



Research Article

Individualized Music Intervention for Agitation in Dementia Care and Disaster Preparedness and Resilience

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Abstract

Persons with Alzheimer's Disease and Related Dementias (ADRD) have a progressive decline in their stress threshold, causing an increased susceptibility to anxiety and advancing to agitation. This has important considerations during times of disaster that result in an unstable environment, unfamiliar surroundings (e.g., evacuation shelter) and a heightened level of activity. Disaster preparedness must address the special needs of these persons, such as non-pharmacological interventions for the management of agitation. The purpose of this article is to discuss the *Evidence-Based Guideline of Individualized Music for Persons with Dementia* (5th edition) and its potential use in mitigating agitation during and following a disaster. Key points to the success of this intervention include appropriate timing and selection of specific song titles and performers. Ethnicity is an inherent criterion for the selection of music. Individualized music is versatile and may be used in a variety of settings, such as an evacuation shelter. Following appropriate training, this protocol has been successfully implemented by health care professionals, certified nursing assistants and family members. In addition to managing agitation, individualized music has been shown to promote positive affect and meaningful interaction with others. A web address for free online access to supplemental resources on individualized music intervention is included (<http://sgec.stanford.edu/Individualized-Music-in-Persons-with-ADRD.html>).

Keywords: Agitation; Alzheimer's Disease; Dementia; Disaster preparedness; Evidence-based guideline; Individualized music

Introduction

Disasters are occurring at an increased frequency throughout the world. A disaster is any event that leads to circumstances that go

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beyond the organization's or local responder's abilities to cope. Disasters overwhelm natural defenses, established contingency plans, incapacitate people and/or deplete institutionalized resources [1,2]. Persons with Alzheimer's disease and related disorders (ADRD) are uniquely vulnerable during times of disaster. In part, this is attributed to a lowered tolerance to stress [3]. There are 5.3 million Americans diagnosed with Alzheimer's disease [4] with an estimated 44 million people throughout the world diagnosed with ADRD. This number is expected to triple by the year 2050 [5]. A number of resources have been written to guide family and health care providers in the care of these vulnerable older adults during and following a disaster [6-8]. All identify a decreased tolerance to stress in persons with Alzheimer's disease that leads to an increase in behavioral and psychological symptoms of dementia (BPSD), such as agitation. Levine and Kallymer [8] even provide actual case examples that spotlight the presentation of wandering and other agitated behaviors. Diversional activities have been recommended to alleviate these behaviors, but no specific guidelines have been provided. In addition, the Alzheimer's Association et al., [6] identify the importance of person-centered care to promote quality of life. Furthermore, Toner and Almai [9] emphasize the need to implement evidence-based interventions during times of disaster to promote quality of life.

The purpose of this article is to supplement existing resources on the care of persons with ADRD during and following disaster, by providing a theory driven, evidence-based guideline for the use of individualized music for the management of agitation in this population. We begin by explaining the lowered tolerance to stress as experienced by persons with ADRD throughout the normal disease process with enhanced vulnerability during and following a disaster. The theory driven evidence-based guideline for individualized music is explained for the daily management of agitation in persons with ADRD. This content is conceptually applied to persons with ADRD for the management of agitation when confronted with overwhelming external stressors during and following a disaster.

Agitation in Persons with Dementia

ADRD is characterized by cognitive impairment, a key antecedent to agitation [10-12]. Studies have reported agitation as high as 67.5% to 90% in persons with dementia [11,13]. This is attributed to a progressive decline in the stress threshold resulting in an increased susceptibility to anxiety, advancing to agitation and without intervention culminating in catastrophic behaviors [3].

With a lowered stress threshold, person's with ADRD become especially vulnerable to both internal and external stressors [3,14,15] that include: fatigue; change of environment, caregiver, or routine; misleading or inappropriate stimulus levels; affective response to perception of loss; internal or external demands that exceed functional capacity; and physical stressors (i.e., pain, discomfort, infection).

Originally, Cohen-Mansfield and colleagues [16] classified agitation into the following syndromes: aggressive behaviors (i.e., hitting, kicking, cursing), physically non-aggressive behaviors (i.e., restlessness, pacing, inappropriate robing and disrobing), and verbally agitated behaviors (i.e., complaining, negativism, repetitious

phrases). Subsequent research involving factor analysis led to the refinement of these syndromes by subdividing verbally agitated behaviors into: verbally aggressive (i.e., cursing) and verbally nonaggressive behaviors (i.e., negativism) [17]. However, there remains a strong interrelationship between these subdivisions [18]. Agitation in persons with ADRD is one of the foremost patient management problems reported by caregivers, service providers and family.

Agitation During and Following a Disaster

During times of disaster the frequency and intensity of agitated behaviors are expected to increase because the person with ADRD is confronted with an unstable environment, unfamiliar surroundings and has less physical reserve [19]. Disaster and evacuation also disrupt the established routine of daily activities. All of these environmental factors serve to exacerbate previously identified stressors, such as misleading or inappropriate stimulus levels, affective response to perception of loss, and external demands that exceed functional capacity.

Overall, Furukawa and colleagues [20] report an exacerbation of BPSD in persons with dementia, residing in emergency shelters following the earthquake and tsunami in Japan. In addition, persons with cognitive impairment are especially vulnerable to post-traumatic stress syndrome following a disaster [21]. This may be attributed to the intense emotional experience associated with the event and the role that the amygdaloid complex plays in emotional memory [22].

Moreover, Brown and colleagues [23] report that persons with severe cognitive impairment who were evacuated from nursing homes following a hurricane were at an increased risk of death 30 to 90 days post-evacuation, compared to a control group. The authors emphasize the need to reduce stressors through environmental management. Brown and colleagues [23] identified the need for behavioral interventions for persons with moderate-to-severe dementia. These types of interventions are critical, especially in the early period of recovery following a disaster [9]. This includes reassuring elderly survivors with dementia that they are safe and to divert their attention to positive interactive and relaxing activities. The evidence-based guideline for individualized music [24] is one intervention that has potential to prevent or reduce anxiety and agitation during and following a disaster. Although this intervention has not been tested on adults with dementia during disaster, it has been clinically and empirically tested with persons whose agitated behaviors were identified as being the most challenging to professional and family caregivers within a variety of settings (i.e., long-term care facilities, respite care, and home care).

Theory Driven Intervention for Agitation

Gerdner [25] was the first to develop and systematically test a protocol for the use of individualized music for the management of agitation in persons with ADRD. The mid-range theory of *Individualized Music Intervention for Agitation* (IMIA) [26] provides the underlying framework for this intervention. Theoretical elements of IMIA include the following [26]: cognitive impairment, lowered stress threshold, agitation, and individualized music. The first three theoretical elements have been discussed. The theoretical element of individualized music is defined as music that has been integrated into the person's life and is based on personal preference [25]. Individualized music may be introduced to the person as a means of

alleviating anxiety and agitation. To explain further, receptive and expressive musical abilities appear to be preserved in persons with ADRD even in the advanced stages of the disease process. It is therefore believed that the cognitive processing of music and language are conducted independently. Various theories have been proposed to explain the exact processing of music in persons with ADRD [27]. Of primary importance is that music may be used as an alternative method of communicating, even when the person has difficulty or is unable to understand verbal language and has a decreased ability to interpret environmental stimuli. Because long-term or remote memory also remains intact well into the advanced stages of ADRD, the person is expected to be able to process music that was meaningful to them during their earlier years, prior to the onset of the disease. 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 is theorized to have a soothing effect on the person with dementia, which in turn will prevent or alleviate agitation [26]. The protocol for individualized music and key propositions of IMIA were later tested using a more rigorous design and larger sample size [28]. These two seminal studies served as the foundation for an expanding body of empirical evidence that tested the theoretically driven intervention in the United States, Canada, Great Britain, France, Sweden, Norway, Japan and Taiwan [29-42].

Evidence-Based Guideline

An evidence-based guideline for individualized music was originally developed in 1996 and has been revised and strengthened with an ongoing base of empirical and clinical evidence. In addition, to the previously identified studies, Oslo Resource Center for Dementia and Psychiatric Care of the Elderly, under the direction of Dr. Audun Myskja, implemented the evidence-based guideline 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 [43].

Additional information regarding the evolution and application of this evidence-based guideline has previously been published [44,45]. The *Evidence-based Guideline of Individualized Music for Persons with Dementia*© is now in its 5th edition [24] and was specifically written for professional health care providers. This 49-page guideline identifies risk factors for agitation, assessment criteria, and a detailed description of the intervention. An evidence grade schema is used to assign a specific grade, based on strength and type of evidence, for each recommendation within the guideline. In addition, a section is included on the evaluation of the patient outcome and process factors. Free downloadable copies of the complete guideline along with a *Quick Reference Guide* [46] and a free on-line teaching module are available through the Stanford Geriatric Education Center at Stanford University, School of Medicine [47].

A key aspect to the success of individualized music is identifying specific music preferences including exact song titles and performers. Many times persons identify a song title with a specific performer. For example, listening to Barbra Streisand sing the song, *Somewhere* elicits a very different emotional experience within the first author than hearing anyone else sing the same song. Her music transports the author to a more carefree time of life filled with contentment.

The Assessment of Personal Music Preference [48] was developed to assist in the process of music selection. Two versions of this

questionnaire are available. The first may be completed by a person who is in the early stages of dementia. The second version was adapted for completion by a knowledgeable family member. Both versions are included in the guideline [24]. In either version, questions begin by determining the importance of music prior to the onset of cognitive impairment and advance by learning the role of music in the person's life. This includes exploring the importance of ethnicity and spirituality in the selection of music [49]. These memory triggers serve to guide the selection of specific performers and song selections.

The guideline advances with a detailed description of the intervention. During real-life application (as described here) the music may be delivered in a manner that is most appropriate and convenient for the intended listener. Music may be delivered free-field to promote socialization or per head phone to prevent the music from disturbing others in the immediate environment. Optimal effectiveness is achieved by introducing the music when the person first begins showing signs of anxiety or agitation [14,28,32]. A reduction in agitation is expected within a relatively short period of time when the music is played.

Disaster Preparedness

Planning is a critical aspect of disaster preparedness. The *Assessment of Personal Music Preference* should be used to identify the most appropriate selection of music for the individual, well in advance of a disaster. Next, it is important to assess the person's response to these music selections under normal conditions and during the first signs of anxiety or agitation. If the person responds favorably it is recommended that individualized music be incorporated into the person's daily care.

Disaster preparation includes a personal preparedness pack for the older person's safety and recovery [50]. We recommend that the selected music, a playing device, and the *Quick Reference Guide* [46] be stored in a watertight container. This container could be included in the preparedness pack that the older person with dementia takes when transported to an evacuation center or used at home if sheltering-in-place is an option.

Discussion

Physical safety is the primary concern during a disaster. Health care providers must be especially alert to potential internal stressors during and following a disaster that may cause the person to become agitated. Examples might include pain from a physical injury or the discomfort associated with an infectious process. Such concerns should be assessed and treated medically. Individualized music may be used to supplement medical care but not replace it.

Psychological needs and well-being become secondary to safety and physical needs. An important consideration for the care of persons with ADRD during and following a disaster includes becoming informed on the use of non-pharmacological interventions for the prevention or alleviation of anxiety and agitation. Individualized music is being proposed as one such intervention. The risk for negative outcomes in persons with cognitive impairment underscores the need for an early response to any disaster [51]. Individualized music is versatile, can be used in a variety of settings (i.e., evacuation shelter), does not require special skill, is relatively inexpensive and can be easily taught and implemented by others. The evidence-based guideline is consistent with Kitwood's [52] premise of preserving personhood in the person with dementia. Although the focus of this article is on managing agitation, individualized music

has also been shown to promote positive affect and meaningful interaction with others [24,32] Individualized music provides a holistic intervention that is person centered, to empower family and health care providers in the management of agitation in persons with ADRD.

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