CREATING AUDITORY ASSSOCIATIONS THROUGH THE USE OF PREFERRED MUSIC TO INCREASE INDEPENDENCE IN AN ACTIVITY OF DAILY LIVING FOR A PERSON WITH DEMENTIA

by

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ABSTRACT

The purpose of this single-case research design was to investigate a means to increase independence in an activity of daily living for a person with dementia by means of a six-week program conducted by the researcher utilizing music paired to picture, video, and conversational stimuli. Independence was measured in five domains including task location, task initiation, required tools, general task performance, and post-performance activities. An increase in overall independence was observed when analyzing results of the six-week study. A direct association between the preferred music and the target task was never explicitly created; however, the evidence suggests that the use of the preferred music did increase the PwD's independence in the target ADL.

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This thesis is dedicated to my mother, for raising me with the expectation of curiosity and inspiring my academic pursuance with love and encouragement for as long as you could.

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CHAPTER I

INTRODUCTION

"Musical training is a more potent instrument than any other, because rhythm and harmony find their way into the inward places of the soul." – Plato

The great philosopher Plato's description of the power of music is an idea applicable in many of life's circumstances. The power of music may be beneficial in even the most average of experiences, but what are the benefits of music when applied to some of life's most challenging trials? A tragic life challenge that affects approximately 3.4 million people in the United States (Plassman et al., 2007) is the diagnosis of dementia. Dementia is defined as a general term for a decline in mental ability severe enough to interfere with daily life (Alzheimer's Association, 2016), and these interferences can have severe consequences for the quality of life (QoL) for an individual living with dementia. In the book entitled *Finding Meaning in the Experience of Dementia: the Place of Spiritual Reminiscence Work* by MacKinlay and Trevitt (2012), the authors reported that individuals living with dementia experience the stereotype of being regarded as "non-persons" in the course of their disease. Furthermore, individuals with dementia have reported great concerns for being burdensome to others along with losing control of their lives (Read, Toye, & Wynaden, 2016). With these negative feelings and stereotypes reported by this population, healthcare professionals should recognize the merit in exploring strategies to combat these feelings and concerns faced by our patients. More

specifically relevant to this study, how can healthcare professionals utilize the power of music to ease these concerns?

In the case of such a challenging life experience as dementia, how could the power of music be harnessed to give this population more power over their life experience? In my undergraduate career, I worked as a caregiver in a supported living facility for adults with disabilities. It was this early experience that initiated my interest in discovering ways to improve independence for the adult population living with disabilities. It occurred to me very early on that by facilitating opportunities for my clients to do things with less support, I was empowering them with independence and dignity, as well as lessening the workload for myself as the caregiver. Seeing the difference that small alterations to an environment can make to both the clients and the caregiver instilled in me a passion for advocating for higher levels of independence in activities of daily living (ADL) for people with disabilities. ADLs are defined as "activities routinely performed in the course of an average day" (Bayles & Tomoeda, 2014). The independent performance of these activities may be taken for granted by a healthy adult; however, when further investigated, they have a significant impact on the QoL for a person with dementia ([PWD] C. Andersen, Wittrup-Jensen, Lolk, K. Andersen, & Kragh-Sorensen, 2004).

The idea of increasing independence for others propelled me further into the field of social services where I was able to reach out to more individuals with disabilities and their caregivers. Eventually I found myself in a clinical setting as a graduate student in speech language pathology. My first semester I was placed at a skilled nursing facility and began working with a man with severe dementia. Observing how dependent he was

on others for almost all aspects of his care disheartened me, and I began brainstorming ways this man could improve his independence in his daily activities. My clinical supervisor mentioned that he loved music, so I began playing music in the background during our therapy tasks. When comparing sessions with music to sessions without music, a pattern of improved performance began to emerge. This improvement was exhilarating to observe and further propelled my idea about how the powerful tool of music could be more functionally utilized to improve this patient's QoL in the difficult time of life he was facing.

My experience with this man led me to the questions of the current research study. Can music be used as a functional tool in the case of dementia care to improve independence in an ADL? Furthermore, could repeated exposure to task-related materials with a preferred song playing simultaneously create an association between the song and the task? An association is defined by the Merriam Webster Dictionary (n.d) as "the process of forming mental connections or bonds between sensations, ideas, or memories." The purpose of this study was to investigate a potential approach that aims to create a mental connection between a song and a target task through a systematic procedure aimed to replace a verbal cue with a musical cue. The ideal outcome of this process would be that a caregiver could enter a PWD's room, press play on a recorder to play a song, and this would cue a PWD to perform the target task more independently.

A study such as this one would be beneficial to the field of speech language pathology because it investigates a potential approach to improve independence and QoL for individuals living with dementia. By expanding the literature and providing more evidence based therapy options for persons living with dementia, we expand hope for a

better QoL in what is often times a very difficult phase of life for a PWD and their loved ones.

CHAPTER II

LITERATURE REVIEW

The Alzheimer's Association (2016) defined dementia as a general term for a decline in mental ability severe enough to interfere with daily life. The cause of dementia varies by case and is dependent on location of brain cell damage. While the specifics of treatment may vary depending on the location of damage, there are commonalities in treatment of all patients with dementia. This study addressed a common symptom of all dementias: the deterioration of performance in ADLs.

Activities of Daily Living and Dementia

One of the most prevalent characteristics of persons with dementia (PwD) is the decline in their ability to perform ADLs (Giebel, Sutcliffe, & Challis, 2015). Bayles and Tomoeda (2014) defined ADLs as "activities routinely performed in the course of an average day such as feeding, bathing, dressing, and grooming" (p. 50). ADLs are an important part of life for all people, and independence during their performance is ideal for a typical adult. The decrease of independence in these activities has many consequences for a PwD and their family. One implication of this decline is that dependency during ADLs greatly influences a PWD's health-related QoL (C. Andersen et al., 2004). In a study investigating how ability to perform ADLs affects QoL in a PwD, it was found that the factor that most affects the health-related QoL of a PwD is their dependency status when performing ADLs (C. Andersen et al., 2004). There has been an increased interest in measuring QoL in relation to health care in recent years (Fitzpatrick

et al., 1992), and there should be no exception for the speech language pathologist or other professional working with dementia. With overall concern for a patient's QoL, ADL performance should be of interest for a therapist working with a PwD. Another notable concern for circumstances with a dementia patient is the wellbeing of the caregiver. Although this study is focused on the PwD, not the caregiver, it is important to note that a large body of literature exists on the wellbeing of caregivers for a PwD (Epstein-Lubow, Davis, Miller, & Tremont, 2008; Fauth, Femia, & Zarit, 2016; Clarke, Adams, Wilkerson, & Shaw, 2016). A relationship between caregiver symptoms of depression and anxiety and the functioning of a PwD has been supported in research (Epstein-Lubow et al., 2008). With the overall wellbeing of our patients and their families as a concern in practice, the benefits of increasing independence for a PwD and decreasing caregiver involvement in ADLs could potentially be beneficial for all parties involved in the case of dementia care.

Communication and Dementia

A primary concern for the dementia therapist is the question of how can one increase or maintain independence in ADLs when a symptom of dementia is the decline in communication ability (Nazarko, 2015). Communication is defined as the sharing of information by means of a shared symbol system (Bayles & Tomoeda, 2014). As dementia progresses, communication skills gradually decline (Alzheimer's Association, 2015). When a PwD's symbol system breaks down as a consequence of disease, they no longer share a system to communicate with their caregivers. A PwD demonstrates a decline in traditional forms of communication such as word comprehension, loss of verbal fluency (Klimova & Kuca, 2016), anomia, and an eventual loss of ability to

express themselves using speech and language (Hopper et al., 2013). Could it be possible to create a new, shared symbol system for communication by means of music?

Music and Dementia

Music therapy is widely researched in the area of dementia. Music-based interventions including music therapy, community singing groups, and music listening are widely accepted as beneficial for the psychological wellbeing of people with dementia (McDermott, Orrell, & Ridder, 2014). The integration of music into treatment of a PWD is not a new idea; a research study investigating the benefits of regular music therapy in early dementia supported that everyday musical leisure activities such as singing and listening to familiar songs in persons with dementia can be cognitively, emotionally, and socially beneficial (Sarkamo et al., 2013). In a critical review of literature related to music therapy for dementia patients conducted by the University of Manchester in the United Kingdom, it was concluded that the evidence in literature is promising and suggests that music therapy is a safe non-pharmacological intervention that may improve the quality of therapeutic interactions between the patient and their caregivers (Blackburn & Bradshaw, 2014). The overall agreement of these evidence-based claims support that music is generally beneficial to a PWD. This agreement of the literature provides further support for the theoretical foundation that music could potentially be applied to improve performance in an ADL. A final point to make in favor of the use of music in cases of dementia is the easy accessibility and inexpensive cost of music. Even patients with limited resources would have access to music, in many circumstances with the assistance of the therapist.

Neurophysiologic Evidence of Music Stimulation

It is estimated that ninety-five percent of right-handed individuals have left hemisphere dominance for language and speech. With right-handers composing an estimated ninety percent of the world population (Price, 2009), it is not unreasonable to hypothesize that left hemisphere dominant individuals are the majority in the population. In research investigating the effects of music on the brain, twelve right-handed volunteers underwent brain-imaging scans while listening to music. After analysis of the scans, it was found that more areas of the right hemisphere were activated by music listening than in the left hemisphere (Raglio et al., 2015). Although resources prohibit neuroimaging in the present study, it is worthy to note that the use of music with right-handed individuals with dementia may somehow be able to stimulate right hemisphere functions to compensate for the loss of language and communication abilities in left hemisphere dominant individuals. Although limited research has been conducted to investigate this idea in patients with dementia, a body of research does exist focusing on brain plasticity principles in patients who have experienced other brain injuries including stroke or traumatic brain injury. Chen, Epstein, and Stern (2010) observed a variety of physical changes to the brain following injury and concluded that neural plasticity after an injury can allow for unaffected structures to compensate for the function of damaged structures. When examining reorganization of the language system after a left hemisphere infarct, Saur et al. (2005) observed neurophysiological compensation including a large increase of activation in the bilateral language network just thirteen days post-stroke. These neurological reorganizations can be spontaneous or training techniques can induce these reorganizations (Chen et al., 2010). In a review of literature, Hartwigsen (2016) stated that, “the capacity of the human brain to flexibly change the functional weight within a

network is a core feature of adaptive reorganization and compensation after brain lesions" (p. 1). This phenomenon in dementia patients would be grounds for a completely separate research investigation, but the research related to brain injury supports the rationale for the current study's logic.

Theoretical Framework

With positive evidence stated in the above articles in the areas of music therapy for dementia and a link between QoL and independence in ADL's for a PwD, a program to combine these two topics of interest could be beneficial for a PwD and their caregivers. For this study's purpose, the vision of this combination is to create an auditory association between a specific song and a specific ADL to be utilized as a cuing strategy for ADL performance. Would it be possible to train a PwD to match a song to an ADL by multiple exposures to training material including photographs, videos, objects, and practice of an ADL with a preferred song playing? Could a caregiver play a song to cue a PwD to initiate an ADL task, therefore decreasing caregiver involvement? Could music potentially create a new, shared symbol system between a caregiver and a PwD?

When pondering the theoretical framework behind these questions, the term "classical conditioning" comes to mind. According to Sparzo (2014), "The core of [classical] conditioning is the pairing of stimuli to elicit responses." The methodology of this study targets pairing music to task materials in an effort to build an association between the two, so when the stimulus of the music is played, the response of performing the task is elicited. Further expansion on associative relationships may be beneficial to further understand the concept. According to Burgess (1998) "The typical assumption behind associative relationships is that associations are caused by temporal co-occurrence

in language or elsewhere in the environment" (p. 192). Burgess continued on to state that stimuli can be constructed so that these associative relationships can be for the most part, manipulated. Can we manipulate a PwD's association from a lexical symbol to a music symbol to match to a target activity? Can repeated exposure to manipulated stimuli be strong enough to form a new association for a PwD when the previously used symbol system is no longer efficient? By combining the principles of classical conditioning with this information about associative relationships, the rationale for this study is further supported.

CHAPTER III

METHODS

This single case research study investigated a program designed to target the effects of preferred music on performance of an activity of living (ADL) for a PwD. This study aimed to investigate the possibility of creating an auditory association between a preferred song and an ADL for the PwD in order to decrease caregiver involvement during performance of the task. This program's methodology included regular exposure to video, photograph, music, and conversational stimuli related to the target activity over a six-week period. The stimuli exposure occurred twice per week during twenty-minute sessions with the PwD and the researcher. During the study, the researcher recorded measurements of independence once per week during session visits and the PwD's caregiver recorded levels of independence on days when the researcher was not present. The PwD's caregiver also played the preferred song during the activity at least four days per week to continue supports in an effort to build an association between the song and the target activity.

The Participants

This study consisted of two participants. The first was a Caucasian, right-handed female with a reported moderate-stage dementia diagnosis. The participant lived at a long-term care facility. The PwD's caregiver was also a research participant and worked regular shifts with the PwD. Two PwD participants were originally recruited for the study; however, the second participant was dropped from the study during the second week due to her hearing aids not being provided during the researcher's visits. Her hearing impairment greatly affected her ability to hear the music stimuli.

Ethics

Permission for this study was granted by the institutional review board to ensure ethical practice. A copy of study approval can be found in Appendix F. The caregiver of the PwD, the PwD, and the PwD's legally appointed representative all received and signed informed consent forms following appropriate guidelines and agreed to research participation. Copies of the informed consent forms can be found in Appendices D and E. Participants were informed of their right to leave the study at any time. The caregiver participant was provided with a two hundred dollar incentive for her participation in the study.

Preliminary Interview

Before beginning the study, the researcher, PwD, and caregiver participated in introduction interviews to investigate variables affecting the study. The researcher spoke privately with the caregiver participant to discuss the current levels of independence for the PwD in order to gain information about the PwD's independence levels without upsetting her. Questions discussed in the introduction interview were as follows:

1. Question (Q): What type of music does the PWD prefer?
2. Q: Are there any preceding auditory associations the PwD may have for particular songs to particular tasks?
3. Q: What activities does the PwD participate in most independently at home?
4. Q: What activities require the most support for the PwD at home?
5. Q: What activities are most important to the PwD to function at most independently?

From these initial interview questions the researcher, caregiver, and PwD all agreed upon drinking water as the target ADL and the song to match was "I Walk the Line" by singer Johnny Cash.

Measuring Independence

Levels of independence were measured once weekly by the researcher in five areas for this study. A copy of the self-developed measurement form can be found in Appendix A. Areas measured included:

- Task location - Task location was defined as the patient proceeding to the correct location to complete the task.
- Task Initiation - Task initiation was defined as the participant taking a reasonable action to start the activity (e.g. turning on the faucet or opening the cabinet to look for a cup for water to get a drink).
- Required Tools - Required Tools were defined as the participant choosing appropriate tools for the target task (e.g. picking up a glass for water).
- General Task performance - General task performance is defined as the participant performing the task appropriately following navigating to the correct location, choosing the correct tools, and initiating the task. Criteria for a measurement in task performance ended when the participant finished filling the glass with water.
- Post-Performance Activity - Post-performance activities were defined as the participant appropriately cleaning up following the performance of the activity (e.g. turning off the faucet, wiping up any spilt water, rinsing out a cup).

Each of the five areas received a score from 0 – 7. These numerical scores represented the level of support required to complete the task. Scores for each of the five areas were weighed equally, with no area carrying a higher value than another when calculating the weekly Overall Independence Score (OIS). The numerical score, level of support required, and the prompting required in order to qualify for that level of support are outlined in Table 1.

Numerical Measurement	Level of Support	Prompting Required
0	Independent	No Assistance
1	Minimal Verbal Support	Verbal Direction Required 1x
2	Moderate Verbal Support	Verbal Direction Required 2x
3	Maximum Verbal Support	Verbal Direction Required 3+x
4	Minimal Physical Support	PwD was touched 1x
5	Moderate Physical Support	PwD was touched 2x
6	Maximum Physical Support	PwD was touched 3x
7	Total Caregiver Support	Caregiver performed all aspects of activity.

Table 1 – Scoring Criteria for Measuring Independence

The five areas of independence targeted were measured on a weekly basis. The researcher turned on the music stimulus for ten to fifteen seconds in an attempt to prompt the PwD to begin the task. Following fifteen seconds, the researcher began providing supports as necessary for completion of each area. The sum of the five areas was calculated to provide a weekly Overall Independence Score (OIS). The purpose of the OIS was to paint a large-scale picture of general independence in the activity to be compared weekly. The OIS provided the researcher with a means to track overall independence weekly, while the five separate areas were also tracked independently to identify areas of strengths and challenges.

Data progress was analyzed weekly compared to a baseline measurement of performance. This baseline performance was determined by the performance of week 1. The baseline is the measurement of performance in the activity that the PwD

demonstrated before music was introduced. Following the baseline week, each successive week was compared to the baseline performance. A decrease of points indicates an increase of independence, while an increase of points indicates a decrease in independence.

Caregiver Involvement

Caregiver involvement was of great importance for measuring outcomes in this study and to cross-verify the researcher's findings with observations from the caregiver. The researcher met with the PwD two times per week and during other days of the week, the caregiver participant measured independence in the target ADL using a form provided by the researcher. A copy of this form can be found in Appendix B. The researcher educated the caregiver on her responsibilities during the study and provided training on how to correctly document the PwD's performance on the "Caregiver Record" sheet. The caregiver's role for support is outlined in the following guidelines:

1. The caregiver agreed to maintain as static of an environment as possible in the PwD's bedroom, not changing the environment in any major way throughout the program.
2. The caregiver played the target song at least four times per week. She entered the PwD's bedroom, turned on the song, and allowed ten to fifteen seconds before facilitating the target task of drinking water.
3. The caregiver recorded the level of support required during the task on the "Caregiver Record" sheet provided by the researcher.

The caregiver participant reported to the researcher in a variety of contexts during the study including recordings of the PwD's independence during the week; the PwD's

response each week to the question “What do you think of when you hear this song?”; and a final exit report in the form of a Likert questionnaire with responses including: Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree.

Researcher Procedures

The researcher and PwD held sessions two times per week for twenty minutes each session. Twenty minute timed sessions were chosen by the researcher based on realistic session times in the field for a clinician working in dementia care. Sessions were broken into five-minute increments. Increments consisted of five minutes of photograph stimuli, five minutes of interactive stimuli in which the PwD and researcher played a memory game with the photo cards, five minutes of video stimuli, and five minutes for review, caregiver and patient questions, and guidance for at-home practices. Once per week the researcher took measurements of independence. These measurements were prompted with the researcher playing the music for ten to fifteen seconds and then beginning other necessary prompts to complete the task.

Materials

Session materials included photograph stimuli. These photographs were all pertinent to drinking water such as images of water fountains, cups, and water bottles. The researcher presented video stimuli in the form of a short video outlining the importance of drinking water and how much water someone should drink.

Music

The specific music stimulus was only played during the exposure of the other study stimuli and while performing or talking about the target task. The goal of this music exposure was to solely associate this song to the task being targeted. To avoid confusion

for the PwD, the song was not played while participating in other tasks. Caregivers were informed to only play this song in the home during task performance.

Photographs

A copy of the photograph stimuli can be found in Appendix C. The researcher began playing the song at the beginning of stimuli presentation. While playing the assigned song, the researcher presented the PwD with photographs of the task and objects required for the task. The researcher prompted the PwD with questions pertaining to the photographs and music such as, "What room do you enter when you hear this song?", "What do you need when you hear this song?", and "What will you do when you hear this song?" The researcher added appropriate statements and questions for the PwD as necessary to support the conversation. Following the review of the photographs, the participant played a memory game in which the researcher flipped the photographs over and the participant was asked to match two photographs together. The researcher provided positive reinforcement for each correct match and facilitated a conversation about the photograph.

Video

The researcher began playing the song at the beginning of stimuli presentation. While playing the assigned song, the researcher presented the PwD with a video outlining the importance of hydration and drinking water. The researcher prompted the PwD with questions pertaining to the video and music such as "What room do you enter when you hear this song?" "What do you need when you hear this song?" "What will you do when you hear this song?" The researcher added statements and questions for the PwD as

necessary to support the PwD's attention to the task. The researcher turned the songs and videos off upon completion of task or at desired breaks.

Treatment Termination Procedures

Following the six weeks of stimuli presentation and measurements collected by both the researcher and the caregiver, the program was concluded. The conclusion procedures included administering an exit questionnaire to the caregiver participant. Results of this questionnaire are outlined in the results section of this paper. A final measurement of independence was administered to the PwD and the researcher facilitated a conversation with the PwD in which they discussed that the study was concluded.

CHAPTER IV

RESULTS

The following results section outlines the findings over the six-week study period. Results are organized into the researcher's collected data and the caregiver participant's reports. Individual results for the areas of Task Location, Task Initiation, Required Tools, General Task Performance, and Post-Performance activities are outlined in the following line graphs. The researcher's observation of overall independence is included as well, along with reports from the caregiver participant.

Preliminary Interview Responses

The participants' answers to the preliminary interview are as follows:

1. Question (Q): What type of music does the PWD prefer?

   Answer (A): The PwD replied that she loves all kinds of music, especially old rock like Elvis Presley and Johnny Cash.

2. Q: Are there any preceding auditory associations the PwD may have for particular songs to particular tasks?

   A: The PwD and the caregiver both agreed that there were no present auditory associations between a song and a task.

3. Q: What activities does the PwD participate in most independently at home?

   A: The caregiver replied that the PwD required the most assistance in initiating daily tasks, but once the task was initiated she could hold her independence fairly well. The PwD replied that she did not need assistance with anything and remembered everything she needed to do.

4. Q: What activities require the most support for the PwD at home?

A: The caregiver replied that the PwD required the most assistance in the form of verbal cues to initiate tasks such as getting dressed, bathing, going to meals, and drinking water.

5. Q: What activities are most important to the PwD to function at most independently?

   A: The caregiver replied that it would be beneficial for the PwD to drink more water independently. The PwD would regularly get dehydrated from not drinking enough water. The PwD replied that she always drinks enough water and does not need reminding.

Researcher Collected Data

Task Location

Task location was measured weekly. Task Location was defined as the participant proceeding to the correct location to complete the task. Results for performance in Task Location are outlined in Figure 1.1.

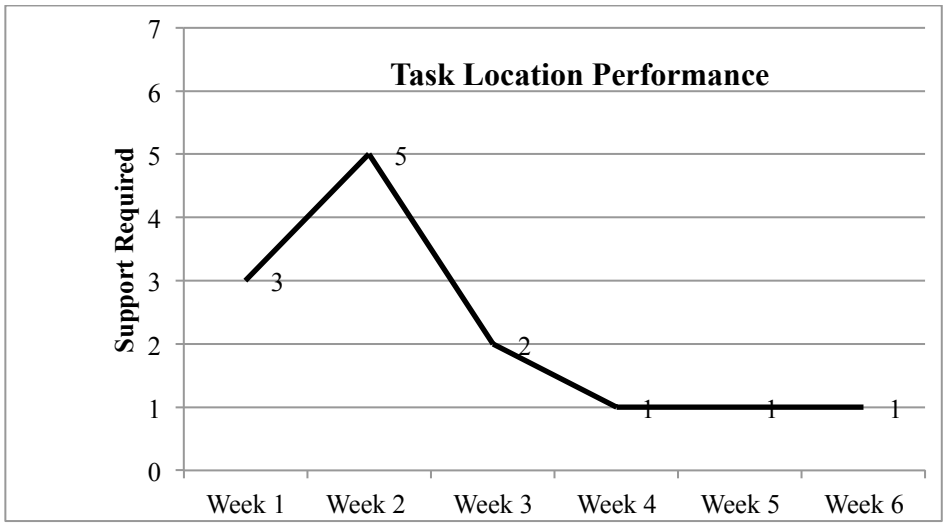

Figure 1.1 – Levels of Support Required for Task Location

Baseline performance for Task Location area (W1): 3. Clinically equating to the requirement of maximum verbal support to perform the task. The following Table 2 provides a weekly interpretation of the PwD's performance compared to the baseline.

Week	Baseline	Performance Points Score	Decrease/Increase Compared to Baseline (3)	Interpretation
2	3	5	Increase of 2 performance points	The participant decreased independence from requiring maximum verbal cues to requiring moderate physical cues.
3	3	2	Decrease of 1 performance point	The participant increased independence from requiring maximum verbal cues to requiring moderate verbal cues.
4	3	1	Decrease of 2 performance points	The participant increased independence from requiring maximum verbal cues to requiring minimal verbal cues.
5	3	1	Decrease of 2 performance points	The participant increased independence from requiring maximum verbal cues to requiring minimal verbal cues.
6	3	1	Decrease of 2 performance points	The participant increased independence from requiring maximum verbal cues to requiring minimal verbal cues.

Table 2 – Weekly Performance in Task Location

Task Initiation

Task Initiation was measured weekly. For the purposes of the current study Task Initiation was defined as the participant taking a reasonable action to start the activity (e.g. turning on the faucet or opening the cabinet to look for a cup for water to get a drink). Performance for Task Initiation is outlined in the Figure 1.2.

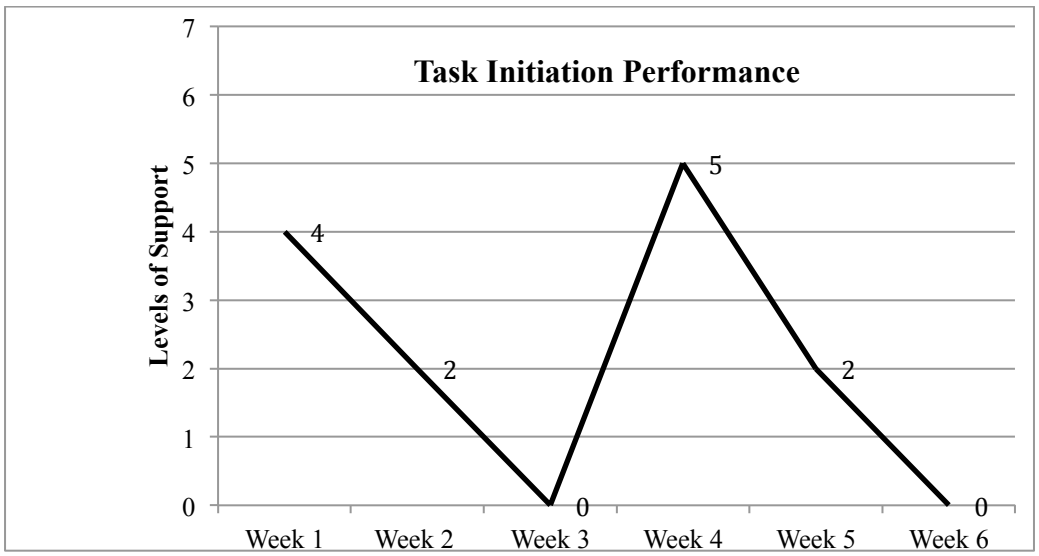

Figure 1.2 – Levels of Support Required for Task Initiation

Baseline performance for Task Initiation area (W1): 4. Clinically equating to minimal physical assistance. The following Table 3 provides a weekly interpretation of the PwD's performance compared to the baseline.

Week	Baseline	Performance Points Score	Decrease/Increase Compared to Baseline (4)	Interpretation
2	4	2	Decrease of 2 performance points	The participant increased independence from requiring minimal physical support to requiring moderate verbal supports.
3	4	0	Decrease of 4 performance points	The participant increased independence from requiring minimal physical support to

				independent performance.
4	4	5	Increase of 1 performance point	The participant decreased independence from requiring minimal physical support to requiring moderate physical supports.
5	4	2	Decrease of 2 performance points	The participant increased independence from requiring minimal physical support to requiring moderate verbal supports.
6	4	0	Decrease of 4 performance points.	The participant increased independence from minimal physical support to completing the task independently.

Table 3 – Weekly Performance in Task Initiation

Required Tools

For the purposes of the current study, performance in this area is outlined in Figure 1.3. Required Tools were defined as the participant choosing appropriate tools for the target task (e.g. picking up a glass for water).

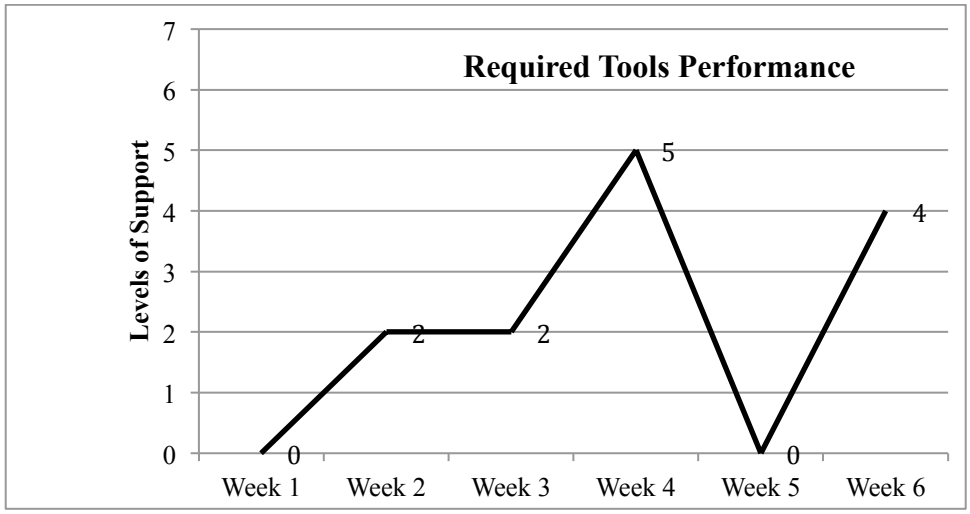

Figure 1.3 – Levels of Support Required for Required Tools

Baseline performance for Required Tools area (W1): 0 - Clinically equating to independent performance of the task. The following Table 4 provides a weekly interpretation of the PwD's performance compared to the baseline.

Week	Baseline	Performance Points Score	Decrease/Increase Compared to Baseline (0)	Interpretation
2	0	2	Increase of 2 performance points	The participant decreased independence from independent performance to requiring moderate verbal support.
3	0	2	Increase of 2 performance points	The participant decreased independence from independent performance to requiring moderate verbal support.
4	0	5	Increase of 5 performance points	The participant decreased independence from independent performance to requiring moderate physical supports.
5	0	0	No change in performance points	The participant maintained independent performance.
6	0	4	Increase of 4 performance points.	The participant decreased independence from independent performance to minimal physical supports.

Table 4 – Weekly Performance in Required Tools

General Task Performance

For purposes of the current study, General Task Performance is defined as the participant performing the task appropriately following navigating to the correct location, choosing the correct tools, and initiating the task. Criteria for a measurement in General Task Performance ended when the participant finished filling the glass with water. Performance in General Task Performance is outlined in Figure 1.4.

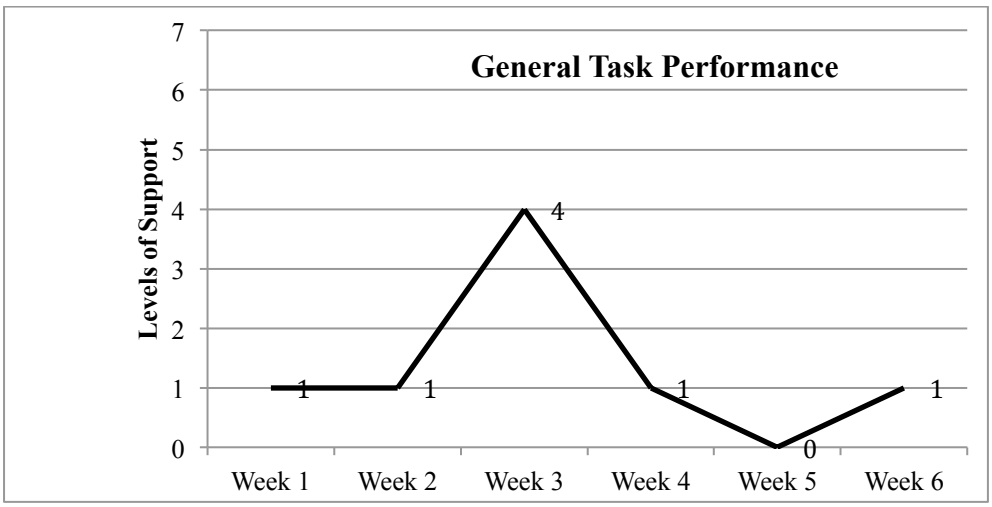

Figure 1.4 – Levels of Support Required for General Task Performance

Baseline performance for Required Tools area (W1): 1. Clinically equating to minimal verbal supports for performance. The following Table 5 provides a weekly interpretation of the PwD's performance compared to the baseline.

Week	Baseline	Performance Points Score	Decrease/Increase Compared to Baseline (1)	Interpretation
2	1	1	No change in performance points.	The participant performed the task at the same level of baseline, with minimal verbal supports required.
3	1	4	Increase of 3 performance points	The participant decreased independence from requiring minimal verbal support to requiring minimal physical support.

4	1	1	No change in performance points.	The participant performed the task at the same level of baseline, with minimal verbal supports required.
5	1	0	Decrease of 1 performance point.	The participant increased independence from requiring minimal verbal support to independently performing task.
6	1	1	No change in performance points.	The participant performed the task at the same level of baseline, with minimal verbal supports required.

Table 5 – Weekly Performance in General Task Performance

Post Performance Activities

For purposes of the current study, post-performance activities were defined as the participant appropriately cleaning up following the performance of the activity (e.g. turning off the faucet, wiping up spilled water, rinsing out a cup). Performance for Post-Performance Activities is outlined in Figure 1.5.

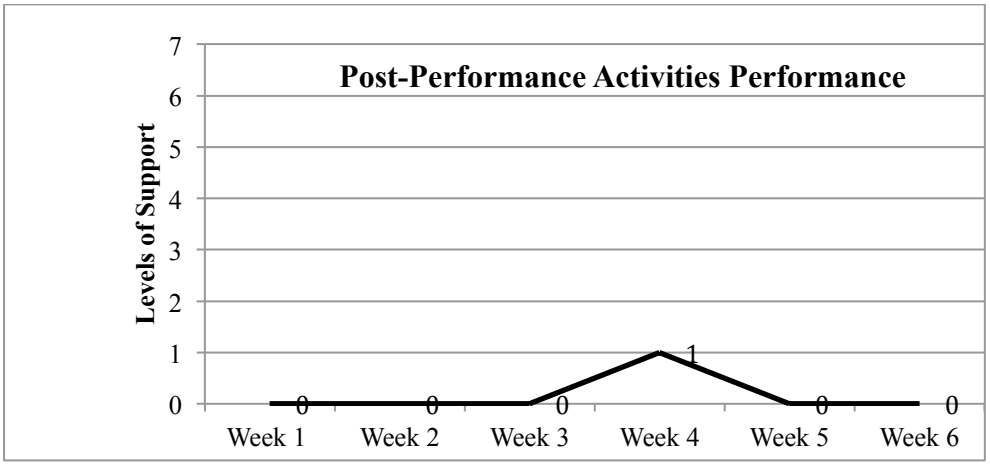

Figure 1.5 – Levels of Support Required for Post-Performance Activities

Baseline performance for Required Tools area (W1): 0. Clinically equating to independent performance in this area. Table 6 provides a weekly interpretation of the PwD's performance compared to the baseline.

			Decrease/Increase	

Week	Baseline	Performance Points Score	Compared to Baseline (3)	Interpretation
2	0	0	No change in performance points	The participant maintained independent performance.
3	0	0	No change in performance points	The participant maintained independent performance.
4	0	1	Increase of 1 performance point.	The participant decreased independence from independent performance to requiring minimal verbal support.
5	0	0	No change in performance points.	The participant maintained independent performance.
6	0	0	No change in performance points.	The participant maintained independent performance.

Table 6 – Weekly Performance in Post-Performance Activities

Overall Independence Measurements

An Overall Independence Score (OIS) was computed each week by totaling the scores from each of the five supporting areas of independence. Overall Independence Measurement scores are outlined in Figure 1.6.

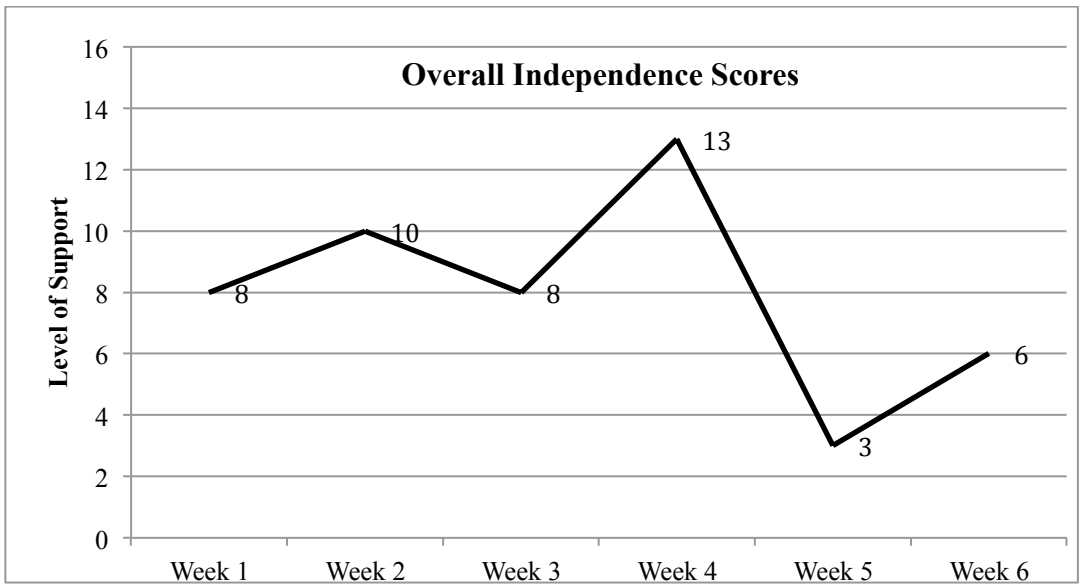

Figure 1.6 – Overall Independence Scores (OIS) Weekly.

The score of week 1 was compared to the final score of week 6 to determine overall impressions of the effect that the preferred music had on independence in the target activity over the six-week study period.

Baseline (W1) in Performance Points	Week 5 in Performance Points	Percent Increase in Independence
8	6	25%

Table 7 – Overall Difference in Independence

The researcher divided the difference of week 1 and week 6 (2) by the baseline (8) to determine a percentage of difference between the weeks. From the first week of the study compared to the final week, the participant increased their independence in the target task by 25%.

Caregiver Reports

The caregiver participant reported to the researcher in a variety of contexts during the study including weekly verbal reports, recording independence measures on a provided form, and an exit questionnaire in the form of a Likert scale.

Caregiver Verbal Reports

The caregiver provided a verbal report each week to the researcher regarding the PwD's performance in the target activity with the music playing. The caregiver also reported on the PwD's response to the following question: "What do you think about when you hear this song?"

The PwD's verbal responses to the caregiver are recorded in Table 8.

Week	PwD Response to Caregiver Question "What do you think about when you hear this song?"
1	Johnny Cash is a good singer with a dialogue about Johnny Cash and the PwD's memories and thoughts about the singer.
2	Johnny Cash is a good singer with a dialogue about Johnny Cash and the PwD's memories and thoughts about the singer.
3	Johnny Cash is a good singer and the student.
4	Johnny Cash is a good singer and the student.
5	Johnny Cash is a good singer and the student.
6	Johnny Cash is a good singer and the student.

Table 8 – PwD's responses to question asked by caregiver of "What do you think about when you hear this song?"

Caregiver Record of Supports Required

The caregiver participant recorded the levels of support required when assisting the PwD in completing the target activity on days when the researcher was not present. These observations are recorded in Figure 1.7.

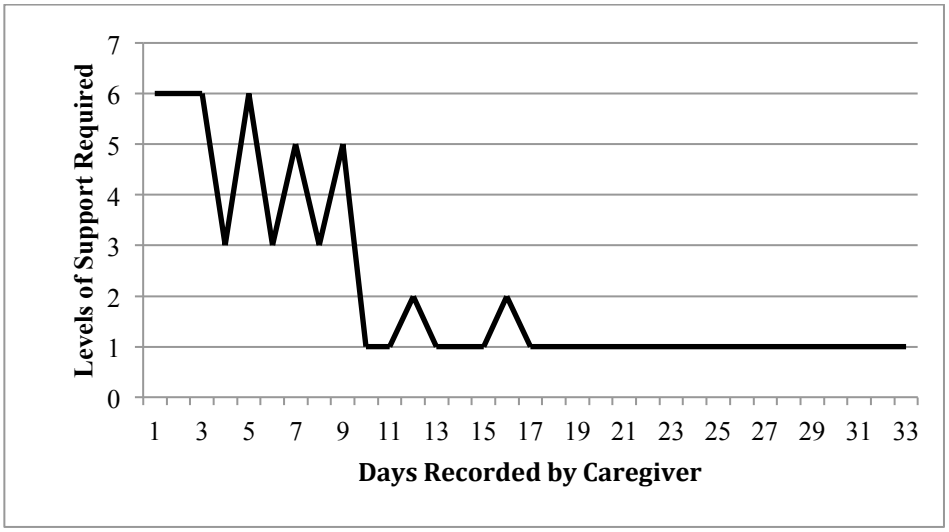

Figure 1.7 – Caregiver Observations of Support Required to Complete Task

Caregiver Questionnaire

A final caregiver report was collected during exit from the study in the form of a Likert questionnaire with responses including: Strongly Agree, Agree, Neutral Response, Disagree, and Strongly Disagree. Questions and caregiver responses are outlined in Table 3.

Questionnaire Inquiry	Caregiver Response
The music assisted the person with dementia's awareness of the location of where a task should take place.	Agree
The music assisted in the person with dementia starting a task more independently.	Agree
The music assisted in the person with dementia choosing the correct tools for the task more independently.	Agree
The music improved the general performance of the task for the person with dementia.	Strongly Agree
The music improved the person with dementia's ability to clean up following the task more independently.	Agree
The music playing during the activity made the task more enjoyable for the person with dementia.	Strongly Agree
The music playing during the activity made the task more enjoyable for you as the caregiver.	Strongly Agree
I feel less stress related to my duties of this task with the music playing than when it is not.	Neutral
The person with dementia seems to show an improvement in independence during the task with the music playing.	Neutral
I will continue to use this music during the task following completion of the research study.	Strongly Agree

Table 9: Caregiver Exit Questionnaire Questions and Responses

CHAPTER V

DISCUSSION

Research has supported the idea that music has positive impacts on people with dementia in domains such as emotion and cognition. The aim of the current study was to investigate a potential way to make music a more functional tool in the case of dementia care. Could the use of preferred music be utilized as an environmental stimulus to cue the independent performance of an activity? The benefits of harnessing this idea are multifaceted, including increasing independence for a patient with dementia, decreasing caregiver involvement and work-induced stress, and decreasing negative interactions between a caregiver and PwD.

The methodology behind this study attempted to build an auditory association between one song and one task by means of consistent exposure to task related material while preferred music stimulus played simultaneously. Ideal outcomes of this type of program would be increased independence in all areas measured; however, the data collected showed interesting results that perhaps make the goal of creating auditory associations more attainable given different circumstances. When analyzing the findings, it is most helpful to think of the target task in a linear format, with each observed area happening in sequence to one another starting with task location.

Initiation and Location

The two areas that demonstrated a clear increase in independence were the areas of Task Location and Task Initiation. In a clinical sense, these increases are the most exciting to observe in relation to the goal of creating an auditory association. These are domains that occur during the beginning of a task, and these results perhaps suggest that music could potentially be used to cue initiation of a task for a PwD. Cuing the initiation of a task with a music stimulus instead of a verbal prompt from a caregiver would be clinically beneficial for both the caregiver and the PwD.

In the area of Task Location, the participant began with a baseline of 3, meaning they required maximum verbal assistance to navigate to the appropriate location for the task in the initial week. Overall, support required for navigating to the correct location decreased from requiring maximum verbal assistance to requiring minimal verbal supports in the final three weeks of the study. A general decreasing trend in supports required was present in 80% of the weeks recorded, indicating increased independence in the area of Task Location with the use of preferred music.

In the area of Task Initiation, the participant began with a baseline performance score of 4, indicating she required minimal physical support to initiate the task. In weeks 2, 3, 5, and 6, the participant performed the task more independently than she did so in the initial week of the study. Performance in week 4 decreased to requiring moderate physical assistance to initiate the task. In the five weeks following the baseline week, the participant performed more independently in 80% of opportunities, with the exception of decreased independence in week 5. The general trend of data observation indicated that

the use of preferred music generally increased independence in the area of Task Initiation throughout the study.

A basic social psychological problem for people with dementia is the sense of losing control. A study conducted by Read, Toye, and Wynaden (2016) examined experiences of individuals diagnosed with dementia and found that all participants reported feeling emotions of fear and panic daily as they were confronted with situations that were beyond their ability to control. This same study found that most participants felt grief as they coped with their loss of independence. By taking away the factor of being told what to do by a caregiver, and replacing it with something more enjoyable such as music, perhaps the sense of loss of control could be decreased and the overall environment could be more positive. By enabling a PwD to complete a task more independently, maybe feelings of grief related to their loss of independence could be eased. Perhaps reinstating independence can empower a PwD to have a higher QoL. The increased independence in areas of Task Initiation and Task Location provide insight to a potential technique that could possibly bypass feelings of grief, fear, panic, and loss of control related to a PwD's performance of a task.

Required Tools

The only area where the music negatively impacted performance was the area of Required Tools. In this area, the participant began with a baseline performance score of 0, indicating independence when choosing the appropriate tools. Throughout the study, scores fell above the baseline in 80% of the following weeks, indicating that the participant's independence decreased in choosing appropriate tools more so than it increased throughout the study. In the area of Required Tools, week 4 showed the highest

level of support required of all six weeks measured, following the same trend as was recorded in the area of Task Initiation. General trend of data observations indicate that the use of music generally decreased independence, possibly suggesting that music had a negative effect when combined with tools on this recorded area.

This decrease of independence was discouraging at first glance, as the goal of any type of clinical intervention would never be to decrease independence for a client. However, when further analyzed, these observations make sense in the case of a PwD. According to the American Speech Language and Hearing Association (2016), common attention deficits for a PWD include "having difficulty attending, unless input is restricted and/or simplified." In this study, just the opposite inadvertently took place. The preferred music added additional, more complex input and perhaps the music stimulus distracted the PwD's attention away from the required tools. This distraction away from the required tools could very well be responsible for the observed decrease in independence in this domain.

General Task Performance and Post-Performance Activities

The two areas that noted no change in levels of independence were the areas of General Task Performance and Post-Performance Activities.

In the area of General Task Performance, the participant began with a baseline performance score of 1, indicating they required minimal verbal support to choose to perform the task. Throughout the study, performance scores fell above the baseline in 20% of weeks recorded, below the baseline in 20% of weeks recorded, and had no change from the baseline in 60% of weeks recorded. More often than not, the preferred music had no effect on the participant's level of independence in this domain.

In the area of Post-Performance Activities, levels of support remained static at the independent level with the exception of week 4. During week 4, the participant increased her support needs to requiring minimal verbal supports. In 80% of weeks recorded, the participant showed no changes in independence levels with the use of preferred music. Data observations indicate that the use of preferred music had no impact on increasing her level of independence in this domain.

When reviewing the results of these areas, no increase in independence was observed. However, when further investigated, the results of these areas are clinically logical. Both of these areas take place toward the end of the task execution. Once the areas of task location and initiation were in motion, perhaps a motor sequence took over for the performance of the following areas, and perhaps motor memory is responsible for the overall static performance observed in these areas. Stefan et al. (2005) reported that most motor skills are acquired through physical practice and after a lifetime of practicing the study's target task, it is reasonable to surmise that the participant's motor memory may have played a part in the static performance of these tasks.

It may be beneficial to think of the PwD's performance as a car rolling down a hill. The car takes an initial push to get going, just as a PWD may need assistance in deciding on where to go, or how to start the activity. But once in motion, the wheels continue to turn with no real further support required. The areas of general task performance and post-performance activities are just like the car once it is in motion down the hill. This analogy can perhaps better explain the automatic completion of the two unaffected areas of the task, General Task Performance and Post Performance Activities.

Overall Independence

According to the researcher's weekly findings, there was an overall increase of independence of 25% in the target ADL when comparing performance of week 1 to week 6. The caregiver's recorded observations of increased independence throughout the study agree with the researcher's findings, both showing a decrease in supports required over time. The caregiver's recordings demonstrate an increase of independence during the target task that took place following the 18th day of playing the music during the task. Following the 18th day of caregiver measurements, the PwD performed the task with minimal verbal supports required. This reduction to minimal verbal supports from higher supports required in the preceding days recorded indicates that the use of preferred music during the target task was possibly a contributing variable to this increase of independence. The researcher's observations align with the caregiver's findings and indicate an increase in independence below the baseline beginning in the fifth week of researcher visits and continued into the sixth and final week. With both the researcher and caregiver finding a similar trend of increased independence with the use of preferred music, it is reasonable to assume that the music was a contributing factor in the PwD's increase in overall independence in the target activity.

Cerebral Hemisphere Involvement

When pondering how music could replace a language function, the researcher took into account basic neurophysiological principles. Evidence supports that most people have left-hemisphere cerebral dominance for their language areas. When dementia starts affecting these language areas, communication begins to become affected.

As a way to compensate for these left hemisphere deficits, would it be possible to tap into activities that are traditionally right-hemisphere dominant such as music and re-purpose it to act with pseudo-language functions? Could there be a way to reprogram the brain to utilize the persevered areas and take advantage of their functions? Can right hemisphere activities become symbols for language? Instead of explicitly saying an instruction such as "drink some water", which a PwD may no longer understand, could a right-brain activity now act as that instruction to bypass the deficit in the left brain? This research study touched on the brains ability to do just that.

Other Clinical Applications

Further research would be necessary to investigate a true creation of an auditory association in a PWD to a target task, as this research study did not explicitly succeed in creating one. During the study, the caregiver reported that the PWD never said that she thought about the target task when the music was playing. However, she did say that she thought about the researcher when the music played. This association to the researcher instead of the target task does not come with much surprise. As humans, we form attachment bonds to other people (Browne, C.J. & Shlosberg, E., 2003). This is evident even in newborn infants, as their first instinct is to reach for their mother, not a toy or inanimate object. This principle of longing for human connection may explain the association of the music to the researcher above the music to the target task.

Although creating an association between music and a person was not the aim of the current study, these results may provide evidence that creating an auditory association in a PWD is possible. The clinical application of this association may warrant further investigation. Perhaps matching music to individual people, instead of tasks, could

increase the ability to remember loved ones or caregivers in the case of dementia care. Further research would be necessary to investigate this contemplation.

Results from this study suggested that the PwD was never obviously cued by the music to perform the target activity; however, there is a trend of increased overall independence during the activity with the music playing. The researcher did not solely observe this result; the reports on performance from the caregiver provided similar subjective findings. The agreement between the researcher's findings and the caregiver reports provide validity to the results of this study.

Future Research

Further exploring ideas that came from the findings of this study is of high interest to the researcher. Several future research ideas were generated during the study including expanding upon the current study and investigating this approach with a larger sample size. By testing this technique on a larger scale, it would provide further validity to the efficacy of the approach that this study found. A new study to identify areas of the brain stimulated by music in patients with dementia is also a topic of interest. A study utilizing brain-imaging technology would be greatly beneficial to solidify the neurophysiological theories behind this study's approach. Future possible research also includes the potential of standardizing the independence measurement strategy. The self-developed tool used in the study may benefit other healthcare professionals, and standardizing this method would possibly be a beneficial addition to the tools available to professionals targeting increased independence in a single ADL.

Study Limitations

Limitations of the study involve the reliability of the caregiver's collection. The researcher trained the caregiver on how to collect and record information; however, without the researcher's daily oversight there is no way to be sure the participant's performance was judged with the same criteria each day. Another consideration in study limitations would be the length of the study. In calculating overall independence scores, week 1 was compared to week 6. A significant decrease in supports required began presenting in weeks 5 and 6, however in the preceding weeks no increase in independence was notable. A longer study would be beneficial to truly investigate if this increasing trend in independence continued, or if weeks 5 and 6 were a random coincidence. A final consideration in the study's limitations is the quantity of data collected in the study. Data on independence was collected by the researcher only once per week. Collecting more data would provide a more in-depth view into the realistic functioning level of the participant, and the limited data collection in this study raises questions of accurate representation of the participant's abilities.

Conclusion

Overall, the use of preferred music increased the participant's independence in the target activity. A direct auditory association between the song and the target activity was never created; however, an association between the song and the researcher started to emerge in week three of the study. This information will be a beneficial addition to research in the field of speech-language pathology and other health-related professions, as it provides a basic outline for a potential strategy to increase independence and QoL for a PWD.

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APPENDIX A

Measurement of Independence in a Single Activity of Daily Living

Targeted ADL: _____

TASK LOCATION

Does the patient enter the correct room to participate in task?

Support required: Verbal Physical Total caregiver support (7) Independent (0)
Min Mod Max Min Mod Max
(1) (2) (3) (4) (5) (6)
Task Score: _____

TASK INITIATION

Does the patient initiate the task?

Support required: Verbal Physical Total caregiver support (7) Independent (0)
Min Mod Max Min Mod Max
(1) (2) (3) (4) (5) (6)
Task Score: _____

REQUIRED TOOLS

Does the patient choose the correct objects for task?

Support required: Verbal Physical Total caregiver support (7) Independent (0)
Min Mod Max Min Mod Max
(1) (2) (3) (4) (5) (6)
Task Score: _____

TASK PERFORMANCE

Does the patient appropriately perform the task?

Support required: Verbal Physical Total caregiver support (7) Independent (0)
Min Mod Max Min Mod Max
(1) (2) (3) (4) (5) (6)
Task Score: _____

POST-PERFORMANCE ACTIVITY

Does the patient clean up after activity?

Support required: Verbal Physical Total caregiver support (7) Independent (0)
Min Mod Max Min Mod Max
(1) (2) (3) (4) (5) (6)

Verbal Cues
Minimal: Verbal Direction 1x Task Score: _____
Moderate: Verbal Direction 2x
Maximum: Verbal Direction 3+x

TOTAL INDEPENDENCE SCORE: _____

Physical Cues
Minimal: Touches PwD 1x to support task completion.
Moderate: Touches PwD 2x to support task completion. Clinician Notes:
Maximum: Touches PwD 3+x to support task completion.

APPENDIX B

BRUSHING TEETH

Verbal Cues

Minimal: Verbal Direction 1x
Moderate: Verbal Direction 2x
Maximum: Verbal Direction 3+

Physical Cues

Minimal: Touch 1x to support task completion.

Moderate: Touch 2x to support task completion.
Maximum: Touch 3+x to support task completion.

CAREGIVER INSTRUCTIONS:

1. Enter the room
2. 2. Press "Play" on the provided CD Player.
3. Give the client 10-15 seconds to hear the song before saying anything about the task, such as "Time to brush our teeth."
4. If the client does not initiate, begin task as normal.
5. Be sure to provide client with ample time to be as independent as possible.
6. Mark provided sheet with levels of support required for activity completion for that day.

DATE	Maximum Assistance	Moderate Assistance	Minimum Assistance	Patient Completed Independently
6/27	V PH	V PH	V PH	
6/28	V PH	V PH	V PH	
6/29	V PH	V PH	V PH	
6/30	V PH	V PH	V PH	
7/1	V PH	V PH	V PH	
7/2	V PH	V PH	V PH	
7/3	V PH	V PH	V PH	
7/4	V PH	V PH	V PH	
7/5	V PH	V PH	V PH	
7/6	V PH	V PH	V PH	
7/7	V PH	V PH	V PH	
7/8	V PH	V PH	V PH	
7/9	V PH	V PH	V PH	
7/10	V PH	V PH	V PH	
7/11	V PH	V PH	V PH	
7/12	V PH	V PH	V PH	
7/13	V PH	V PH	V PH	
7/14	V PH	V PH	V PH	
7/15	V PH	V PH	V PH	
7/16	V PH	V PH	V PH	
7/17	V PH	V PH	V PH	
7/18	V PH	V PH	V PH	
7/19	V PH	V PH	V PH	
7/20	V PH	V PH	V PH	
7/21	V PH	V PH	V PH	
7/22	V PH	V PH	V PH	
7/23	V PH	V PH	V PH	
7/24	V PH	V PH	V PH	
7/25	V PH	V PH	V PH	
7/26	V PH	V PH	V PH	
7/27	V PH	V PH	V PH	
7/28	V PH	V PH	V PH	
7/29	V PH	V PH	V PH	
7/30	V PH	V PH	V PH	
7/31	V PH	V PH	V PH	
8/1	V PH	V PH	V PH	
8/2	V PH	V PH	V PH	
8/3	V PH	V PH	V PH	
8/4	V PH	V PH	V PH	
8/5	V PH	V PH	V PH	
8/6	V PH	V PH	V PH	

APPENDIX C

APPENDIX C CONTINUED

APPENDIX D

INFORMED CONSENT FORM – Participant

Increasing Independence in Activities of Daily Living For a Person with Dementia Through the Use of Preferred Music

INTRODUCTION
You are invited to join a research study to look at how the use of music can increase independence in daily activities for a person with moderate to severe dementia. Please take whatever time you need to discuss the study with your family and friends, or anyone else you wish to. The decision to join, or not to join, is up to you.
In this research study, we are investigating how music affects a person with dementia's ability to perform routine, daily activities. Music has been show to create positive effects for people with dementia, and this research study will investigate if music has the ability to increase independence during activities.

WHAT IS INVOLVED IN THE STUDY?
If you decide to participate you will be asked to participate in an interview with your caregiver and us. We will also communicate with your legally appointed representative to gain extra information on your musical preferences and performance in activities. During these conversations, we will decide upon a song of your choice and an activity of daily living that requires caregiver support. The researcher will also administer the St. Luis University Mental Status screening tool in order to measure your cognitive ability at the beginning and at the end of the study. This tool will take 5 – 10 minutes to administer. Following this communication; face-to-face sessions with us will take place twice per week for six weeks. During these sessions, we will attempt to create a connection between the chosen song and the activity of daily living. We will do this in thirty-minute sessions twice per week by reviewing objects, photographs, and videos related to the chosen activity and practicing the activity together while the chosen song is being played in the background. We are attempting to build a connection between the song and activity so in the future a caregiver could possibly play this song and you would know that the song means a specific activity. Your caregiver will be asked to play this song four to five times during the week on days we are not available in order to continue building this connection. The goal of this research is to see if the music could possibly increase your ability to be more independent. For example, instead of a caregiver telling you multiple times and having to come and physically escort you to where an activity takes place, the song could potentially send you that message and you could go to the location more independently.

We will measure your independence of these activities in five separate areas including: your ability to go to the correct location to perform the task (e.g. the bathroom for brushing your teeth), whether or not you start the task, if you choose the appropriate tools for the task (e.g. a toothbrush for brushing your teeth), if you performed the task once you had the tool, and if you performed activities following the activity that were necessary (e.g. putting the toothbrush back on the counter). This will be measured on a seven-point scale with 0 being completely independent and 7 meaning you require the highest level of support.

Your caregiver will also be provided with a questionnaire at the end of the research to see if they feel your independence has improved with the music playing. This will give us an inside perspective on if the music was truly beneficial on a day-to-day basis for your activities.

The investigators may stop the study or take you out of the study at any time they judge it is in your best interest. They may also remove you from the study for various other reasons. They can do this without your consent.

You can stop participating at any time. If you stop you will not lose any benefits.

RISKS
The study may involve the risk of emotional irritation to you. The same song will be played many times

during the six-week study and it may cause agitation. This is a very low risk, as music has been shown in research to improve emotion and mood in people with dementia and the researcher does not anticipate this as a problem, but the risk still exists.

The risk for breeching confidentiality also exists as a very small concern. The researcher will take all measures possible to avoid this, including assigning numbers instead of names to you and all of your paperwork. The key to this number-name system will be kept in a secure location that only the researcher has access to in order to avoid this. At the end of the research, this information will be destroyed. There may also be other risks that we cannot predict.

BENEFITS TO TAKING PART IN THE STUDY?
Benefits from this study may include an increase in independence during daily activities. However, this study is an experiment and we can't guarantee that you will personally experience benefits from participating in this study. Others may benefit in the future from the information we find in this study.

CONFIDENTIALITY

We will take the following steps to keep information about you confidential, and to protect it from unauthorized disclosure, tampering, or damage: we will assign a number to replace all identifying information such as your name and birth date on all research documentation. This number system will only be known to us and will be kept in a secure, password protected electronic location. It will be destroyed upon completion of the research study. We will keep all data and documentation during the study in a secure, locked location.

If this research study is published or shared with others, no names or identifying information will be included. Names will be replaced with numbers in all shared information.

YOUR RIGHTS AS A RESEARCH PARTICIPANT?
Participation in this study is voluntary. You have the right not to participate at all or to leave the study at any time. Deciding not to participate or choosing to leave the study will not result in any penalty or loss of benefits to which you are entitled.

If you desire to withdraw from the study early, please notify us at the time of your decision.

CONTACTS FOR QUESTIONS OR PROBLEMS?
Call the researcher if you have questions about the study, any problems, unexpected physical or psychological discomforts, any injuries, or think that something unusual or unexpected is happening. You may contact the Vice President of Research and Compliance at the Kilgore Research Center at West Texas A&M University or the Assistant Professor of Communication Disorders at West Texas A&M University if you have any questions or concerns about your rights as a research participant or with any other concerns you may have.

AGREEMENT TO PARTICIPATE IN RESEARCH: I have read, or have had read to me, the purpose and procedures of this research and have had an opportunity to ask questions which have been answered to my satisfaction. I voluntarily agree to participate in this research.

_____ _____
Date Subject's Name

APPENDIX D CONTINUED

_____	_____
Date	Signature of Subject
_____	_____
Date	Signature of legal representative
_____	_____
Date	Signature of person obtaining consent

APPENDIX E

INFORMED CONSENT FORM – Caregiver

Increasing Independence in Activities of Daily Living For a Person with Dementia Through the Use of Preferred Music

INTRODUCTION
You are invited to join a research study to look at how the use of music can increase independence in daily activities for a person with moderate to severe dementia. Please take whatever time you need to discuss the study with your family and friends, or anyone else you wish to. The decision to join, or not to join, is up to you.
In this research study, we are investigating how music affects a person with dementia's ability to perform routine, daily activities. Music has been show to create positive effects for people with dementia, and this research study will investigate if music has the ability to increase independence during activities.

WHAT IS INVOLVED IN THE STUDY?
If you decide to participate you will be asked to participate in an interview with your client and us. During this conversation, we will decide upon a song of the person with dementia's choice and an activity of daily living that requires your support. Your role as the caregiver during the six- week study will be to play the song of choice while the person with dementia is performing the chosen task. This music will be provided to you, and you on a CD-ROM and you will be provided with a device to play it on. You will play this song during the daily activity and record on a form provided how the person performed such as they independently performed the task, required you to talk them through it, or required you to do the activity for them completely. The goal of this research is to see if the music could possibly increase the person with dementia's ability to be more independent. For example, instead of you telling the person with dementia multiple times to do something and having to physically escort them to where an activity takes place, the song could potentially send them that message and they could go to the location more independently with less support from you as the caregiver.

You will be provided with a questionnaire at the end of the research to see if the person with dementia's independence has improved with the music playing and your feelings about the results.

The investigators may stop the study or take you out of the study at any time they judge it is in your best interest. They can do this without your consent.

You can stop participating at any time. If you stop you will not lose any benefits.

RISKS
The study may involve the risk of emotional irritation to the person with dementia. The same song will be played many times during the six-week study and it may cause agitation. This is a very low risk, as music has been shown in research to improve emotion and mood in people with dementia and we do not anticipate this as a problem, but the risk still exists.

The risk for confidential information being released without your consent also exists as a very small concern. The researcher will take all measures possible to avoid this, including assigning numbers instead of names to you and all of your paperwork. The key to this number-name system will be kept in a secure location that only the researcher has access to in order to avoid this. At the end of the research, this information will be destroyed.
There may also be other risks that we cannot predict.

BENEFITS TO TAKING PART IN THE STUDY?
Benefits from this study may include an increase in independence during daily activities for the person with

dementia. Caregiver symptoms of anxiety and depression have been connected to lower levels of independence in dementia patients they work with. If this music increases independence, it may be possible to lower your levels of stress related to your work as a caregiver. However, this study is an experiment and we can't guarantee that you will personally experience benefits from participating in this study. Others may benefit in the future from the information we find in this study.

CONFIDENTIALITY

We will take the following steps to keep information about you confidential, and to protect it from unauthorized disclosure, tampering, or damage: we will assign a number to replace all identifying information such as your name on all research documentation. This number system will only be known to us and will be kept in a secure, password protected electronic location. It will be destroyed upon completion of the research study.

We will keep all data and documentation during the study in a secure, locked location. If this research study is published or shared with others, no names or identifying information will be included. Names will be replaced with numbers in all shared information.

INCENTIVES

You will be compensated for your full participation in this study with twenty five dollars per week for the full six-week study. This money will be paid to you in cash at the end of the study on the basis that you honestly and accurately recorded all information on the provided form and played the music during all activity opportunities. This information is very important to see if the music was effective, and your honest recording of information is greatly appreciated.

YOUR RIGHTS AS A RESEARCH PARTICIPANT?
Participation in this study is voluntary. You have the right not to participate at all or to leave the study at any time. Deciding not to participate or choosing to leave the study will not result in any penalty or loss of benefits to which you are entitled.

If you desire to withdraw from the study early, please notify us at the time of your decision.

CONTACTS FOR QUESTIONS OR PROBLEMS?
Call the researcher if you have questions about the study, any problems, unexpected physical or psychological discomforts, any injuries, or think that something unusual or unexpected is happening. You may contact the Vice President of Research and Compliance at the Kilgore Research Center at West Texas A&M University or the Assistant Professor of Communication Disorders at West Texas A&M University if you have any questions or concerns about your rights as a research participant or with any other concerns you may have.

AGREEMENT TO PARTICIPATE IN RESEARCH: I have read, or have had read to me, the purpose and procedures of this research and have had an opportunity to ask questions which have been answered to my satisfaction. I voluntarily agree to participate in this research.

_____ _____
Date Subject's Name

APPENDIX E CONTINUED

_____	_____
Date	Signature of Subject
_____	_____
Date	Signature of Caregiver
_____	_____
Date	Signature of person obtaining consent

APPENDIX F

West Texas A&M University
ACADEMIC RESEARCH ENVIRONMENTAL HEALTH AND SAFETY
WTAMU BOX 60217 • CANYON, TEXAS 79016 • 806.651.2270

INSTITUTIONAL REVIEW BOARD FOR HUMAN SUBJECTS
Letter of Approval

August 25, 2016

Stephanie Tavenner
7101 Wolflin Ave, Apt 1502
Amarillo, Texas 79106

Dear Ms. Tavenner,

We are pleased to inform you that your proposal **#04-05-16** submitted to the West Texas A&M University Institutional Review Board for Human Subjects Committee (IRB) for your study titled, **"Increasing Independence in Activities of Daily Living for a Person with Dementia Through the Use of Preferred Music"** has been reviewed and found to meet the requirements of the WTAMU Standard Operating Procedure 15.99.05.W1.01AR Institutional Review Board (Human Subject Research) and 45 CFR 46.117 (c) 1 or 2/ 21 CFR 56.109 (c) 1 and approved by the WTAMU IRB committee. This approval expires on **June 12, 2017**.

This research project has been approved. As principal investigator, you assume the following responsibilities

1. **Continuing Review:** The protocol must be renewed by the expiration date in order to continue with the research project. A Continuing Review application along with required documents must be submitted by the continuing review deadline. Failure to do so may result in processing delays, study termination, and/or loss of funding.
2. **Completion Report:** Upon completion of the research project (including data analysis and final written papers), a Completion Report must be submitted to the IRB.
3. **Unanticipated Problems and Adverse Events:** Unanticipated problems and adverse events must be reported to the IRB immediately.
4. **Reports of Potential Non-compliance:** Potential non-compliance, including deviations from protocol and violations, must be reported to the IRB office immediately.
5. **Amendments:** Changes to the protocol must be requested by submitting an Amendment to the IRB for review. The Amendment must be approved by the IRB before being implemented.

6. **Consent Forms:** When using a consent form or information sheet, you must use the IRB approved version. If you are unable to locate the approved version, please contact the office.
7. **Audit:** Your protocol may be subject to audit by the IRB Administrator during the life of the study. Investigators are responsible for maintaining complete and accurate study records and making them available for inspection.
8. **Recruitment**: All approved recruitment materials will be approved by the IRB. For materials that are distributed to potential participants electronically and for which you can only feasibly use the approved text rather than the original document, the study's IRB Protocol number, approval date, and expiration dates must be included in the following format: WTAMU IRB#XX-XX-XX Approved: XX/XX/XXXX Expiration Date: XX/XX/XXXX.
9. **FERPA and PPRA:** Investigators conducting research with students must have appropriate approvals from the FERPA administrator at the institution where the research will be conducted in accordance with the Family Education Rights and Privacy Act (FERPA) if applicable to the research being proposed. The Protection of Pupil Rights Amendment (PPRA) protects the rights of parents in students ensuring that written parental consent is required for participation in surveys, analysis, or evaluation that ask questions falling into categories of protected information.

Within sixty (60) days of the expiration of this proposal, you will receive a notification that your IRB will expire and you will need to complete the closeout form.

Thank you for your cooperation with the IRB and we wish you well with your research project.

Sincerely,

Dr. Gary Bigham
Chair, WTAMU IRB

Dr. Angela Spaulding,
Vice President of Research and Compliance