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Exploring the Hinterland: The Development of a Person-Centered Music Therapy Method for a Hospice Patient with Lewy Body Dementia

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**Exploring the Hinterland: The Development of a Person-Centered Music Therapy Method
for a Hospice Patient with Lewy Body Dementia**

Capstone Thesis

Lesley University

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Music Therapy

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Abstract

This thesis explores the development and implementation of a music therapy method with an individual diagnosed with dementia with Lewy Bodies (DLB) receiving home hospice services. There is very little known about the effect of music therapy on patients diagnosed with DLB. Informed by Tom Kitwood's Person-Centered Care (PCC) philosophy for dementia care, Yumiko Sato's Musical Life Review (MLR) model, and Lisa Kelly and Bill Ahessy's Reminiscence-Focused Music Therapy (RFMT) model, a clinical method was developed to explore the effects of person-centered music therapy on reminiscence, caregiver connection, and identity. I drew inspiration from music therapy concepts by Tony Wigram as well as Hanne Mette Ochsner Ridder's utilization of acoustic cueing with patients with dementia. Over a period of five weeks, I conducted five sessions each lasting forty-five minutes to an hour. Data were collected in the form of personal reflections and summaries of the method technique as well as recorded musical reflections. Inductive analysis was carried out for each reflection and summary. Themes from reflections and summaries were cross referenced with Tom Kitwood's flower of psychological needs to further observe what occurred and assess how the method functioned within the PCC framework. Results suggest that person-centered music therapy can assist in promoting reminiscence, addressing psychological needs, and creating connection with a caregiver. In addition, the act of simple reminiscence allowed for the preservation of participant identity and personhood, and empowered him to hold and share his own lived experiences.

Keywords: dementia, dementia with lewy bodies, music therapy, person-centered care, reminiscence, hospice, dementia caregivers

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Hospice Patient with Lewy Body Dementia

Introduction

Dementia is an insidious, rapidly growing global concern. There are over 55 million people diagnosed with dementia worldwide, according to Alzheimer's Disease International (2020). Over the next 30 years, that number is predicted to increase by more than double. In my clinical training, I have utilized music therapy to support hospice patients and caregivers in their journeys through the end of life. I have since come to know dementia in a variety of its manifestations, one being dementia with Lewy bodies (DLB). DLB is a subtype of Lewy Body Dementia (LBD) that primarily impairs executive functioning, focus and attention, bodily movement, and behavior and mood. Other core features include visual hallucinations, sleep disorders, changes in blood pressure, and bowel and bladder functioning (Lewy Body Dementia Association, 2022). Despite being the second most common form of progressive dementia next to Alzheimer's disease (AD), DLB is widely misunderstood, under-researched, and often misdiagnosed due to overlapping symptomology with other forms of dementia (D'Antonio, 2021). Extreme sensitivity to neuroleptics is a common clinical feature of DLB, and medications that may be effective in treating symptoms of other forms of dementia have been shown to induce severe negative reactions or even death in patients with DLB (Capouch et al., 2018). Thus, there is a critical need for the development of nonpharmacological interventions to help manage symptoms associated with DLB.

In her article about dementia and the self, Brown (2016) writes that there is still so much to glean from people "living with dementia and navigating its effects, about the possibilities of living with a fragmented identity" (p. 1006). In this thesis, I explored the use of a person-

centered musical method with a hospice patient diagnosed with DLB to foster reminiscence, caregiver connection, and the preservation of personhood and identity. The method was inspired by the dearth of research on the relationship between DLB and music therapy, the tender commitment of spousal caregivers, and the sacred nature of end-of-life care.

Literature Review

Given the overall lack of DLB literature, defining the relationship between DLB and music therapy is an undertaking. This thesis explored as much DLB-focused research as possible and drew from studies that utilized the word ‘dementia’ as an umbrella term. In the case of the latter, I attempted to specify exactly why that research was important and why it was related to DLB, usually due to similar symptom presentation.

Dementia with Lewy Bodies

Diagnostic Criteria and Clinical Features

Lewy Body Dementia (LBD) is a neurodegenerative spectrum that consists of two subtypes—dementia with Lewy bodies (DLB) and Parkinson’s disease dementia (PDD). According to the Lewy Body Dementia Association (2022), a diagnosis of DLB is typically made when the preliminary symptoms include cognitive and executive functioning impairment, visual hallucinations, or behavioral issues. Conversely, a diagnosis of PDD is typically made when the preliminary symptoms are movement-related such as tremors, slowed movement, or rigidity. DLB is caused by the buildup of alpha-synuclein proteins in the brain, aptly named Lewy bodies (Capouch et al., 2018). It can be difficult to diagnose DLB due to insufficiency of disease awareness and overlapping symptomology, and a concrete diagnosis can usually only be made after a post-mortem autopsy (McKeith et al., 2017).

The main clinical feature of DLB is dementia, defined by Capouch et al. (2018) as “measurable cognitive impairment in conjunction with an impact on activities of daily living” (p. 249). However, the cognitive impairment brought on by DLB is more closely tied to visuo-perceptual, attention, and executive functioning skills rather than memory recall skills (Taylor et al., 2020). Individuals diagnosed with DLB often experience difficulty with language, daytime somnolence, fatigue, apathy, depression, and autonomic nervous system functioning (McKeith et al., 2017). Other indicators of DLB include difficulty focusing, visual hallucinations, and Parkinsonism, including rigidity, slow movement, coordination issues, and tremors. (D’Antonio et al., 2021). DLB also brings significant fluctuations in cognitive functioning and alertness that sometimes “vary over minutes, hours, or days [and] occur in 50% to 75% of patients” (McKeith, 2004, p. 336).

Key Differences of DLB to Other Forms of Dementia

DLB differs from other forms of dementia in both order of symptomology and symptom presentation. The Lewy Body Dementia Association (2022) clarifies that LBD is unfortunately frequently misdiagnosed as AD, especially in its early stages. However, over time, key features of LBD can appear to differentiate from AD such as visual hallucinations, changes in movement, and sleep disturbances. Also, memory impairment—a common indicator of AD—does not typically occur in the early stages, instead becoming apparent later in the disease progression (Capouch et al., 2018). Other key differences between LBD and other forms of dementia include the presence of REM sleep behavior disorder, detailed visual hallucinations, and extreme sensitivity to psychiatric drugs (Connors et al., 2018).

Current Treatment

While there is no cure for DLB, or any form of dementia, there are pharmacological and non-pharmacological options for symptom management. However, research on both approaches is scarce. According to a recent review on new evidence on managing LBD, Taylor et al., (2020) stated that “no comprehensive guide to the management of patients with Lewy body dementia exists” (p. 2) and clinical drug trials for DLB are often built using frameworks from AD trials. While there is overlap in symptomology, more research on DLB-specific treatment is needed. These researchers discovered that the cholinesterase inhibitors Donepezil and Rivastigmine were both helpful in managing cognition and assisting with activities of daily living (ADLs) for patients with DLB and AD. Both drugs were originally used to treat patients with AD.

There is currently “no evidence [to support] the use of any antipsychotic drug in patients [with LBD]” (p. 6). Up to 50% of DLB patients are at risk for extreme antipsychotic sensitivity which can lead to significantly reduced quality of life and even death. Hallucinations may not necessitate pharmacological intervention if the patient feels neutral to them or finds them enjoyable. Evidence of the efficacy of antidepressants for managing symptoms of depression or anxiety is lacking as well, and there are questions around the use of these drugs worsening sleep disorder symptoms. The researchers suggested more large-scale trials specific to patients with DLB.

Connors et al., (2017) noted in a systematic review that conducting studies on non-pharmacological interventions is necessary given the likelihood of DLB patients being sensitive to psychotropic drugs. The researchers listed music therapy, occupational therapy, cognitive behavioral therapy, physical therapy, and sensory stimulation as having some evidence of efficacy with symptoms of dementia.

Person-Centered Dementia Care

Carl Rogers laid the foundation for person-centered care (PCC) in the 1950s (Wilson, 2021), and the late psycho-gerontology professor Tom Kitwood pioneered its application to dementia care in 1988. PCC challenged both the traditional medical model's approach to dementia care and what Kitwood (2019) referred to in his book as the "malignant social psychology that surrounds dementia" (p. 3). Kitwood postulated that the fundamental goal of dementia care is "to maintain personhood in the face of failing of mental powers" (p. 94) and that environment can impact a person's quality of life just as much as their dementia diagnosis. He examined the historic and cultural issues associated with the treatment of people living with dementia and how personhood and identity are often undermined due to the progression of cognitive decline. In order to effectively care for dementia patients, he asserts that our culture must push against the dehumanization of people with disabilities and view personhood through a relational lens. The purpose of PCC in dementia care is not to 'fix' the person, it is to "[move] beyond our own anxieties and defenses, so that true meeting can occur, and life-giving relationships can grow" (p. 11).

Kitwood determined that the six most salient needs of people with dementia are love, comfort, attachment, identity, inclusion, and occupation. Visually, he represented each of these needs as petals, with the center of the flower being love. While these are universal needs in general, they "are more obvious in people with dementia, who are far more vulnerable and usually less able to take the initiatives that would lead to their needs being met" (p. 93). As cognitive impairment increases so does the urgency of the expression of the need. These needs intricately impact each other. For instance, if a person engages in an enriching activity that brings them joy (occupation), they may be more likely to feel a stronger sense of self (identity).

Brown (2016) describes dementia and attachment, stating:

People living with dementia can also remind us vividly of the importance of relatedness. Attachments are maintained in the face of loss. Our understanding of people with dementia is of people who have had important attachments, even when they are beyond articulating them, and when we have no specific knowledge of them. (p. 1011)

Every person's experience of dementia is unique, regardless of what type or what symptoms are experienced. Fazio et al. (2018) published a literature review focused on person-centered dementia care which offered information on the history of PCC, published pieces on PCC guidelines in facilities, and evidence-based studies that show the outcomes of PCC used with patients with dementia. This review touched upon Kitwood's philosophy and the necessity of maintaining identity and personhood, as well as offering alternate perspectives to providing care, such as providing uniquely tailored activities that correspond to a persons' interests or preferences. The authors also offered practice recommendations for PCC with dementia patients, and highlighted the need to understand their multi-faceted humanness, facilitate meaningful interaction, support relationships, and hold space for consent "and success, [recognizing] that even when the dementia is most severe, the person can experience joy, comfort, and meaning in life" (p. S18).

Expressive Arts and Dementia

The body of research on the use of expressive arts with DLB patients is scarce. Most studies that examined creativity and dementia focused primarily on patients with AD or used the word 'dementia' as an umbrella term without specifying which subtype was being studied. Although Drago et al.'s (2006) case report did not implement art as an intervention for management of LBD symptoms, but it did focus on the artwork produced by one visual artist

diagnosed with DLB. Researchers studied the way the artist's paintings changed throughout different stages of his illness in order to determine if the artist's visuospatial abilities deteriorated as the illness progressed. The results of the study confirmed that as his illness progressed, it became increasingly difficult to produce visual art on paper. However, researchers were ultimately unsure about what specific parts of the brain were being inhibited. Researchers suggested more exploration into understanding DLB through an arts-based process, but I was not able to find any other recent studies of this kind. While it is not a therapeutic study, this case report is one of few published instances of art being used as data to learn about this highly under-researched disease.

Camic et al. (2018) published a paper on creativity and dementia in *Frontiers in Psychology*. They suggested taking a 'process over product' approach to conducting arts-based dementia research studies. To avoid biases that focus only on aesthetics, "optimal conditions in the design of art interventions for the dementias to foster creativity need to be identified [that focus on] the process of engaging with the creation of art" (p. 3). The idea of focusing on the process rather than the responses or products was strongly considered in the development of my method.

Music Therapy and Dementia

Music therapy is defined by the American Music Therapy Association (AMTA) as "the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship" (AMTA, 2005). In their book, *Music Therapy*, Darnley-Smith and Patey (2003) stated that even in late-stage dementia, "musical sounds still evoke responses. Exactly how this occurs is currently not clear, although the phenomenon is extensively documented in research literature" (p. 102). In my research, I was not able to find any studies

focusing solely on DLB and music therapy, which further emphasizes the importance of more comprehensive research. There have, however, been studies on the benefits of music therapy with patients diagnosed with other forms of dementia.

A systematic review published in the *Journal of Alzheimer's and Neurodegenerative Diseases* by Mercadal-Brotons and Alcântara-Silva (2019) compiled studies that used music therapy with patients with non-Alzheimer's dementia, including LBD and other forms. The review reiterated that most of the studies on music therapy and dementia are conducted with patients with Alzheimer's. The researchers noted that while "dementia is a syndromic entity, there are distinct subtypes that differ in their etiology, presentation form, and clinical course and associated disorders" (p. 1). In this systematic review, researchers asked questions about what specific music therapy methodologies are most frequently used in studies, and what symptoms are most frequently addressed. The areas addressed included quality of life, mood, cognition, affect, behavioral and psychological symptoms of dementia, and stress among both patients and caregivers. The studies all showed improvement in certain areas of focus, notably in behavioral and psychological symptoms, emotional state, and caregiver stress. However, only two of the articles were randomized controlled trials, and those were the studies that yielded the most significant results. This is to say, the gap in research of music therapy and non-Alzheimer's dementia is evident. Researchers stated that the music therapy interventions used in the studies "with people with non-AD dementias are not different from those with AD in spite of the difference in in the clinical manifestations, stage and course of the different types [...]" (p. 7).

A brief case example from Hsu et al.'s (2015) feasibility study examined the use of music therapy interventions with a patient diagnosed with LBD. In the study, researchers conducted a five-month individual music therapy program at two residential dementia care facilities in the

United Kingdom. Researchers used a control group and a standard care group at each facility to evaluate the efficacy of music therapy interventions in alleviating neuropsychiatric symptoms of dementia such as anxiety, apathy, general distress, and depression. Sessions were held weekly, and participants included 17 residents and 10 staff members. The results consisted of both qualitative and quantitative data, the quantitative being measured by scores on the Global Deterioration Scale (GDS) to measure a patient's level of cognitive decline and the Neuropsychiatric Inventory for Nursing Homes (NPI-NH) to characterize dementia symptoms and evaluate their severity. The qualitative data were collected by interviewing staff members at baseline, three and five months into the study, and seven months post-intervention.

The musical interventions were conducted individually by trained music therapists, informed by interactive live music therapy methodology, and were videotaped to later be shown to caregivers in order to offer education on music therapy, observe what symptoms were addressed, determine if any symptoms were lessened, and observe how the patients' "remaining abilities [enhanced their] expressions, mood and cognitive and sensorimotor functioning" (p. 4). The latter of these suggests a person-centered and strengths-based approach to music therapy, showing that the music therapist noticed, valued, and worked with the patients' already existing abilities.

Researchers provided a single case example in the study to provide qualitative input on their music therapy processes. The case focused on a patient named 'B' with a primary diagnosis of DLB who experienced paranoia and hallucinations which led to substantial anxiety and distress. During baseline data collection, 'B' was highly agitated and aggressive, but as the MT engaged her in soothing music to start, she began to calm. At one point, she even made eye contact and smiled. 'B' even shared some memories with the MT without being prompted. They

were able to reach attunement and after the session, 'B' was no longer showing signs of agitation. In fact, she was in good spirits. In my research, this was the only case example I came across that explored using music therapy interventions with a patient explicitly diagnosed with LBD.

Music therapists and scholars Ridder and Gummesen (2015) published an explorative case study to assess the efficacy of an improvisational music therapy technique called extemporizing, developed by Tony Wigram (2004), to promote communication with one person with dementia and global aphasia. Wigram defined extemporizing as “[improvising] on some existing composed musical material, or in a known style” (p. 113). In the Ridder and Gummesen case study they expounded on that clinical choice, positing that extemporizing “provides a safe ground for engaging in communicative dialogues” (p. 21). With their client, they also focused on “using clear, amodal, and non-verbal cues focusing on timing, flow and communicative regulative elements” (p. 13). The results of the study showed that the client expressed more engagement when he was first presented with familiar music. After that, the client was able to remain in the music, “and would initiate interaction [...] adding his own personal expressions and small melodic fragments” (p. 18). This technique provided both familiarity and spontaneity, successfully increasing communication, engagement, and self-expression with their client. They concluded in stating that extemporizing can promote “sharing statements, expressions, or acts, [and] may be specifically important in people with moderate/severe dementia [...] as it takes a starting point in preferred musical material and well-known musical forms” (p. 21). My method participant had deficits in verbal communication, often unable to express his thoughts clearly. Ridder and Gummesen’s study informed my method and encouraged me to keep him in the music with me.

A Randomized Controlled Trial (RTC) study by Ridder et al. (2013) focused on the effects of individual music therapy on quality of life and agitation in patients with dementia. The participants included individuals living in nursing homes diagnosed with moderate to severe dementia. Trained music therapists ran a six-week bi-weekly music therapy program using interventions such as improvisation, music listening, singing, and dancing. The control group received standard care. The data were collected by respondents and used multiple scales measuring agitation, disruptiveness, and quality of life. Researchers also recorded the dosages and medications patients were taking during the duration of the study. The results provided evidence that agitation and disruptiveness scores were significantly lower in the group receiving music therapy than in the standard care group. Two patients in the group receiving music therapy had their medication dosages significantly reduced. Researchers concluded that “music therapy might have potentials to reduce the prescription of psychotropic drugs” (p. 675). The results of this study are important in suggesting music therapy as a nonpharmacological intervention to alleviate negative symptoms associated with dementia. Although agitation is not a core feature of DLB, it can be a common occurrence in patients.

Person-Centered Music Therapy

Kasayka’s (2001) opened the book *Healing Arts Therapies and Person-Centered Dementia Care* by stating that “the core functions of healing arts therapies in the care of persons with dementia are the reclamation, the regeneration and the celebration of the human spirit [and so are] the primary goals of person-centered care” (p. 9). The essence of music therapy is to create connection, to appreciate communication in all its forms, and to consider someone’s existing strengths and abilities rather than their deficits. In Wheeler and Ridder’s (2017) chapter in the book *Music Therapy Handbook*, they noted that to uphold the person-centered principles

in music therapy, clinicians need to utilize “positive interactions, with validating, holding, and facilitation as particularly useful, to meet psychosocial needs in the person with dementia” (p. 373). Kitwood (2019) outlined twelve types of interactions that clinicians and caretakers can facilitate in work with persons with dementia, a few of them being play, stimulation, creation, holding, and validating. Wheeler and Ridder took those concepts and showed how musical interventions such as therapeutic singing, music and movement, playing instruments, music listening, and improvisation can strengthen those interactions and lead to positive outcomes. This chapter was also my introduction to the concept of acoustic cueing to promote arousal regulation when the participant seemed anxious, agitated, or disengaged. Instead of relying on verbal cues and questions, they advise music therapists to use music as a regulation tool an indication for what is to come. They elaborate on acoustic cueing and its value:

When a person with severe memory deficits, over time, becomes familiar with and starts to (at some level) understand the cues that signal the structure, the music therapist can use music with the goal of regulating the arousal level of the person with dementia. (p. 373)

Despite the cognitive decline that accompanies dementia, Innes and Hatfield (2001) attest that person-centered music therapy can allow people to connect and communicate with others, and experience personal development. Within a detailed table of person-centered expressive arts interventions to use in addressing those needs, they suggested reflecting the person’s musical actions back to them to validate and empower them, another Wigram concept. They also noted the power of giving the client ample room for choice and preference. Lastly, they encouraged music therapists to use the music as a container to cultivate a safe and positive therapeutic environment.

Musical Reminiscence and Life Review

To preface this section, it is important to differentiate reminiscence from life review, and briefly outline the different therapeutic frameworks of both. Engelbrecht et al. (2022) define simple reminiscence as concentrating on “shared storytelling or thematic discussions around particular experiences, topics, or times” (p. 1). Life review and life review therapy focus instead on “the meaning in life and a coherent identity [and] reframing negative experiences [using] existing coping strategies for problem-solving” (p.1) respectively.

Kitwood (2019) wrote about the ‘holding’ of one’s inner world and narrative:

To have an identity is to know who one is, in cognition and in feeling. It means having a sense of continuity with the past; and hence a ‘narrative’, a story to present to others [...] even if a person cannot hold on to his or her own narrative identity, due to loss of memory, it can still be held by others. (p. 94)

Dementia severely effects a person’s cognitive functioning. However, long-term memory can remain in place after much else is lost (Kelly & Ahessy, 2021). In the case of people in late-stage dementia, tapping into memories and making clear meaning of them can be challenging. However, musical stimulation has been shown to promote life review and reminiscence, as well as provide a person-centered experience, especially when using client-preferred music (Hatfield & McClune, 2001).

Kelly and Ahessy (2021) published an exploratory study on using Reminiscence-Focused Music Therapy (RFMT) to improve the mood, engagement, and musical and verbal interactions of people with moderate dementia. They collected quantitative data through Dementia Care Mapping (DCM), a standardized tool developed to observe and evaluate the quality of care of patients with dementia. They also collected qualitative data through analyzing their own

reflective journals. Prior to beginning their work, they performed individual assessments for each participant, noting their cognitive abilities and preferred music and songs. Researchers then conducted five structured and themed RFMT sessions with a small group of individuals in a residential dementia care facility. During their sessions, they utilized singing preferred songs, verbal conversation, and ‘associative items’—for instance, a rosary bead necklace to coincide with a spirituality theme—to provide multiple ways to assist with the patient’s reminiscence, mood and engagement. One facilitator ran the session and the other recorded observations using the DCM method. The RFMT sessions were effective in promoting positive mood and engagement according to the DCM scores and the qualitative data. This was especially prevalent during the group singing interventions. However, at times a few participants became overstimulated and disengaged. The music therapists used the music as a grounding tool, and it gently called those who became disengaged back into the group.

Researchers offered considerations for future studies, stating that the work “should incorporate description and reflection of [music therapists’] practices [...] to work towards an aligned practice method” (p. 20). Also, they recommended comparing the experiences of the RMFT group to a regular care group in a RCT study because the body of research in this area remains limited.

The Musical Life Review Model (MLR Model), developed by Yumiko Sato (2011), was designed with hospice patients in mind to encourage emotional expression, reflect on lived experience, and improve mood. At its core, the model was designed to support people with terminal illnesses in accepting the end-of-life process and finding peace. Sato published the model in *Music Therapy Perspectives* and used brief case vignettes to demonstrate each

component of the model. The five components include stimuli, theme, response, evaluation, and therapeutic outcomes.

In the model, music serves as the primary stimulus to draw thoughts and emotions to the surface, however other stimuli can include photographs, poetry, or art. The theme is either informed by the stimulus or vice versa. An example of this is one of the case vignette patients expressing that she had been thinking about her father and her hometown. The music therapist then played a song about home, and the patient started to cry and talk about her father's death and her nostalgia for childhood. The music therapist continued by validating her feelings and playing another song to mirror her nostalgia. The third component, response, is highly variable as every person's experience is different. One of the participants may have reacted with tears, but another reacted by joining in the music and tapping along to the beat. It was suggested that patients may either avoid or lean towards certain emotions brought on by the musical stimulus, and the model may not be appropriate for everyone. It is also important to note that the MLR requires the music therapist to be trained to manage intense responses, as the stimuli could potentially evoke deep unresolved trauma. Evaluation, the fourth component, is what differentiates the model from a reminiscence-focused model because it consists of the patient examining life events, making meaning of them, and considering the relatedness between them. It can include verbal or creative processing and can also involve family members and other participants.

The final component is therapeutic outcomes. Some of the MLR outcomes Sato wrote about included generating feelings of hope and strength, improving patients' moods, facilitating emotional intimacy and quality time between patients and family or friends, processing complex emotions, and building the therapeutic relationship. In the piece, Sato offered a more in-depth

case study in which she utilized MLR to assist her patient, a terminally ill 58-year-old man, with developing a sense of peace with the end of life. The model assisted in repairing strained familial relationships and a building a sense of confidence in what Sato called a person's "last stage of growth" (p. 37). The music was used as a tool to meet the patient's unique need for relational security and relationship completion, which Clements-Cortés and Yip (2021) define as "the importance of feeling a sense of peace, wholeness, and closure at end of life and in bereavement" (p. xv). The patient had been carrying memories he had not fully processed and seldomly discussed. Sato's study emphasized the value in deep listening, understanding a patient's cultural background, and tending to their unique set of musical and non-musical needs.

The Sato (2011) article on MLR significantly inspired the development of my method. I drew from both the components of her model as well as her therapeutic considerations such as utilizing musical elements like melodic and lyrical familiarity, asking open-ended questions to accompany the music, and developing the necessary musical skills of a music therapist intending to implement the MLR model. Certain musical qualities like melody and timbre can be triggering to patients, which I took into consideration. Sato encouraged the use of open-ended questions related to the music played. For example, asking a question about the circumstances of a patient's life at the time a song was introduced to them. Sato also explained that when a patient is in significant decline, they "prefer music that is simpler and less demanding [...] and less discussion and more silence may be needed" (Sato, 2011, p. 35). She also discussed the importance of having cultural sensitivity, curiosity, and a wide musical repertoire to meet the patient's unique musical needs. Another important consideration for me was my limited training in holding a person's trauma, and the knowledge that music can open unknown doors to untouched memories. It was critical for me to keep my scope of practice at the forefront.

Hospice Care and Caregiver Burden

Hospice care is interdisciplinary care that shifts the focus from medical treatment to comfort measures and symptom management in the last phase of a person's illness. The American Cancer Society (2019) described the hospice philosophy as “[the acceptance of] death as the final stage of life: it affirms life, but does not try to hasten or postpone death” (p. 1). It is essential to note that my method was conducted with a participant receiving home hospice services from my internship agency, meaning he and his spousal caregiver opted out of curative or life-sustaining treatments.

According to Alzheimer's Disease International (2020), fifty percent of dementia caretakers globally noticed a decline in their own health and well-being while caring for their loved one. More qualitative and quantitative research is needed to expound on the experience of caregiving for a patient with DLB, and the subsequent effects on caregivers' health and identity.

In a study by Armstrong et al. (2019) about former caregiver experiences during the end-of-life phase, researchers conducted semi-structured telephone interviews with 30 caregivers and family members about their experiences caring for people with DLB. Using a qualitative approach, they analyzed the transcripts and extracted key themes that presented a severe lack of end-of-life education around disease progression timeline and decline, DLB symptomology, advanced directives, the definition of hospice care, medications, observing the dying experience, and ways to enhance end-of-life experiences to provide their loved ones with a good death. Participants also mentioned difficulty communicating with healthcare professionals and difficulty predicting their loved one's death. The emergence of these themes further highlighted the unmet needs regarding specifying care strategies to DLB needs, as well as end-of-life education in general. One post-analysis result showed that many families weren't even aware

that their loved one could die from the disease. With the lack of communication from healthcare providers, many families turned to self-education resources such as the Lewy Body Dementia Association website, Facebook groups, and books. There was a great deal of mystery around how to directly tend to DLB related needs, notably the sensitivity to antipsychotics. The researchers state that education around this is essential in hospice planning.

Armstrong et al. (2022) conducted another more recent interview study focused on non-professional DLB caregiver experiences in end-of-life. In this study, most of the participants were children and spouses. They were recruited from a survey posted on The Lewy Body Dementia Association's website. Investigators used a semi-structured interview format that was informed by already existing dementia caregiver studies. The interview questions consisted of open-ended questions about general caregiver experiences and questions about end-of-life. The qualitative analysis yielded five distinct themes. Themes included feeling as though they were "the main drivers of care [and had to] figure out what to do on their own" (p. 291). They also discussed the unique experience of caring for a loved one with DLB, as the core features differ from other forms of dementia. The other themes were centered around the experience of caregiver burden. Study participants expressed feeling as though they lacked support from medical teams and other family members. They also reported having trouble sleeping, keeping up with their finances, and needing more understanding around the dying process. Several participants discussed difficulty with managing symptoms such as REM sleep behavior disorder and incontinence. They also noted challenges with independently lifting or repositioning their loved one as their mobility declined.

These qualitative inquiries are critical because there are currently no other studies that specifically analyze the lived experiences of informal caregivers of DLB patients, even though

research shows DLB caregivers experience more burden than caregivers of those with AD (Armstrong et al., 2022).

Methods

I utilized a qualitative single-subject approach to explore how person-centered music therapy could promote identity and personhood, positive reminiscence, and spousal caregiver connection.

I conducted one music therapy session per week for five weeks in the participants' home, each session lasting forty-five minutes to an hour. The intervention was semi-structured and informed by my prior discoveries of the primary participant's interests, preferences, life history, and needs. I consulted with the participant's spouse regarding topics and songs of interest, as well as topics to approach with caution. Following each session, I engaged in three different forms of reflection. I used inductive analysis to pull themes from my data and presented the themes in various tables and charts.

Participants

The primary participant for this project was a man in his early seventies with DLB who was receiving home hospice services. In addition to his late-stage dementia diagnosis, he also had reduced mobility, rigidity, daytime somnolence, confusion, and hallucinations. Because he was quite far in his disease progression, he also had difficulty with memory recall. He was oriented to person, but frequently needed reassurance of place and time. He had a history of singing and playing several instruments. He was a quiet, intelligent, and quick-witted person. I had been visiting the participant for a few months prior to conducting my method which allowed me to get to know him and understand his needs. That privilege influenced my method development.

The secondary participant was his spouse and primary caregiver. She referred her husband to music therapy because of his interest in music and her desire to cultivate joy in the home. She was involved in the planning phase, took part in almost every session, and was a regular consultant throughout data collection process. I received permission from my hospice supervisor to conduct this method, and received consent from both participants.

Anticipated Outcomes

I initially intended to focus on life review, and through that work, nurture identity and personhood. However, as I got to know the participant and gained a deeper understanding of his illness and subsequent decline, I adjusted both my procedure and my expectations. I moved away from the more complex structure of musical life review so as not to confuse or overwhelm him, and shifted focus to positive reminiscence. My hope was that the participant would feel safe enough to share with me, connect with his identity through familiar and preferred music and topics, and experience joy through reflecting on his life.

Other goals were to create opportunities for connection between the participants, and give the participant's spouse the option of taking a break from caretaking if that was what she needed. I wanted to offer them the opportunity to connect through memory and music that otherwise would not be offered through my internship site's home care services. I also hoped to challenge myself and better understand my own professional and personal identities through three different methods of post-session reflection.

Procedure

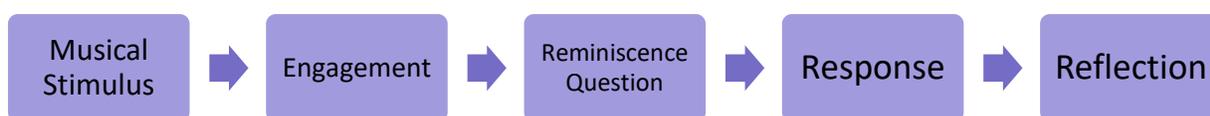
The method followed a simple, straightforward procedure. Each session, I brought with me a guitar and an ocean drum. The participant had various homemade shaker instruments at his

side he occasionally liked to use, although sometimes appeared distracted by them. In my experiences with him prior to data collection, I found that he was more engaged and responsive to musical stimulation than to verbal dialogue or questioning.

Each session had a pre-planned theme. Themes included travel, work, love/marriage, humor, and life in general. Sessions began with a musical stimulus. Examples included live guitar playing, singing, percussion, playing recorded music, or vocalizing. Usually, the stimulus consisted of live music and singing a familiar song that lyrically or melodically aligned with the theme. The participant would then engage in the music with me. After allowing space for music-making to unfold naturally, I would ask him a simple, prepared reminiscence question. He would then respond, either verbally or musically. Afterwards, I engaged in a personal reflective process. A visual representation of the procedure is shown below in Figure 1.

Figure 1

Flow Chart of Session Procedure

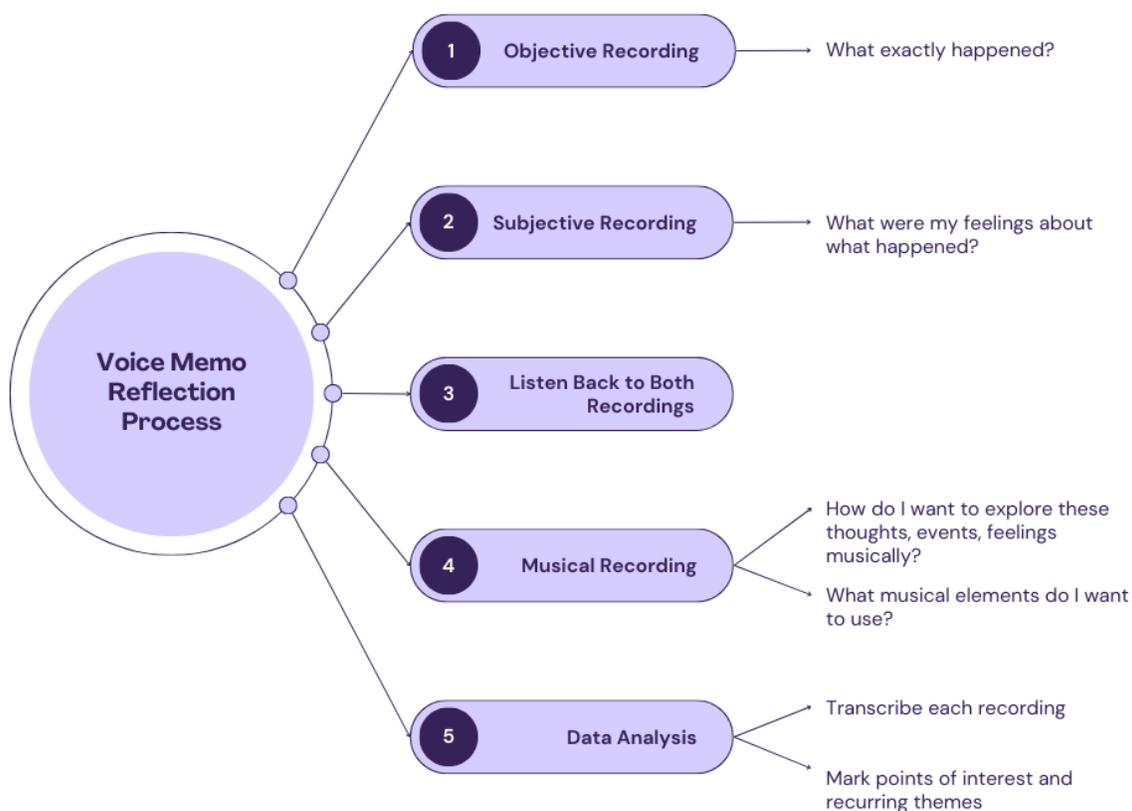


The reflection process involved multiple stages. I created three separate audio reflections for each session using my iPhone's voice memo app. In the first recording, I objectively summarized the events of the session. In the second recording, I subjectively reflected on the events of the session, including my own feelings and reactions to what happened. I then listened back to both recordings, and engaged in a musical reflection which resulted in a third and final recording. This process was designed to foster self-reflection, observe both objective and

subjective experiences, as well as reflect on what it was like to run my method. The purpose of the musical reflection was to explore how my experiences with the participant impacted my own creative music-making process. A visual representation of the reflection process is shown below in Figure 2.

Figure 2

Flow Chart of Reflection Process



Adaptations

Adaptations that deviated from the procedure were at times called for, but I had anticipated that. The chapter by Hatfield and McClune (2001) reinforces the importance of “allowing the content of a session to unfold in response to the needs of the person with

dementia” (p. 101). As this was a person-centered method, I was committed to following the participant’s lead and being flexible to the immediate needs of both participants. I also had to be sensitive to the variability of the participant’s energy level and mood, which was known to fluctuate.

The participant’s spouse popped in and out of most sessions, playfully chiming in with the music and conversation. She was present for the duration of the love/marriage themed session; her presence appeared calming and grounding to the participant. During two out of the five sessions, the participant’s spouse was able to rest in another room, reporting that she found the music comforting. Other times, if she was out of sight, the participant seemed to be distracted by her absence or her movements in another room. This impacted his ability to stay in the moment with me. However, it was usually easy to redirect him using musical cues.

Inductive Analysis

I analyzed the data by session, in order of occurrence. First, I listened to the objective and subjective recordings numerous times and meticulously transcribed them, making note of points of interest and emerging themes or commonalities. I then used Thomas’ (2006) general approach to inductive analysis to pull themes from the transcriptions, color coding as I went. I created a table for each reflection type listing the themes, including descriptions and examples of each theme. I also created stacked bar charts for each of the three reflection types. These charts display the number of occurrences of each theme across all five sessions. I cross referenced the objective summary themes with Tom Kitwood’s flower model of psychological needs to visually observe how they fit within the PCC framework.

To analyze my musical reflections, I listened deeply to each recording and took notes on what exactly happened. I used timestamps to mark moments that felt meaningful or reflective of

the corresponding session experience. Once again, I color-coded themes as they appeared. This was an exciting process because I was able to examine exactly what musical choices I made in the moment and how I could connect them to my experiences with the participant. I took note of elements like improvised or pre-composed lyrics, melodic and lyrical structure, cover song choice, key changes, and anything else that seemed compelling. The structure of the musical reflections ranged from improvisations to cover songs to dream reflection and analysis to a continuation of a ‘story song’ that was spontaneously co-created with the participant. I created another table and stacked bar chart to illustrate the musical themes.

Results

Objective Summaries

From the data analysis of my objective summaries, seven salient themes emerged. In Figure 3 below, I outlined the themes including descriptions and examples of each. Figure 3a visually depicts the themes as they evolved session-to-session.

Figure 3

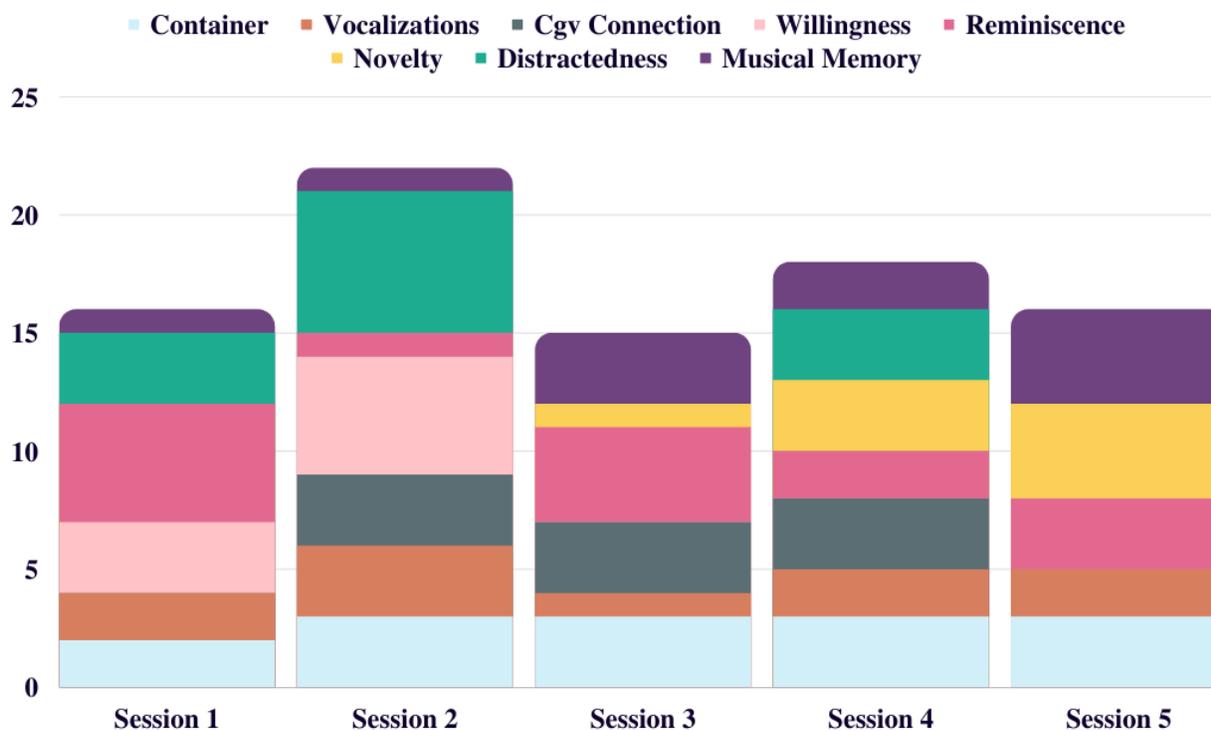
Table of Objective Summary Themes

Theme	Description	Example
Musical Container	Using music to provide consistency and safety	Consistent warm-up, vamping throughout sessions, keeping him ‘in the music’
Vocalizations/Vocal Play	Playful vocal sounds, vocal percussion, humorous singing	Self-initiated popping of lips
Caregiver Connection	Moments of relational connection	Discussion of personal history, eye contact, singing songs together

Willingness	Willingness to try musical activities	Trying unfamiliar instrument, improvising a thematic ‘story song’
Distractedness	Session-to-session moments of distraction or disengagement	Staring out window, stopping musical engagement, expressing fatigue
Non-Verbal Musical Memory	Remembering intricacies of songs	Singing the horn section of “All You Need is Love”
Reminiscence/Verbal Memory Recall	Memories or details from personal history	Recalling details from past travels
Novelty	Observable behavior or responses to music not previously observed	After musical stimulation, disclosing on-topic information without being asked a question

Figure 3a

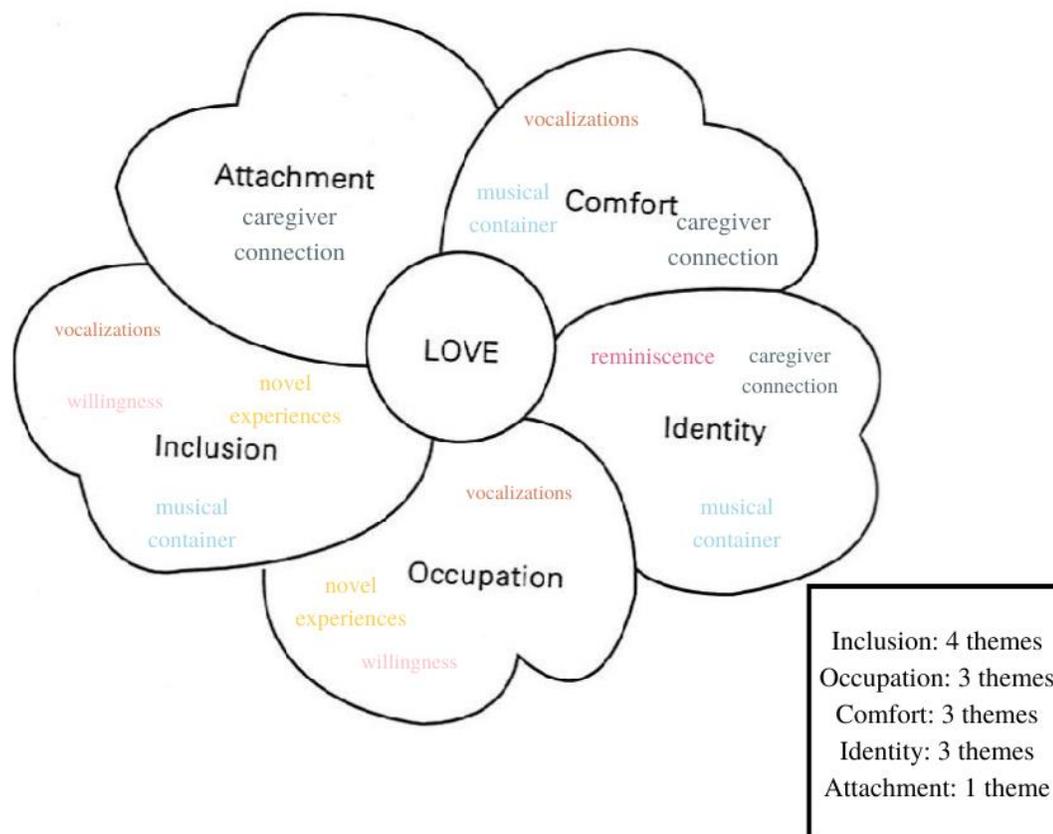
Stacked Bar Chart of Objective Summary Themes



Kitwood's Flower Model

Figure 3b

Kitwood's Flower Model with Corresponding Objective Summary Themes



The results from my objective summaries were cross referenced with the Kitwood (2019) flower model of psychological needs of persons with dementia. As seen above in Figure 3b, each theme was associated with one or more need. For example, the need for identity is met when a person feels “a sense of continuity with the past [and has] some kind of consistency across the different roles and contexts of present life” (p. 94). From my results, the themes associated with the need for identity include reminiscence, caregiver connection, and the musical container.

As seen in the figure, there was a bit of overlap. For example, the theme of caregiver connection correlates to the need for attachment, comfort, and identity. In his book, Kitwood

emphasized that if one need is met effectively, other needs can be more easily met. For example, he stated that “a person who feels more secure in attachment is likely to be able to give more attention to an occupation [and] the sense of identity will be replenished” (p. 95).

Subjective Reflections

The results of my data analysis revealed five themes from my subjective reflections, detailed below in Figure 4. Included are descriptions and examples of each theme. Figure 4a visually depicts the themes as they evolved session-to-session.

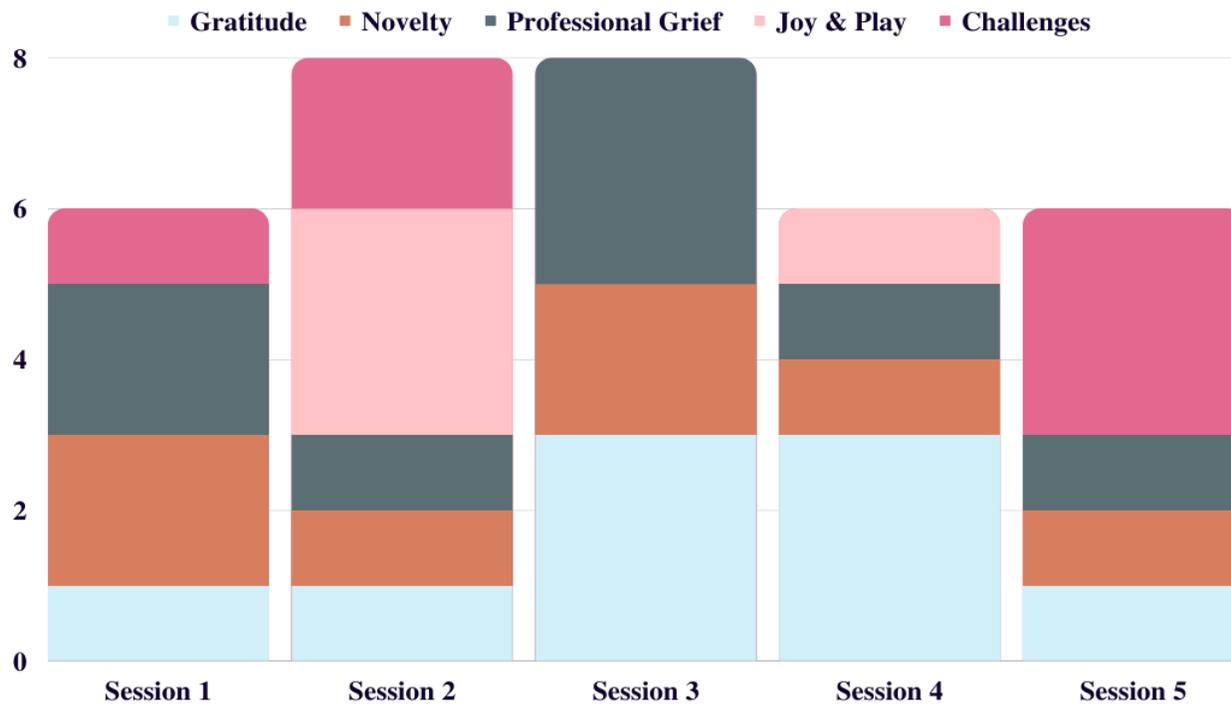
Figure 4

Table of Subjective Reflection Themes

Theme	Description	Example
Gratitude	Feeling grateful for experiences	“I can’t believe I’m doing this work. I’m so grateful I can be fully present with him.”
Novelty	New experiences as an MT in training in hospice, reacting to novel experiences	Allowing a theme to develop organically mid-session
Professional Grief	Struggling with the knowledge of prognosis and decline	Witnessing moments of clarity and disease awareness
Inspiring Joy and Play	Feeling inspired to step out of comfort zone musically, reactions to play and joy	Feeling freer in my own artistic practice
Challenges	Feelings of exhaustion and insecurity around clinical experience	Worrying about the progression of the method and about being overwhelming

Figure 4a

Stacked Bar Chart of Subjective Reflection Themes



Musical Reflections

The data analysis of my musical reflections revealed seven themes, which I presented below in Figure 5. In Figure 5a, I visually represented the themes as they evolved session-to-session.

Figure 5

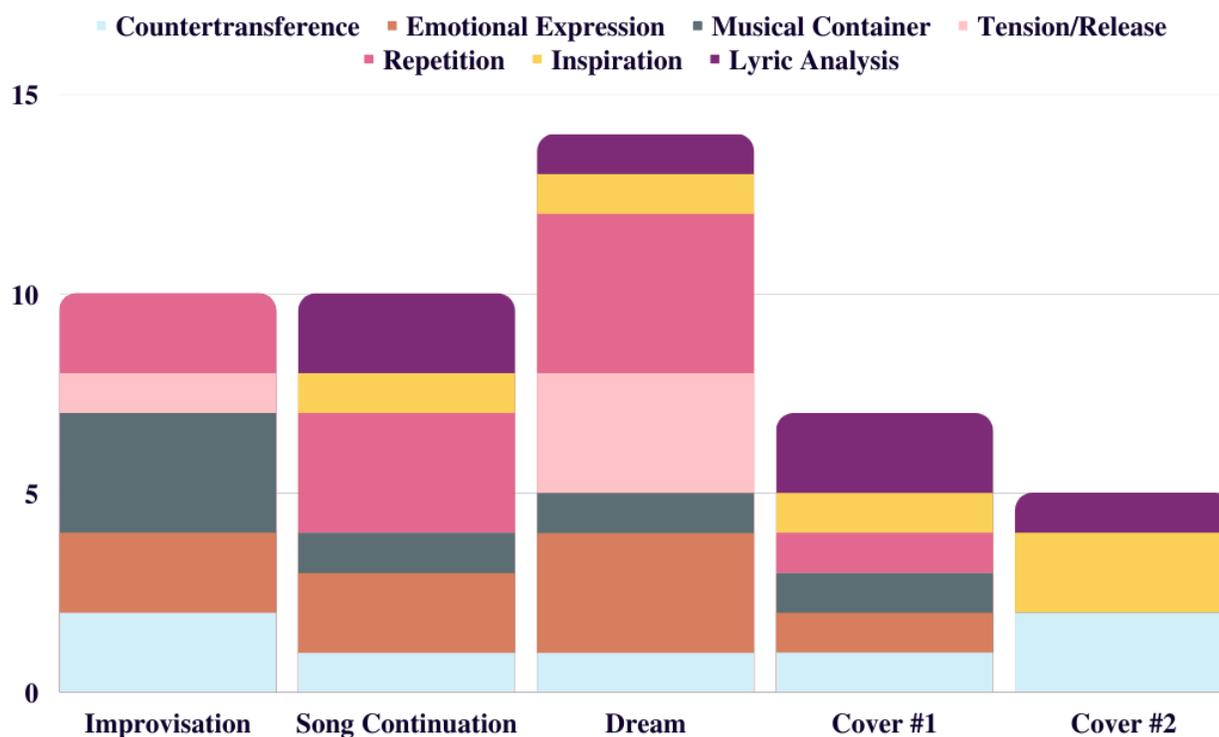
Table of Musical Reflection Themes

Theme	Description	Example
Countertransference	Emotional responses to participant and our shared experiences, parallel processing	Finishing a song we had started together, becoming emotional at the thought of participant decline

Expression of Unknown Emotion or “The Hinterland”	Using music to express or understand what is unknown	Improvisational dream interpretation and analysis over music
Musical Container	Using music to provide consistency and safety, holding space with music	Keeping the melody and chord structure between only the I and V chords
Tension and Release	Using music to mirror tense emotions and bring them to a resolve	Singing a note that clashes with the chord, then resolving to the stable note
Repetition	Repeating motifs or musical structures and chords	Repeating the same lyric multiple times
Inspiration	Feelings of musical inspiration in response to experiences with participant	Covering a song we had sung together
Lyric Analysis	Making meaning from song lyrics, improvised or pre-composed	Reflecting on a Beatles lyric discussed in a session

Figure 5a

Stacked Bar Chart of Musical Reflection Themes



Overarching Themes

Overarching themes from all my data analysis included the consistent presence of a musical container, play and joy, professional grief, connection, countertransference, ‘the unknown’, and verbal and non-verbal memory. This project took me on a comprehensive journey into clinical work. The data show not only the wide range of experiences I had with the participants over just five weeks, but also the depth of knowledge I gained as a researcher and aspiring hospice music therapist.

Discussion

Project Summary

For my thesis project, I developed a person-centered music therapy method to foster personhood, identity, and positive reminiscence in one patient with late-stage LBD. I also set out to create opportunities for connection with a caregiver. The method was person-centered in design, as it was formulated using information about personal interests, history, and identity. Through data collection of my personal and musical reflections and inductive analysis of that, I deduced that person-centered music therapy can be designed to help preserve identity and meet the psychological needs of a person with LBD. The method can also facilitate connective moments between participant and caregiver. The collaborative musical stimulation promoted reality orientation, attention and focus, clear speech and language, and increased energy in the participant. He engaged in spontaneous singing and vocal play, exhibited vivid musical memory, and accurately answered certain reminiscence questions. In my personal reflections, I made discoveries about my clinical and creative processes, as well as my ongoing challenges with professional grief and countertransference. The method aligned with the person-centered

philosophy, as shown by the objective reflection data. I also received positive feedback from the secondary participant.

Key Details from Objective Summaries

Establishing the Procedure

As shown in Figure 3a, the first two sessions essentially served as the establishment of the method procedure and the musical container. The participant exhibited willingness to try new musical activities and seemed to be ‘settling in’ to the work. It is possible that after two ‘introductory’ sessions, he felt a sense of safety in the therapeutic space.

Reminiscence and Memory

Themes related to both verbal and non-verbal memory emerged from the results of the objective inductive analysis, including verbal reminiscence and musical memory, defined and explained further in the Figure 3. The reminiscence, at times, was assisted by the presence of and response to the secondary participant. In every session, the participant accurately answered at least one reminiscence question. In most of the sessions, he was able to answer more than one question without tiring or disengaging. Details within his answers varied session-to-session. During one session, he answered one question before explicitly refusing to answer any others. To honor that, I gave him control over the session and we engaged in improvisational music-making instead.

Non-Verbal Musical Memory. The participant’s non-verbal musical memory was consistent and powerful. As seen in Figure 3a, he expressed instances of musical memory in every session. The sessions with the most instances of musical memory were the sessions focusing on the themes of education/work history (session 3) and life in general (session 5). Coincidentally, the secondary participant was present for session 3, which likely had something

to do with the increased amount of both musical memory and reminiscence. The last session, however, took place in the participant's bedroom while he was still in bed. His spouse was not present, yet increased expressions of both musical memory and novel experiences were identified.

Another example of non-verbal musical memory occurred during a moment of singing the Beatles song "All You Need is Love" together. The participant enthusiastically sang the horn section that directly precedes the second line in the chorus. He consistently remembered intricate parts of songs that went beyond the main vocal melody, such as string parts, background vocals, and basslines. I believe this can be credited to his pre-existing musical abilities. According to Hatfield and McClune (2001), encouraging preserved musical skills "can be very rewarding to individuals with dementia [and] the experience of playing or singing [can be] one that truly expresses the uniqueness of each individual". Kelly and Ahessy (2021) also noted in their research that even in the face of cognitive decline and memory loss, musical skills and "musical details" (p. 3) can remain unscathed.

Reminiscence. In all five sessions, the participant reminisced to various degrees. In my literature review, I referenced the exploratory study conducted by Kelly and Ahessy (2021). In the study, they utilized a consistent thematic structure in their RFMT sessions to encourage reminiscence, and began each session with the same song to establish familiarity in the group. Music was the primary stimulus and the conduit to memory recall. I drew inspiration from this, keeping my method music-focused, consistent, and simple. Kelly and Ahessy explained how "songs from participants' past elicited memories related to their social and national identity" (p. 4) and research from Hatfield and McClune (2001) suggests that songs participants listened to as young adults "can elicit positive responses and stimulate memory skills" (p. 99).

In my results, the participant elicited the most instances of reminiscence during session 1, which focused on his past travel history. As soon as I started singing the song “Moon River”, the participant immediately began singing along with me. I repeated the lyric “There’s such a lot of world to see” (Mancini, 1961) a few times. Still holding the space with soft fingerpicking on guitar, I started to ask him questions. He accurately recalled the movie the song is featured in, as well as the actress who starred in it. Then, I asked him to describe to me a part of the world he had seen, and he accurately recalled copious details from a past trip. In line with the research mentioned above, the participant had first heard the song during his young adulthood. Regarding the participant’s social identity, the other session that yielded significant reminiscence was session 3. The theme of that session was education and work history, both of which were monumental social chapters of his life. He was able to answer questions about his professional life and passions which seemed to coincide with the increase in his musical memory as well. It is also worth noting that no notable instances of distractedness were recorded during that session.

Participant Novel Experiences

There was a steady increase in novel experiences from sessions three through five. These novel experiences included reminiscing on the theme without being asked a question, the participant asking me questions about myself, expressing disease awareness, independently stating a musical preference that his spouse was not aware of, and making personal connections to song lyrics. The novel experiences began during the third session, and increased in frequency as we progressed. After session 2, the theme of willingness seemed to transform into the theme of novel experiences. I hypothesize that this was a result of the participant becoming familiar with the session structure and method procedure, and hopefully feeling safe in the space. This hypothesis ties back into Wheeler and Ridder’s (2017) writing about acoustic cueing. One of the

purposes of the musical cues is to help the participant understand what is happening by “[triggering] memory, which helps the person connect certain music with certain events” (p. 373). It is possible that the repeated use of acoustic cueing each week—and the use of music as a container—created a safe enough environment where the participant could act freely and spontaneously.

Key Details From Subjective Reflections

Countertransference and Professional Grief

My feelings of countertransference and professional grief were present in each subjective reflection, especially after the third session—coincidentally a very emotional session full of lucid moments, connection between the participant and his spouse, and reminiscence. In the book *When Professionals Weep: Emotional and Countertransference Responses in Palliative and End-of-Life Care*, the authors discuss how invaluable awareness of the clinician’s countertransference is (Katz & Johnson, 2016). They write: “it is normal, in fact universal, to have strong feelings and reactions in this work [and] we must take time to reflect on the personal underpinnings of the journey that has brought us to this work” (p. 214). While conducting this research, I felt grateful for how thorough my reflection process was, but also noticed how my minimal experience with end-of-life care was impacting me personally and professionally. In the book, the authors validate how “coming face-to-face with dementia pushes not only our personal buttons but also the limits of our professional identities” (p. 42).

I conducted this research personally as I went through the data collection phase, hence why it is not discussed in my literature review. In my subjective reflection recordings, I discussed feeling exhausted and challenged. At times, I almost felt the need to create distance between myself and the participant because his lucid moments felt painful and disorienting.

There were few moments in the process where the participant expressed awareness of his disease and his cognitive deficits. It seemed the reminiscence questions at times triggered his insecurity in his own orientation and memory. This was also painful and created profound doubt and guilt within me. In my research on PCC in dementia care, I discussed Kitwood's (2019) work in detail, specifically the significance of the clinician moving through their own personal defenses and fears of losing cognitive abilities so that what Kitwood referred to as "true meeting" (p. 11) can be created. Moving through my own defenses was a necessary part of this exploration.

Key Details From Musical Reflections

I found the process of translating my thoughts and feelings into music to be a highly emotional task. Both musical and non-musical themes emerged from my analysis. Music-focused themes included the musical container (present in every musical recording), lyric analysis, repetition, and tension/release. The non-musical themes were the expression of unknown emotions, countertransference, and feelings of artistic inspiration. A link to selected recordings of my musical reflections can be found in Appendix A.

Inspiration vs. Boundaries

The participant consistently inspired me to be creative and exploratory in my musical reflections. At the same time, it is evident in Figure 5a that I consistently craved a clear boundary or musical container to operate within, which I suspect was due to a need for comfort and safety.

For example, in the first musical reflection, I improvised using only two chords on guitar and utilized repetitive melodies. It bloomed into a meditative improvisation. In the moments before pressing the record button, I remembered feeling very challenged by the participant, and I felt 'opened up' by the clinical experiences and the evidence of his decline. By the end of that recording, I felt noticeably calmer and more grounded.

Musical Countertransference

Viewing the data in Figure 5a enabled me to see that I was actively and persistently reacting to the participant during every reflection. It was also evident that the songs we played together in our sessions directly influenced my cover song choices, as the final reflection consisted of a cover of the participant's favorite Beatles song, "Strawberry Fields Forever". I also covered "The Circle Game" by Joni Mitchell, a song that I hadn't shared with the participant, but spontaneously came to mind when I was reflecting. I thought then about my own life as the circle Mitchell sings about, and realized that in my prompting him to reminisce on his life, I had subconsciously been doing the same thing myself. Mitchell (1970) sings:

And the seasons, they go round and round
 And the painted ponies go up and down
 We're captive on a carousel of time
 We can't return, we can only look behind from where we came
 And go round and round and round, in the circle game. (stanza 2)

The participant experienced sleep disturbances, a core feature of DLB. At one point during the third session, his spouse shared that he had been having vivid dreams. I pondered this during my reflection process that evening, as I had also been having vivid dreams that week. In reflection 3, I started out by improvising on guitar. Then, spontaneously, I began to verbally recount one of my own dreams and conducted dream analysis in real time over the music. As I recounted, the music began to mirror the dream. I speculated that the content of my dream was related to my own feelings of fear, anxiety, and inadequacy.

The Unknown

One salient theme was the unknown, or the expression of unknown emotions. I used the word “hinterland” in Figure 5, the table of musical reflection themes. There were unknowns to every aspect of this project—the participant and my ever-evolving understanding of him, my different reflections, the themes drawn from the data, and perhaps most importantly the diagnosis itself.

One day, the participant’s spouse was showing me a word game they enjoyed playing together called “Wordsmithery”. The participant was a highly intelligent person who, even in late-stage dementia, could explain the meanings of obscure, antiquated words. She pulled a card from the deck, and it said “hinterland”, a word I had never heard before. On the reverse side, there were three possible definitions to choose from, and the participant chose the correct definition: “A realm beyond the things that are known (about someone or something)”. Weeks later, when I was conducting my data analysis, the word somehow returned to me and seemed to be a thread weaving through all aspects of the project. The hinterland was possibly the most ubiquitous theme, and I felt that the word—and the way it was introduced to me—completely captured the essence of the project.

Caregiver Considerations

As my project progressed, I realized the extent of the spousal caregiver’s efforts. Thus, it became more important to discuss than I had originally anticipated. The multiple Armstrong et al. studies I presented in my literature review focused on dementia caregiver burden, as well as lack of education for caregivers surrounding DLB and the disease course. Some of the feedback I received from the participant’s spousal caregiver aligned with this research. During data collection, I witnessed moments of sincere connection between her and her husband, both inside

and outside of the music. She also expressed gratitude for providing a safe place for him to engage in musical play. She was also able to take occasional breaks from caretaking during our sessions. She was able to hold both moments of connection and moments of autonomy. Although my findings were on a significantly small scale, my method results showed that caregiver ease during sessions was a salient theme.

Over the course of five weeks, the participant's spouse mentioned that he seemed to have prolonged cognitive clarity after our sessions. She also reported that he would spontaneously self-initiate musical experiences for himself outside of sessions. Hatfield and McClune (2001) support this idea, writing those changes in social behaviors "may be a result of musically produced cortical arousal that can create situations in which cognition is enhanced" (p. 102).

Challenges

Throughout this process, I was consistently unaware of what the participant's mood or energy level would be at any given moment. This was reflective of the unpredictable nature of working in hospice care. For example, there is no guarantee of a second session with a patient, let alone a fifth. It was worrisome to make plans with no certainty of the weeks to come.

I found it surprisingly difficult to witness moments of lucidity in the participant, as it felt like I was getting a glimpse of him before dementia. The more I got to know him, the more jarring those moments became. I processed and reflected the experiences in my subjective and musical recordings, which outlined my struggle with countertransference and professional grief.

Considerations for Future Research

Because the research on the relationship between DLB and music therapy is incredibly scarce, more arts-based research and RCTs should be conducted to explore the interplay between patients with DLB and music therapy. I believe the positive outcomes of this method and the

data presented can be valuable in crafting future studies on this topic. The person-centered nature of music therapy makes it an ideal non-pharmacological intervention for people with DLB and their caregivers. However, my approach was very limiting in that there were only two participants involved. My own personal reflections made up a significant portion of the data gathered, but in the Kelly and Ahessy study on RFMT, the researchers encouraged the utilization of detailed reflections “to further legitimize research via possible replication” (p. 20).

In the future, I hope to see studies that measure the effects of music therapy on core DLB symptoms such as hallucinations and REM sleep behavior disorder, because they are two of the key differentiators of DLB from other forms of dementia. That work would also increase overall awareness of the disease.

If future researchers were to implement a five-session method with this population on a larger scale, I would recommend utilizing the first two sessions as a means of helping the participants “settle in” to the method. This would allow them ample time to get ready to do the work in the following weeks. Keeping the participants in the music using the musical container is also an advised procedural consideration. An active and consistent musical container was effective in this method, and I could see it being a crucial aspect of future methods addressing DLB symptoms such as issues with memory recall, executive functioning, and movement.

Conclusions

This project explored the efficacy of a person-centered music therapy method, the purpose of which was to foster identity, reminiscence, and caregiver connection for a man living with DLB. From this process, I gained more than I could have ever anticipated. We shared joy and reveled in play, and he experienced moments of freedom and autonomy. We sang and

laughed together. He shared memories with me, and I listened. He connected with his spousal caregiver and with different parts of himself throughout different phases of his illustrious life.

I did not set out to ‘fix’ or ‘treat’ this participant. What I did do was tread lightly and curiously into the inner world of a wonderful, amiable, and musical person who had been diagnosed with a largely misunderstood disease. This exploration was about trying to help him, for just an hour a week, explore artistic expression. It was about providing a calm and consistent space, a weekly touchpoint amid home hospice visits from other providers that sometimes involved moments of profound invasiveness, confusion, and discomfort. It was about creating opportunities for genuine connection and mutual reminiscence between the participant and spouse. It was about bringing him back to times in his life that made him smile, even if the reminiscence amounted to a fleeting moment, or a single sensory detail. Any response was a big response, and any meaning-making was inherently meaningful. I am grateful for the shared experiences with both participants, and for the gifts they gave me through our time together in and out of the music.

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Appendix A

Link to selected musical reflections:

https://drive.google.com/drive/folders/1YnK0UoJmyS8v48z-ordFiPN9M583RrOP?usp=share_link

- “Improvisation #1” accompanies session 1
- “The Circle Game” accompanies session 4
- “Strawberry Fields Forever” accompanies session 5

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