideline also incorporates work of the Agitation Definition Work Group (ADWG), established by the International Psychogeriatric Association [47].

### Assessment of Individualized (Personal) Music Preference (2<sup>nd</sup> Edition).

In 2000, two questionnaires were developed by Gerdner, Hartsock, and Buckwalter [36] to determine the person's individualized music preference. These questionnaires have always been included in the evidence-based guideline. The first version provides an opportunity for the recipient, in the early stages of cognitive impairment, to answer questions about the role of music during early life along with specific music preferences. The second version is for completion by a knowledgeable family member or friend.

These questionnaires were updated in 2020 to reflect a broadened selection of music genres and dancing styles, and include appropriate gender terminology. The title was also revised for consistency in terminology of the intervention

itself, *Assessment of Individualized Music Preference* (2<sup>nd</sup> Edition) [48]. As in the original questionnaire, a holistic approach is used to identify the role of music in the person's life, prior to the onset of cognitive impairment. Questions are sequenced from general to specific. This guides the informant in an effort to narrow the focus to individualized selections that are meaningful for the promotion of positive memories. Copies of these questionnaires are included in the guideline.

### Ethnicity an Inherent Criterion

Individualized music is a person-centered, holistic intervention that has been used by researchers and clinicians from a variety of countries. Importantly, ethnicity is an inherent criterion for assessment of individualized music for persons with ADRD [2]. Wade [50], an ethnomusicologist, explains “every known people in the world exercise their creative imaginations to organize sound in some way that is different than the way they organize speech” (p. 6). This is done to make “music meaningful and useful in their lives” (p. 1). Music is one means of ethnic expression and identity [49].

Although the majority of research has been conducted in the United States, there are growing numbers of countries that are making important contributions to the literature. These include: France [52], Germany [53,54], Hong Kong [55], Iran [56], Italy [57], Japan [38,58,59], Norway [60], Sweden [61], Taiwan [62-64], and the United Kingdom [65].

Importantly, both versions of the original questionnaire were adapted and translated into Mandarin Chinese in 2021, by researcher, Pei-Chao Lin. She is conducting research through a Taiwanese university to establish psychometric properties of this questionnaire.

Sometimes there may be a relationship between ethnicity and religion. For example, historically Mennonites have Swiss Germanic ethnic roots. Anabaptist religion is also embedded in their lives. The author trained staff and family on the use of individualized music in a Mennonite long-term care facility. The religious sects who lived there were allowed to use electricity. Family members provided music and listening devices. Individualization of music included a variety of hymns sung in acapella four-part harmony.

The author also implemented individualized music at a long-term care facility in South Carolina during the 1990s and found a number of residents who preferred Black Gospel music sung by Mahalia Jackson and Al Green.

### Mode of Delivery

Initially, individualized music was presented “free field” [1,23,35,32,39,66,62,64]. Clinically, this approach is useful

in promoting spontaneous social interaction of the older adult with others. For example, family and staff caregivers have reported that when played “free field,” individualized music became a stimulus for positive social interaction, increased feelings of caregiver satisfaction, as well as perceived improvement in the care recipient’s quality of life [32]. However, if the music becomes disturbing to others in the immediate environment it may be possible to administer music via headphones [2].

With the advancement of technology, many researchers and clinicians began using the latest technology for this intervention. With regard to the use of headphones, the author has consistently cautioned professional and lay caregivers to insure the volume is set at an appropriate level. A volume that is too high may cause agitation or hearing loss. In addition, warnings have emphasized the need to assess the person’s tolerance to headphones, since use may be discomforting or confusing to the persons with advanced dementia.

Please be mindful of these warnings when selecting technology for playing and listening to individualized music. Factors of concern include: volume control, duration, degree of noise cancellation, and appropriate use with hearing aids.

Over time, health warnings regarding the use of headphones have become increasingly prevalent. For example, the World Health Organization (WHO) cautions the use of headphones with regard to volume and duration. More specifically, they recommend only playing music via headphones for a maximum of one hour per day with volume set at approximately 60 percent of maximum [68,69].

A more serious safety issue involves the use of headphones that block external or environmental sounds, as represented in the following example. An adult daughter reported that her elderly father was home alone, “listening to music with headphones, in his bedroom.” Neighbors were alerted to a fire in the man’s home, when flames ignited motorbikes near the physical structure of his house. This resulted in an explosion of “flying magnesium.” Headphones, worn by the elder man, prevented him from hearing the loud explosion. The daughter explained, her father “did not hear anything until glass got broken.” Rescue attempts by neighbors were “thwarted” by the piles of personal items blocking the windows. The fire department was called and the daughter was grateful they were able to rescue her father. The house was destroyed by the fire [70].

**Caution When Using Headphones Over Hearing AIDs:** Chien and Lin [71], conducted the first estimate of hearing aid prevalence in the U.S. population. A large representative sample, based on audio-metric data, found an estimated 3.8

million or 14.2% of Americans 50 years or older, had hearing loss and wore hearing aids. In contrast, 22.9 million older Americans had audio-metric hearing loss but did not wear hearing aids.

Headphones applied over hearing aids may not provide the quality of sound that is intended. Germain [72] identifies a variety of hearing aid types, but concluded they do not work equally well with headphones. One older adult male was assessed and fitted with a pair of hearing aids by the Veteran’s Administration. Unfortunately, he continued to have difficulty finding a set of headphones of the quality he desired to enjoy his favorite music [72]. Under these situations, it may be helpful to consult an audiologist who has a strong knowledge of hearing aid types with regard to fit and tonal quality of available headphones.

### Consumer Version

The full unabridged evidence-based guideline is detailed and lengthy, but critical to providing a complete understanding of the intervention along with the supporting research. The full version also includes tools to assess: temporal patterning of agitation, individualized music preference, as well as outcome and process monitors.

A consumer version is also available that provides more concise information on key concepts. This version is only advised for those who have previously received training or instruction via the unabridged guideline.

### Teaching Modalities

In 2004, Gerdner developed an on-line learning module for nurses through Sigma Theta Tau International. This module provides continuing education units, that are free to members, the most recent version was launched in 2017.

To support multi-disciplinary health care professionals, a free online learning module entitled, *Individualized Music for Persons with ADRD*, is available through the Stanford Geriatric Education Center at Stanford University School of Medicine [51].

### Musical Memories

Individuals with dementia are members of multigenerational families. The learning needs of children are also important. *Musical Memories* by Gerdner and Gearino [73] is an innovative example of how an evidence-based guideline can be translated into an educational tool for children and their parents. As a realistic fiction picture book, this genre portrays a real life scenario with multiple dimensions to teach the basic principles of individualized

music to children and their family members. This knowledge is translated into an age-appropriate story that is engaging and empowering to the child. The book is intended to help children cope with the challenging behaviors associated with Alzheimer's disease and to provide a new model of support to assist in promoting a positive relationship with the person diagnosed with Alzheimer's disease [73]. Author notes that directly relate to and build on content presented in the story strengthens its educational value. The author also created a website that provides additional resources for the child, family members, teachers / health care professionals.

## Conclusion

Individualized music is a theory-driven intervention that uses a person-centered, holistic approach. It is important to assess how music was incorporated into the person's life prior to the onset of cognitive impairment. There is also need to explore the role music may have played in the person's ethnic identity and/or religious practices.

Even if born in the United States, a person may have been raised with the strong ethnic heritage of their parents' country of birth. English may have been a secondary language in their home when they were young. This was the case with two older adults who preferred songs with lyrics sung in the primary language of their youth. One was an Italian American and the other Czech American.

To further promote the use of this intervention both the comprehensive evidence-based guideline and condensed or abridged consumer version is available at no charge on the following websites: <https://www.researchgate.net/profile/Linda-Gerdner> and <https://gerdnerlinda.wixsite.com/musicalmemories/healthcare-professionals>.

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. Gerdner has devoted over 30 years of her career advocating for and supporting both formal, informal and family caregivers of persons with dementia. She has disseminated her work on individualized music at regional, national and international platforms.

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