

## Individualized music for dementia: Evolution and application of evidence-based protocol

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### Abstract

The theory-based intervention of individualized music has been evaluated clinically and empirically leading to advancement and refinement of an evidence-based protocol, currently in its 5th edition. An expanded version of the protocol was written for professional health care providers with a consumer version tailored for family caregivers. The underlying mid-range theory is presented along with a seminal study that was followed by further research in the United States, Canada, Great Britain, France, Sweden, Norway, Japan and Taiwan. Key studies are summarized. Given its efficacy when implemented by research staff, studies have advanced to testing the intervention under real-life conditions when implemented and evaluated by trained nursing assistants in long-term care facilities and visiting family members. In addition, one study evaluated the implementation of music by family members in the home setting. Initial research focused on agitation as the dependent variable with subsequent research indicating a more holistic response such as positive affect, expressed satisfaction, and meaningful interaction with others. The article advances by describing on-line programs designed to train health care professionals in the assessment, implementation and evaluation of individualized music. In addition, Gerdner has written a story for a

picture book intended for children and their families (in press). The story models principles of individualized music to elicit positive memories, reduce anxiety and agitation, and promote communication. The article concludes with implications for future research.

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**Key words:** Individualized music; Dementia; Alzheimer's disease; Agitation; Evidence-based protocol

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### SIGNIFICANCE

In 2009, Alzheimer's Disease International<sup>[1]</sup> estimated by 2010 there would be 35 million people worldwide afflicted with Alzheimer's disease and related dementias (ADRD). This organization also predicted that the prevalence of ADRD would nearly double every 20 years for a total of 65.7 million people afflicted with the disease by 2030 and 115.4 million by 2050<sup>[1]</sup>.

ADRD is characterized by cognitive impairment. Researchers<sup>[2]</sup> estimate the presence of agitation in 70% to 90% of persons in the advanced stages of ADRD. Agitation interferes with care delivery and social interaction, ultimately having a negative impact on the person's quality of life<sup>[3]</sup>.

### THEORY-BASED INTERVENTION

Gerdner<sup>[4]</sup> was the first to develop and test a research

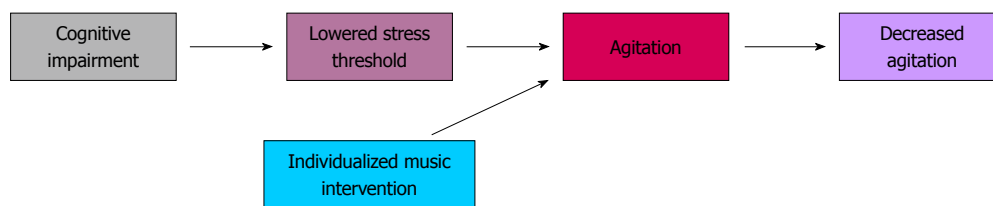


Figure 1 Gerdner's mid-range theory of individualized music intervention for agitation<sup>[11]</sup>.

protocol to evaluate the use of individualized music as an alternative intervention for the management of agitation in persons with ADRD. Individualized music is defined as music that has been integrated into the person's life and is based on personal preference<sup>[4]</sup>. Publication of this pioneer pilot study<sup>[5]</sup> led to additional research, with findings that support the use of individualized music in reducing agitation in persons with ADRD<sup>[6-10]</sup>.

Gerdner<sup>[11]</sup> advanced this work by developing a theoretical foundation for this intervention. Elements of the mid-range theory of individualized music intervention for agitation (IMIA) include: cognitive impairment, progressively lowered stress threshold, agitation, and individualized music (Figure 1).

Cognitive impairment, as found in persons with ADRD, is a key antecedent to agitation. Hall *et al*<sup>[12]</sup> attribute this to a decreased ability to receive and process sensory stimuli, resulting in a progressive decline in the person's stress threshold and a heightened potential for anxiety. In other words, as the disease progresses, fewer stressors are required to meet and exceed the stress threshold, resulting in anxious and agitated behaviors<sup>[12]</sup>. Cohen-Mansfield *et al*<sup>[13]</sup> define agitation as an "inappropriate verbal, vocal or motor activity that is not explained by need and confusion *per se*". They further explain that although agitation probably results from a combination of needs and confusion, these antecedent conditions are not always apparent<sup>[13]</sup>.

Individualized music may be used as an alternative intervention for the management of agitation in ADRD. The intervention involves carefully selected music, based on the person's preference, prior to the onset of cognitive impairment. Gerdner<sup>[11]</sup> theorizes that music may be used as a means of communicating with the person even in the advanced stages of ADRD when the person has an impaired ability to understand verbal language and has a decreased ability to interpret environmental stimuli. It is further theorized that the presentation of individualized music will provide an opportunity to stimulate remote memory. This changes the focus of attention and provides an interpretable stimulus, overriding stimuli in the environment that is meaningless or confusing. The elicitation of memories associated with positive feelings will have a soothing effect on the person with dementia, which in turn will prevent or alleviate agitation<sup>[11]</sup>. It is further theorized that individualized music is most effective when it is implemented prior to the peak level of agitation.

## SEMINAL STUDY

The strengths and limitations of preliminary research were used to design a more rigorous study with a larger sample for the purpose of testing the propositions of the mid-range theory of IMIA. Gerdner<sup>[14]</sup> employed 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 persons with ADRD. Thirty-nine subjects were recruited from six long-term care facilities in Iowa. The sample consisted of 30 women and 9 men (mean age, 82 years) with severe cognitive impairment, as measured by the Global Deterioration Scale<sup>[15]</sup>. Baseline data were collected for 3 wk. Family members completed a written questionnaire that was reviewed by the investigator. Answers were explored with the informant to refine information as a means of determining specific music selections. Subjects were divided into two groups. Group A ( $n = 16$ ) received individualized music for 6 wk followed by a 2-wk "washout" period and 6 wk of classical "relaxation" music. Group B ( $n = 23$ ) received the same protocol but in reverse order. The interventions consisted of pre-recorded music presented for 30 min, two times per week. A modified version of the Cohen-Mansfield Agitation Inventory<sup>[16]</sup> was used to measure 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 "relaxation" music.

This study became the impetus for additional studies conducted in the United States, Canada, Great Britain, France, Sweden, Norway, Japan and Taiwan. These efforts have resulted in an expanding body of research that supports the use of this intervention for the management of agitation<sup>[17-24]</sup>. In addition, a study is currently being conducted in Iran to further test the effects of individualized music.

## EVIDENCE-BASED PROTOCOL

Gerdner's work served as the foundation for an expanding body of empirical and clinical evidence, leading to development of the evidence-based protocol of Individualized Music for Elders with Dementia. This protocol was originally published in 1996 with the 5th and most recent version published in 2007<sup>[25]</sup>. This expanded version was specifically written for professional health care providers.

The protocol identifies risk factors for agitation, assessment criteria, a detailed description of the intervention, evaluation of patient outcomes and process factors. An evidence grade schema is used to assign a specific grade, based on the strength and type of evidence, for each recommendation within the protocol. To facilitate accessibility an abridged and updated version of the protocol was published in a 2010 issue of the *Journal of Gerontological Nursing*<sup>[26]</sup>.

Following instruction, family members may also implement individualized music. Consequently a companion consumer version was added to the evidence-based protocol in 2001 and updated in 2007<sup>[27]</sup>. The consumer version provides a simplified format, tailored for family caregivers.

The evidence-based protocol includes The Assessment of Personal Music Preference Questionnaire (APMPQ)<sup>[28]</sup> that has been developed and tested<sup>[17]</sup> to assist in the selection of individualized music. Questions are used to explore the meaning of music in the person's life and identify preferred song titles. Because musical selections are often closely aligned with specific performers this also become an important part of the assessment process. When cognitive impairment prevents the person from identifying or expressing these preferences an alternate version of the questionnaire is available for completion by a close family member. The alternate version of APMPQ has been successfully used by family members of residents living in long-term care facilities<sup>[17]</sup> and those who care for an elder at home<sup>[19]</sup>.

The expected effect of individualized music is dependent on the identification and implementation of music based on the patient's specific music preferences. For example, one older woman's favorite music was an LP record (now available on compact disc) performed by Elvis Presley entitled, *Amazing Grace: His Greatest Sacred Performances*.

Individualized music may not be suitable for everyone. For example, it would not be appropriate for a person who did not have an appreciation for music prior to the onset of cognitive impairment. A positive correlation is expected between the degree of significance that music had in the person's life prior to the onset of dementia and effectiveness of the intervention<sup>[25]</sup>.

## ADVANCING THE SCIENCE

There is need to advance the science by evaluating the effects of individualized music using biophysiological outcome measures. Japanese researchers, Suzuki *et al*<sup>[21]</sup> incorporated preferred music into a small group singing activity for persons with ADRD. Outcome measure included biophysiological measures in addition to behavioral outcome measures. The study involved 10 subjects with dementia who participated in the music sessions twice per week for 8 wk. During the corresponding time period, 13 subjects participated in a comparison intervention (i.e., games, drawing, pasting pictures). Analysis

compared baseline data to 1-wk post intervention scores. Findings indicated 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 stress index as measured by salivary chomogranin A (CgA) following session 16. The authors concluded, "the changes in CgA levels supported Gerdner's mid-range theory" (p. 17). No significant findings occurred in the control group across outcome measures. It is important to note that music sessions in this study deviated from the evidence-based protocol of individualized music by incorporating active participation (i.e., singing).

Suzuki *et al*<sup>[22]</sup> expanded this research by incorporating immunoglobulin A (IgA) as well as saliva CgA and behavioral outcome measures. The study tested a small group music 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-mo 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.

## ANXIETY IN RELATIONSHIP TO AGITATION

As described by Hall *et al*<sup>[12]</sup>, anxiety is closely related to agitation. Without intervention, anxiety may escalate to agitation. The subtle cues of cumulative stress are often overlooked, advancing to agitated behaviors that present with increased frequency and intensity<sup>[12,29]</sup>. As previously explained, individualized music should be implemented prior to the peak level of agitation, ideally when the person first begins exhibiting subtle behavioral signs and symptoms<sup>[11]</sup>.

Sung *et al*<sup>[30]</sup> conducted a study in Taiwan to evaluate the evidence-based protocol of individualized music on the outcome measure of anxiety. Trained nursing staff implemented the protocol for 23 persons with ADRD, who resided in a long-term care facility. The researchers adapted *The Assessment of Personal Music Preference Questionnaire*<sup>[28]</sup> to be culturally meaningful for the Taiwanese and Chinese sample. The outcome variable was measured using the Rating Anxiety in Dementia<sup>[31]</sup> tool. It should be noted that some items such as restlessness overlap with items represented on the Cohen-Mansfield Agitation Inventory<sup>[16]</sup>. The intervention was implemented biweekly for 6 wk. Statistical analysis was conducted using an ANCOVA. Persons in the experimental group had a significantly lower level of anxious behaviors ( $F = 12.15$ ,  $P = 0.001$ ) when compared to the control group who received "standard care".

Similarly, a study conducted by Guetin *et al*<sup>[32]</sup> in France evaluated the effects of preferred music on persons in the early to moderate stages of Alzheimer's disease. Anxiety, as measured by the Hamilton scale, was incorporated as an outcome variable. A significant reduction in anxiety was identified during the implementation of individualized music.

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## TRANSLATING RESEARCH INTO PRACTICE

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Given its efficacy when implemented by research staff, it is important to evaluate the effectiveness of individualized music when implemented under real-life conditions. As a beginning effort, Gerdner<sup>[17]</sup> conducted a pilot study using mixed methods to evaluate the effects of individualized music when implemented by staff and family. Following training, staff and family implemented individualized music for eight persons with moderate to severe stages of dementia, living in a long-term care facility. The intervention was implemented over a 4-wk period. Individualized music was played daily for 30 min at a prescribed time (prior to the estimated "peak level" of agitation). The mean rate of compliance was 86.3%. In addition, staff administered music on an "as needed" basis (when the person first began exhibiting signs of agitation). Agitation was measured using a modified version of the Cohen-Mansfield Agitation Inventory<sup>[16]</sup>. A statistically significant reduction in agitation was found during the presentation of music, with an overall reduction in agitation on day shift during weeks 1-8 and on evening shift during weeks 5-8. Staff and family interviews provided convergent validity to quantitative findings. In addition, staff and family reported that individualized music provided a catalyst for meaningful interaction between the person with dementia and others.

Researchers in Taiwan also evaluated the use of individualized music when implemented by trained staff in a long-term care facility. Findings were published as two separate articles.

In one article, Sung *et al*<sup>[24]</sup>, focused on knowledge of and adherence to the evidence-based protocol for individualized music when implemented by 17 nursing staff, working in a long-term care facility in Taiwan. Initial training included an interactive educational program. Ongoing reminders, a local opinion leader, and an audit checklist were used to facilitate and monitor continued adherence to the intervention protocol. Analysis used to compare pre and post-test scores found a statistically significant improvement ( $P < 0.001$ ) in knowledge of the intervention following the training session with a mean compliance of 72%.

In a companion study, Sung *et al*<sup>[23]</sup>, focused on the resident's response to individualized music when implemented by trained nursing staff. The Cohen-Mansfield Agitation Inventory<sup>[16]</sup> was used to measure the dependent variable. The sample included an experimental group ( $n$

= 32) that received individualized music for 30 min, twice per week over 6 wk. The control group ( $n = 25$ ) received usual care without music. Findings showed that the experimental group had a statistically significant reduction in overall agitation ( $t = -2.19$ ,  $P < 0.05$ ) and physically non-aggressive behaviors ( $t = -3.75$ ,  $P < 0.0001$ ) compared to the control group.

In another published study, Park *et al*<sup>[33]</sup> report 20 in-home family caregivers were trained in the use of the evidence-based protocol for individualized music. Outcome measures included the modified Cohen-Mansfield Agitation Inventory<sup>[16]</sup>. A quasi-experimental design was used in which individualized music was implemented two times per week for 2 wk. Statistical analysis identified a significant reduction in agitation during the intervention period compared to baseline and post-intervention periods.

Park's dissertation, the study of origin<sup>[19]</sup>, added a quantitative measure for pain in addition to agitation. It is important to note that the evidence-based protocol for individualize music identifies pain as a risk factor for agitation. The protocol also cautions that agitation, secondary to a medical condition, requires treatment of the underlying cause. Under these conditions, individualized music may be used to supplement medical care.

Gallagher<sup>[34]</sup> studied the feasibility of training palliative care staff in the use of individualized music for management of agitation, during the advanced stage of dementia. Twenty-four hospice professionals were trained in the evidence-based protocol. Feasibility was assessed through the participants' knowledge and confidence in using the protocol. Findings support the practicality of training multidisciplinary staff in the implementation of individualized music.

In addition, Oslo Resource Center for Dementia and Psychiatric Care of the Elderly, under the direction of Dr. Audun Myskja, implemented the evidence-based protocol of individualized music in three nursing homes in Oslo, Sweden and has incorporated the intervention into a complementary therapy module designed with academic credits for a master's degree at Buskerud University College<sup>[35]</sup>.

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## ON-LINE TRAINING

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Continuing efforts are underway to promote and support the use of individualized music by clinicians. For example, Gerdner collaborated with Sigma Theta Tau International and the John A. Hartford Foundation for the development of a free interactive on-line continuing educational module to assist nurses in the assessment, implementation, and evaluation of individualized music. The module was first incorporated into the evidence-based protocol in 2004 and was updated in 2008<sup>[36]</sup>.

The module includes a case example, based on a real-life incident with names changed to protect confidentiality. The case example highlights the need to consider cultural background when assessing musical preference.



It involves an Italian American woman who spoke minimal English. Her preferred music includes recordings of Dean Martin singing Italian songs.

Nurse participants of the module are asked to complete an evaluation of the course. The overwhelming majority rated the content as excellent and reported that it would help them in their practice.

The New York State Department of Health has developed a series of free multi-disciplinary on-line training modules referred to as the *Electronic Dementia Guide for Excellence* (EDGE). One of the modules specifically focuses on individualized music<sup>[37]</sup>. The module provides specific guidelines for the development of a 45-min in-service, including learning objectives and a PowerPoint presentation. A sample case study is provided to assist the learner in the application of this knowledge for the assessment, implementation, and evaluation of individualized music. The module is reported to be one of the most popular in the EDGE series.

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## FACILITATORS FOR INTERVENTION

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Individualized music was developed as an alternative intervention for the management of agitation in persons with ADRD. The intervention promotes a humanistic, individualized approach to care. The use of pre-recorded music does not require special musical abilities and can therefore be implemented by trained staff and family caregivers. The recipient's positive response to individualized music has been identified as a facilitator for its continued use by staff and family<sup>[17]</sup>. The process of assessing and implementing music has been shown to promote a collaborative working relationship between staff and family<sup>[17]</sup>. Anecdotal notes and qualitative interviews also indicate that individualized music promotes positive affect, expressed satisfaction, and meaningful interaction with others; thereby supporting personhood<sup>[17]</sup>.

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## PICTURE BOOK FOR CHILDREN AND THEIR FAMILIES

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In 2011, the Alzheimer's Association<sup>[38]</sup> estimated that over 5.4 million Americans had a diagnosis of ADRD with nearly 15 million nonpaid persons caring for someone with the disease. Twenty-six percent of family caregivers have children, younger than 18 years of age, living with them<sup>[38]</sup>. Social worker, Elizabeth Smith-Bovin, declares "children as the forgotten victims of Alzheimer's disease"<sup>[39]</sup>.

Research indicates that the signs and symptoms associated with dementia adversely affect communication and relationships between afflicted grandparents and their grandchildren<sup>[40,41]</sup>. A child's response to a person with Alzheimer's disease will vary depending on factors such as: the child's age, the number of other children in the family, the closeness of the relationship between the child and the afflicted person, the availability of other family members, and the cultural background of the child<sup>[42]</sup>.

Overall, children should be encouraged to ask questions, express feelings openly<sup>[43]</sup> and remain involved with the person at a level that is appropriate to the child's ability and understanding<sup>[42]</sup>. Illustrated children's books with stories that describe children's reactions to Alzheimer's disease can be used to model ways for them to interact with people who have the disease<sup>[44,45]</sup>.

While there are a number of children's books on the market that address Alzheimer's disease, the majority provide an oversimplification of the disease and introduce the same basic content with only slight variations. These books are generally targeted for a younger audience. There is a critical need for a book of high quality for older children and their parents.

Basic principles of the evidence-based protocol of individualized have been translated into a picture book for children and their family. The book, currently in press, is authored by Gerdner and is targeted for children aged 8 to 12 years of age<sup>[46]</sup>. However, the underlying message of understanding and compassion transcends to persons of all ages. The story entitled, *Musical Memories*, is about Gabrielle and her grandmother who has Alzheimer's disease. It provides an honest and respectful depiction of an older person with this disease. The story is unique in that it reflects our current knowledge and understanding of the disease. The story goes beyond the issue of short-term memory to address antecedents of anxiety progressing to agitation. *Musical Memories* promotes a problem solving approach that models the use of a simple inter-generational activity (listening to music) to empower the child in maintaining a relationship with her grandmother. Author notes, located at the end of the book, directly relate to and build upon the story content to strengthen the educational value of the book.

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## RESEARCH IMPLICATIONS

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The accumulation of clinical and empirical data provides a strengthening body of evidence that supports the use of individualized music for persons with ADRD. As research evolves, methods and outcome measures are beginning to capture a more global response to the intervention. There is need to test the evidence-based protocol of individualized music using a stress index measure such as, salivary CgA. In addition, anecdotal data and findings from open-ended interviews indicates a positive behavioral response while listening to preferred music that "illuminates personhood" of the listener<sup>[5,14,17]</sup>. However, the recipient's positive response needs to be measured through more quantifiable outcome measures. There is also need to design large feasibility studies that evaluate the cost effectiveness of individualized music when implemented by staff in long-term care facilities.

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