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"Music & Memory" and improved swallowing in advanced dementia

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Abstract

Background: Dysphagia and difficulty with eating affects a significant portion of individuals with advanced dementia. Such problems with oral intake can have serious health consequences including mealtime distress, dehydration and malnutrition, aspiration, reduced quality of life, and increased mortality risk.

Design: We present the first data indicating that "Music & Memory" interventions improve swallowing in individuals with advanced dementia, thereby making oral feeding easier and potentially diminishing reliance on PEG.

Setting: Columbia Health Care Center, Wyocena, WI (with Music&Memory.org, Mineola, NY and Stony Brook University).

Participants: Residents with advanced dementia (N = 5).

Measurements: Observation by eight professional caregivers.

Results: (1) Enhanced swallowing mechanism with Music & Memory prior to dining; (2) decreased incidents of choking during mealtime; (3) improved nutritional status; (4) reduced weight loss; (5) reduced need for speech interventions; (6) enhanced quality of life.

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Conclusions: The preliminary results call for additional research.

Keywords
swallowing, dysphagia, Alzheimer's disease, oral feeding, percutaneous endoscopic gastronomy, PEG, dementia

The syndrome of progressive dementia has many disease causalities, including Alzheimer's disease (AD), Parkinson's, vascular, Lewy Body, and frontotemporal dementia, all of which can result in the loss of swallowing capacity and decreased oral intake. Earlier in the course of dementia, individuals may manifest irregular feeding patterns; as dementia progresses, they typically lose control over swallowing both solids and liquids (Mitchell et al., 2009). For family members, the observation of weight loss can be ethically and emotionally challenging, and result in requests for artificial nutrition and hydration.

We observed that dysphagia in individuals with dementia is ameliorated through the Music & Memory program. Our pilot study done in Columbia Health Care Center in Wisconsin with Music & Memory provides a possible method of increasing oral feeding in patients with dementia through personalized music. This paper *for the first time* introduces Music & Memory interventions as potentially benefitting oral intake and increasing nutrition and hydration in patients with advanced dementia.

Dementia, dysphagia, and impaired oral intake

Dementia with its resulting dysphagia and decreased oral intake affects a growing population. According to the Alzheimer's Association (2017), there are about 5.5 million people in the US with AD. This number has been projected to increase to 13.8 million by 2050 (Hebert, Weuve, Scherr, & Evans, 2013). As a progressive disease, AD has a median survival time after diagnosis ranging from 3 to 12 years (Todd, Barr, Roberts, & Passmore, 2013). Its ultimate stage, advanced dementia, occurs when memory, verbal skills, ambulation abilities, and the abilities to perform activities of daily living are strongly impaired (Mitchell, 2015).

Eating and swallowing problems are strongly associated with advanced dementia. Mitchell et al. (2009) described that 86% of the 323 patients with advanced dementia in their study had feeding problems. These feeding problems included difficulties with swallowing or chewing, withholding from eating or drinking, and decreased oral intake.

While eating problems are universal among the advanced stages of the different dementias, the mechanisms of dysphagia and decreased oral intake can vary. In AD, there is a delayed oral transit time in both food and liquids likely due to the impaired perception of food within the oral cavity (Priefer & Robbins, 1997; Suh, Kim, & Na, 2009). Priefer and Robbins (1997) noted that changes in eating behavior occurred even earlier in the disease where self-feeding cues or assistance with eating from another person were needed. In vascular dementia, patients have difficulty chewing and forming a food bolus. Such impairments may be due to lesions in the subcortical area (Suh et al., 2009). Advanced

frontotemporal dementia can lead to compulsive eating and intake of large boluses which may lead to aspiration (Langmore, Olney, Lomen-Hoeth, & Miller, 2007). In Parkinson's disease, its symptoms of muscular rigidity and sialorrhea are potential contributors to dysphagia (Nicaretta, Rosso, Mattos, Maliska, & Costa, 2013).

Eating problems and dysphagia in those with advanced dementia can have serious health consequences. Examples of adverse effects include severe agitation and distress at mealtime, dehydration and malnutrition, and aspiration which can lead to relational pneumonia. Such effects can negatively impact quality of life and increase mortality risk (Wirth et al., 2016). Furthermore, pneumonia was found to be the most common cause of death in patients with AD (Todd, Barr, & Passmore, 2013).

Spaccavento, Del Prete, Craca, and Fiore (2009) reported a relationship between nutritional status and functional, cognitive, as well as neuropsychiatric impairments. In addition, Vellas et al. (2005) noted that undernourished patients with AD had a more rapid progression of the disease when assessed with the Mini-Mental State Exam (MMSE) in comparison to well-nourished patients with AD. While both studies were focused on patients with AD, there is a possibility that addressing undernutrition may perhaps prevent or delay the more severe symptoms following dysphagia and eating problems in advanced dementia patients and potentially stave off the decrease in quality of life.

One possible alternative for those with dysphagia and an inability to feed themselves is hand feeding or oral assisted feeding. It is the recommended option for individuals with advanced dementia as opposed to percutaneous endoscopic gastrostomy (PEG) tube feeding by national medical organizations such as the American Geriatrics Society, AMDA—the Society for Post-Acute and Long-Term Care Medicine, and the American Academy of Hospice and Palliative Medicine (ABIM Foundation, 2017). Through hand feeding, the caregiver not only feeds the individual but reminds him or her to swallow, controls and reduces the bolus amount for easier intake, encourages gentle coughs after swallowing, and thickens the food to aid swallowing (Dibartolo, 2006).

Unfortunately, many geriatricians and ethicists continue to note instances (Schulze, Mazzola, & Hoffman, 2016) of unnecessary PEG tube placements in patients with advanced dementia despite recommendations against this procedure. Additionally, several works (Bell, Somogyi-Zalud, Masaki, Fortaleza-Dawson, & Blanchette, 2008; Komiya et al., 2012; Nakanishi & Hattori, 2014; Schulze et al., 2016) indicate that in the US and other medically advanced nations, PEG use remains the default option.

Clinical research emerged questioning the benefits of PEG tubes in advanced dementia in the late 1990s. Research (Meier, Ahronheim, Morris, Baskin-Lyons, & Morrison, 2001; Teno, Gozalo, Mitchell, Kuo, Fulton, et al., 2012a; Gozalo, Mitchell, Kuo, Rhodes, et al., 2012b) showed that the benefits of PEG feeding (decreased aspiration pneumonia, decreased pressure ulcers with improved nutrition, increased survival) were non-existent when compared to hand feeding ("assisted oral feeding") by a caregiver. Gillick (2000) concluded that when weighed alongside the potential disadvantages of PEG use (increased chemical/physical restraints on patients, lack of gustatory pleasure and caregiver bonding), PEG is non-beneficial in addressing decreased nutrition in those with advanced dementia.

With dementia being a progressive disease with no current cure, there are many pharmacological and non-pharmacological interventions that aim to prevent further cognitive decline and reduce behavioral symptoms such as agitation, stress, and anxiety. Eating problems and decreased oral intake associated with advanced dementia may be partially due to "behavioral and psychological symptoms in dementia" (BPSD), which is defined

as "disturbed perception, thought content, mood or behavior" (Finkel, Costa e Silva, Cohen, Miller, & Sartorius, 1996).

One popular non-pharmacological approach for such symptoms is through the use of music. In a systematic review and meta-analysis by Zhang et al. (2016), there is evidence suggesting that music therapy can provide some benefits in treating anxiety and depression, disruptive behavior, and help improve cognitive function and quality of life. Furthermore, a systematic review of systematic reviews by Abraha et al. (2017), showed that music therapy is also effective for reducing BPSD. A study done by Whear et al. (2014) exhibited evidence that musical intervention during mealtime decreased aggression, confusion, depression, and anxiety, which may help to improve weight gain and nutritional status.

The preserved ability to process music in many people with dementia may be in part due to the fact that AD affects the regions of the brain that are linked to music cognition more slowly than the regions correlated with memory (Simmons-Stern, Budson, & Ally, 2010). Furthermore, the impact of music on the behavior of those with dementia may also be due to music's ability to heighten arousal and thus alleviate the attentional deficits that is found in dementia (Simmons-Stern et al., 2010). Thus, there may be potential in music that can allow patients with advanced dementia and dysphagia and eating problems to increase oral intake and ultimately improve quality of life by addressing BPSD symptoms, cognitive function, and attentional deficits.

Methods

Music & Memory (www.musicandmemory.org) is a non-profit organization that brings personalized music into the lives of the elderly or infirm through digital music technology, often vastly improving quality of life. This organization trains nursing home staff and other elder care professionals, as well as family caregivers, on how to create and provide personalized playlists using iPods and related digital audio systems that enable those struggling with AD and other forms of dementia to reconnect with the world through music-triggered memories.

The Music & Memory program is currently being used in more than 3000 elder care facilities across the US and abroad. Music & Memory also provides support and resources to individuals and caregivers not living in care facilities, allowing their loved ones to also have access to their own personalized music.

Columbia Health Care Center in Wyocena, Wisconsin, was one of the first care centers in Wisconsin to be Music & Memory trained and certified in October of 2013. Since that time, approximately 100 residents of Columbia Health Care Center have benefitted from the individualized iPod modality.

In 2015, the clinical team discussed various indicators to focus on that would be beneficial for the Care Center. Activity Department staff members Stephanie Kleist and Kelly Lentz recommended, as one of the Center's Quality Assurance initiatives, to explore the best days and times to use the iPod program to provide a potential model of therapeutic implementation that will benefit the residents and care environment. As a result, the 2016 "QA (Quality Assurance) Rock Away Alzheimer's Committee" began its mission to use Music & Memory as its 2016 QA indicator. The clinical team consisted of a broad base of disciplines such as certified nursing assistants, nurse managers, therapists, activity professionals, and director of nursing. The timeline of our observational intervention is outlines in the Table 1.

Table 1. Timeline of Columbia Health Care Center Swallowing Study.

June 2015	• Research presented to quality assurance team
16 October 15	• Residents identified and short-term care plans completed for participants
30 October 15	• Long-term care plans in place for all participating residents
3 November 2015–9 November 2015	• Sporadic use of iPods and intake tracking three times per week
10 November 2015–30 November 2015	• Staff training for procedure for next phase in research
1 December 2015–7 December 2015	• iPods used daily prior to dinner and intake tracking
8 December 2015–25 January 2016	• Staff training for next phase of study and problem solving for non-use
26 January 2016–1 February 2016	• Non-use of iPods and intake tracking
June 2016	• Summation of data—QA report—June 2016 Quality Assurance Committee Review
Current	• Committee still in effect—Continuous use for all residents identified for decrease in self-feeding, sudden unexplained weight loss, decrease in appetite intake and/or a need for thickened liquids
Future	• Exploring the possibility of using Columbia Health Care Center as a training site for replication of this intervention. Ultimate Goal: to be used for "Restorative Care" to maintain or improve function and explore this for reimbursement within the Minimum Data Set framework

The decision was made to systematically collect data relevant to improved eating and its benefits. The QA team tracked supper meal intake percentages for three months and noticed that residents who were experiencing difficulty with swallowing or feeding themselves, pocketing food (poor mastication), and/or loss of appetite showed improvement when given iPod prior to dining. The subjects were identified when one or all the following goals were written in their care plan:

- Resident's familiar music will stimulate her to be more engaged in the activity of dining.
- Resident's familiar music will stimulate her to feed herself during the supper meal.
- Resident will experience less difficulty in swallowing/pocketing with meal.

The QA Rock Away AZ Committee identified five most problematic residents through CAN charting. The average age of the residents was 89 with diagnosis of late stage cognitive loss/dementia (one had a dual diagnosis) to track.

The profiles of the subjects are as follows:

Resident 1:
Age: 88 years old
Primary diagnosis: Parkinson's with Dementia, Bipolar Disorder
Resident 2:
Age: 88 years old
Primary diagnosis: Alzheimer's Disease, unspecified

Resident 3:
Age: 99 years old
Primary diagnosis: unspecified Dementia without behavioral disturbance
Resident 4:
Age: 80 years old
Primary diagnosis: Vascular Dementia without behavioral disturbance
Resident 5:
Age 88 years old
Primary diagnosis: Alzheimer's Disease, unspecified

The residents chosen for the study were given their iPods with their individualized playlist loaded at 4:30 p.m. daily. Supper was served at 5 p.m. daily.

The team used a systematic delivery method using iPods and determining amount of percentage of food intake per resident over a period of two weeks (one week with iPods and one week without). The data were recorded by CNAs assigned to that unit, as part of their daily charting. The meal intakes were scored in increments of 25%, 50%, 75%, and 100%.

Due to overstimulation with the iPod, Resident #5 had to be removed from the study. With this in mind, it is important to note that persons with dementia can react negatively to a song. Such a reaction may be due to a negative experience associated with that song or due to auditory overstimulation. Whatever the reason, such negative impact is short-lived since we have the ability to remove the offending song, or discontinue the music listening experience if it proves too much to bear.

Additionally, music does not work for everyone; 3–5% of the population finds no enjoyment in music, coined by the term "musical anhedonia" (Abhat, 2017; Mas-Herrero, Zatorre, Rodriguez-Fornells, & Marco-Pallarés, 2014). If someone with dementia falls in the other 95–97% of the population, finding music that holds personal meaning maximizes the chance for positive response. If someone was unable to express their musical preferences, and such information is not forthcoming from family or friends who are unaware, then the likelihood of positive response from the individual is reduced or eliminated. We all respond differently to the music we enjoy. That variability of response can be observed for elders with cognitive decline. While some people upon hearing a song they love from their teenage years might respond by smiling, singing, and interacting more with those around them, others might respond by quietly listening, but clearly enjoying their time with the music.

Results

Our data indicate amelioration of dysphagia. While researching this Music & Memory paradigm of care, the staff became aware of the multiple benefits of Music & Memory, such as a reduction in time needed for care, fewer falls and fewer moments where staff were taken off the floor for resident irritation, and enhanced quiet and joyful moments with residents and staff.

The team also noticed the therapeutic effects the individualized iPod program had on eating behaviors, nutrition, and weight management.

The average intake for all four subjects with the Music & Memory intervention was 71.4%. The average intake without the Music & Memory intervention was 41.4%. The difference proved to have a statistical significance of 72.5% overall increase in the average percentage of intake with iPod intervention prior to dinner.

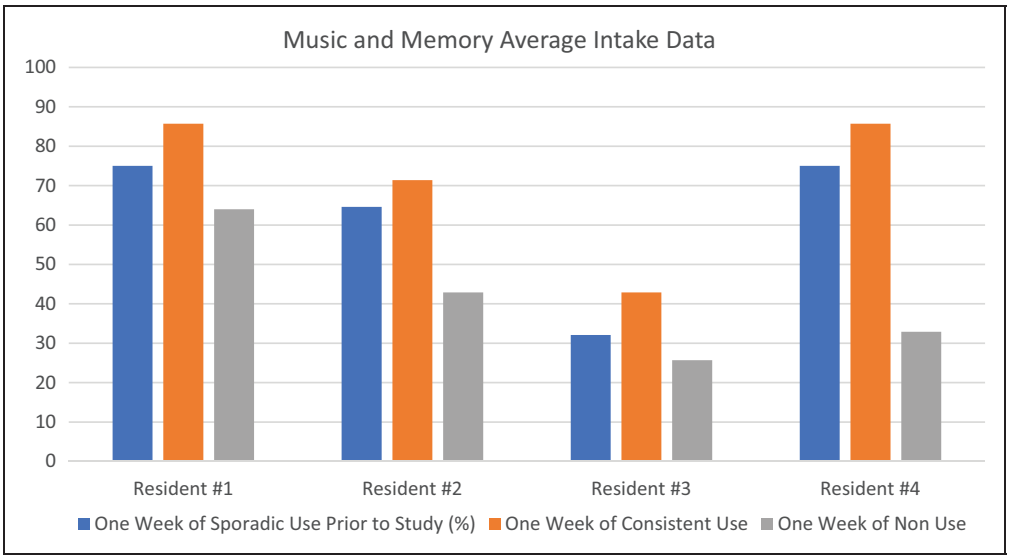

Figure 1. Music and memory average intake data.

While no significant control group was employed in this research design, data collection was recorded in the absence of the intervention and incorporated within the comparison of the study. The following were the conclusions drawn:

1. Enhanced swallowing mechanism with Music & Memory prior to dining
2. Decreased incidents of choking during mealtime
3. Improved nutrition status
4. Reduced weight loss/maintenance of weight
5. Reduced need for speech interventions/thickened liquids
6. Enhanced quality of life/aging in place status

Music & Memory is aware of attempts to replicate the use of this intervention to improve appetite and mimic some of Columbia Health Care Center's work. A large study is warranted.

Conclusions

According to Rösler et al. (2015), dysphagia (difficulty in swallowing) affects high numbers of individuals with dementia, ranging from 13 to 57% depending on subject selection and method of analysis. This can result in weight loss as well as aspiration and related pneumonia, for which PEG feeding is by no means an ideal intervention compared to oral feeding. Based on significant preliminary observational data, we conclude that dysphagia may be in part resolvable through Music & Memory interventions. We recommend a national study of Music & Memory interventions to investigate four outcomes: impact on swallowing capacity, better nutritional outcomes, reduced reliance on PEG tubes, and ease in assisted oral feeding.

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