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USE OF REFLEXIVE THINKING IN MUSIC THERAPY TO UNDERSTAND THE THERAPEUTIC PROCESS; MOMENTS OF CLARITY, SELF-CRITICISM: AN AUTOETHNOGRAPHY

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ABSTRACT

This research followed the phenomenological tradition to deliver an autoethnographic account of my experience as a music therapist working with people living with dementia. My aim was to challenge socio-cultural stigmas surrounding dementia as well as extend the sources of “truth” in regard to epistemological and ontological stances. The autoethnography presented a reflective examination through story of my daily life at a residential treatment facility. In this paper I explore encounters with residents and staff in an effort to better understand myself as a clinician and the therapeutic process. This process included decisions I made, the rationale for those decisions, and the evolution of the relationships.

PRELUDE

The Missing Person

One rarely conducts research that is of no personal interest or gain. Realistically, the researcher’s influence will always be present in the research, as the foundation of the research question comes from the researcher’s personal curiosity to understand the phenomena under investigation (Muncey, 2010). The curiosity that propels research may stem from the memory of a loved one, a personal or professional interaction with another human being, or academic discourse. Aigen (2015) states that researchers, “are passionate advocates for particular theories and these theoretical commitments influence how facts are construed” (p. 12). Aigen further expresses that those in favor of a theory or stance are more likely to present findings that confirm it, while opponents of a theory will do the opposite. The researcher is not only always present in the study, but potentially working toward a personal agenda albeit unconsciously. Therefore, the only real limits of research are those created and accepted by the researcher and the community involved; participant, academic, professional, etc.

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A positivist paradigm is one in which the researcher is expected to remove subjectivity, bracket emotionality, and erase biases in an effort to deliver an “unadulterated” perspective of the research and its results (Prickett, 2005). This is accomplished using randomized control trials (RCTs), paying careful attention to study designs to prevent participants and researchers from discerning the what, who, and how of the study, and utilizing strong criteria in the selection of participants to create a strong sample. While efforts to minimize bias are necessary in positivist research exploring the efficiency of medical based treatments, these same methods may be inappropriate for research that aims to investigate the nuances of the lived experience between humans. An alternative is a constructivist point of view that emphasizes that knowledge and truths are not inherently out there waiting to be discovered, but are constructed by individuals and communities through their interactions with the world and others. The meanings, or knowledge and truths, that emerge are as diverse as the community members and their methods of acquiring them.

Locating the Missing Person

The ability of research to capture knowledge and truth is challenging no matter whether one is using experimental or postmodern methods. For example, the field of anthropology, the study of human behavior and culture, was viewed as scientific research that made use of an objective method, ethnography, to study and present knowledge created and accepted by diverse ethnic cultures, which were often foreign to the researcher and their academic audience (Wheeler & Kenny, 2005; Collins & Gallinat, 2013). The researcher employed translators to explain foreign traditions and concepts while writing field notes to capture their own personal point of view of the phenomena. Because the researchers were not officially interacting or fully integrated with the subjects, they were seen as neutral and the results unbiased (Collins & Gallinat, 2013). However, audiences began to rightfully question *where* the researcher was located during the phenomena and *how* the researcher could live alongside the culture under investigation and not influence the culture or the presentation of it. As this is not possible, it is important for researchers to own their presence and locate themselves in the context of phenomena, in order to accurately and ethically present findings (Wheeler & Kenny, 2005; Collins & Gallinat, 2013; Denzin, 2014).

It is, or should be accepted that we can never fully know the inner lives of any one we meet in research (Forinash & McKnight, 1999; McDonald, 2015). Therefore, we must aim to know ourselves better and to understand how we view, interact, and influence the communities we are involved with in order to provide the most beneficial care. Research that acknowledges and seeks to understand the impact of the researcher’s behaviors, perceptions, and interactions has benefits to personal and professional aspects of life. It is possible that parents, teachers, and clinicians would also see their own behaviors and perceptions in the researcher, granting the opportunity to reflect and improve how they engage and influence those around them.

Acknowledging the Missing Person

Autoethnography aims to move ethnography away from the gaze of the distanced and

detached observer and toward the embrace of intimacy, engagement, and reflexivity by recognizing the innumerable ways personal experience influences the research process (Ellis & Bochner, 2006; Ellis, Adams, & Bochner, 2011). Autoethnography is a reflexive qualitative method that acknowledges the researcher's presence by describing and analyzing the researcher's personal experience within the culture of interest and retelling the experience through a story (Anderson, 2006; Barleet & Ellis, 2009; Chang, 2008; Ellis & Bochner, 2006). Adams, Jones, and Ellis (2015) suggest that in autoethnography both the researcher and the audience are granted the opportunity to understand personal biases and reactions; and of equal or greater importance, their impact and influence on the participant's culture and experience. Furthermore, Hancock (2015) asserts that autoethnography aids in "challenging pre-existing perceptions, dispositions, interactions and power" (p. 20). Also, Sparks (2000) describes autoethnography as a "highly personalized account that builds upon the experiences of the author/researcher for the purposes of extending sociological understanding" (p. 21). The ability for autoethnography to promote sociocultural change is captured by Ellis and Bochner (2006) who present that:

Autoethnography shows struggle, passion, embodied life, and the collaborative creation of sense-making in situations in which people have to cope with dire circumstances and loss of meaning. Autoethnography wants the reader to care, to feel, to empathize, and to do something, to act. It needs the researcher to be vulnerable and intimate. (p. 433)

I would argue that the relationship of self to others is the essence that makes the human experience valuable and worthy of research. Autoethnography moves us closer to not only understanding ourselves, but also the people we come in contact with, the other. The vulnerable reflexivity that autoethnography requires does not allow the researcher to dismiss personal thoughts, experiences, and culture, but requires the researcher to reflect on their impact and examine their usefulness, thus potentially illuminating preconceptions and impartialities that we all may have surrounding the phenomena. One could argue that the generation of knowledge in order to improve practice is the goal of all research, and this is true. What sets autoethnography apart is its use of story to evoke the personal connection and vulnerability of the researcher directly into the reader's lived experience.

Critiques and Answers

Wall (2008) asserts that writing about the "self" (the researcher in sociocultural context) is not as easy an endeavor as it may seem. A lack of systematic and methodological rigor (Anderson, 2006; Sparks, 2008), potential narcissism and self indulgence (Chang, 2008; Coffey, 1999), the ethical considerations of writing about others and the truthfulness of the narrative (Walford, 2004) are all valid criticism of autoethnography. The use of the researcher as a major data source creates tension within the realms of "representation, objectivity, data quality, legitimacy, and ethics" (Walford, 2004, p. 39). Chang (2008) illustrates this by listing five areas of concern that can undermine and devalue

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autoethnography:

1. Excessive focus on self in isolation of others
2. Overemphasis on narration rather than analysis and cultural interpretation
3. Exclusive reliance on personal memory and recalling as a data source
4. Negligence of ethical standards regarding others in self-narratives
5. Inappropriate application of the label “autoethnography” (p. 15).

In addressing some of the previous concerns, Chang (2008) retorts that, “autoethnographers swept by the power of storytelling can easily neglect the very important mission of autoethnography—cultural interpretation and analysis of autobiographic texts” (p. 16). Fossey, Harvey, McDermott, and Davidson, (2002) also highlight the potential pitfall of focusing too closely on the self and express that a key component of good ethnography is whether or not the research participants’ subjective experiences and social context are effectively conveyed in the writing as they understand it. How can a central tenet of research, which is to make known the experience of the participants, be accomplished using autoethnography, which relies on the researcher as a major data source? One effective way is to avoid elaborate narratives with underdeveloped cultural analysis and interpretation by staying focused on the research purpose (Chang, 2008; Shoemark, personal communication, October 25, 2016); others will be explored later on.

When using the researcher’s self as a source data in autoethnography one can easily be tempted to rely solely on personal recall and memory as data sources. Memory is accepted as a data source within autoethnography, even somewhat cherished because it is a source that other researchers have no access to and it can be summoned and reflected upon at any time by the researcher (Chang, 2008; Ellis & Bochner, 2000; Wall, 2008). Muncey (2005) cautions us that “memory is selective and shaped, and is retold in the continuum of one’s experience, [although] this does not necessarily constitute lying” (p. 2). Memory can reframe or censor past experiences leading to the same effect of biased outcomes mentioned earlier. Therefore, when crafting the narrative, autoethnographers are advised against solely drawing on personal memory. Writings, journals, self-observational data, interviews, artifacts and artwork are all considered as valid data sources for autoethnography (Adams, Jones, & Ellis, 2015; Wall, 2014).

To address the earlier critique that autoethnography lacks systematic and methodological rigor, Ellis (2004) asserted that traditional criteria have to be re-evaluated and transformed or one must create a new means of evaluating autoethnography. Adams, Jones and Ellis (2015) present four areas for evaluating autoethnography. First, the text must make a contribution to knowledge. If a major concept in autoethnography is to embrace the researcher’s voice as a source of knowledge then that voice must offer insight to researchers, participants, and readers/audiences alike. Second, the text must place value on the personal and the experiential. The author needs to conscientiously present a level of emotional vulnerability that incorporates the “I,” which as mentioned before is normally left out of academic writing. This sentiment echoes Behar’s (1996) assertion that “the exposure of the [researcher] self who is also an observer has to take us somewhere we couldn’t otherwise go to. It has to be essential to the argument, not a decorative flourish, not vulnerable exposure for its own sake” (p. 14). Third, the art and

power of storytelling is utilized as the means in which “sense making and researcher reflexivity take place to create important descriptions and critiques of culture” (Adams, Jones, & Ellis, 2015, p. 103). Reflexivity is defined as “acknowledging and critiquing our place and privilege in society” in an effort to “break long-held silences on power, relationships, cultural taboos, and forgotten and/or suppressed experiences” (Adams, Holman-Jones, Holman-Jones, & Ellis, 2014 p. 103). Furthermore, Bochner (2002) expresses that effective autoethnography “grasps or seizes the possibilities of meaning, which is what gives life its imaginative and poetic qualities... and helps the reader or listener to understand and feel the phenomena under scrutiny” (p. 270).

Adams, Jones and Ellis’ (2015) fourth goal for evaluating autoethnography is making sure that the research is handled with a relational and responsible approach to both research practice and representation. This addresses Chang’s (2008) aforementioned pitfall of “negligence of ethical standards regarding others in self-narratives” (p. 15). Ethical considerations are in abundance within autoethnography, as often researchers are not only telling their own story, but their story in relation to other people’s stories. Therefore, protecting the identity and privacy of the research participants is of great importance. Adams, Jones, and Ellis (2015) also stress the importance of making the work as “committed and reciprocal as possible... making it accessible to a variety of readers and viewing the work as an opportunity to engage and improve the lives of our selves, participants, and readers/audiences” (p. 104).

Analytical and Evocative Ethnography

On what autoethnographers focus will ultimately determine the type of text produced. Researchers may give consideration to three areas, the self (auto), the cultural link (ethno), and the application of the research process (graphy) (Reed-Danahay, 1997). Ideally, all three areas will be given equal consideration. Currently, there are two major categories of autoethnography; evocative and analytic. Evocative autoethnography is intended to connect to the emotional side of people’s experience as a premise to change or gain insight. It is described as emotional, confessional, therapeutic, creative, and unconventional, requiring considerable narrative and expressive skills (Anderson, 2006; Ellis, 1999; Ellis & Bochner, 2006). Evocative autoethnography is a conscious challenge to how we think about research, knowledge, and sharing knowledge, and therefore tends to place more emphasis in the areas of the “auto” and “ethno” (Ellis & Bochner, 2006). Analytic ethnography is described as descriptive, conventional, realistic, and more academic in its presentation. Anderson (2006) offers a distinction between the two categories. He states, “Analytic ethnographers are not content with accomplishing the representational task of capturing ‘what is going on’ in an individual life or social environment” (p. 387). Anderson extends the distinction by offering five features of analytic autoethnography:

1. Complete member researcher status
2. Analytic reflexivity
3. Narrative visibility of the researcher’s self
4. Dialogue with informants beyond the self
5. Commitment to theoretical analysis (p. 378)

Of these five features offered by Anderson only two actually appear to be different from Adams, Jones and Ellis' (2015) four goals for evaluating autoethnography: complete member researcher status and commitment to theoretical analysis. One could argue that there is no difference in both researchers' first creed, as in order to truly contribute to knowledge one must have a complete member researcher status, which will be further explained below. This leaves only one major difference between evocative and analytic autoethnography, the commitment to theoretical analysis. It is worth noting that Adams, Jones and Ellis (2015) are strong supporters of evocative ethnography, believing that it is not the place for the author to abstract and explain, but for the reader to draw their own conclusions of meaning based on what is conveyed in the narrative. Declining to abstract and explain the narrative does not mean that evocative ethnographers do not analyze data, it simply means that the narrative is not manifestly tied to any former theories, nor do they set out to create one (Ellis & Bochner, 2006).

Music and Autoethnography

Music itself often explicitly or subtly tells a story. Even more so, we as individuals have our own unique stories to the music that we love. For this reason, Bartleet and Ellis (2009) suggest that autoethnography is a useful methodology for musicians and performing artists who wish to examine their practice. Dunbar-Hill's (2014) use of autoethnography vividly presents the culture of Balinese Gamelan music while simultaneously displaying the researcher's difficulty learning the musical style. This vulnerability not only redefines the professional identity of the researcher, but also outlines directions for similar professionals to follow by emphasizing the responsibilities of music educators studying cultures that are not their own. Brown (2014) demonstrates the ability of autoethnography to unveil the perspective of a piano accompanist during a collaborative music performance. Brown's narrative gives the reader insight into the importance of musical taste and its influence on the emotional experience in collaborative performance. This insight aids in removing the "air of mystery surrounding the nature of the music performance experience" (p. 6). Brown argues that subjective autoethnographic narratives create space for researchers to step back from the experience and view it objectively. This objective space allows for the creation and analysis of data that represents the subjective experience. When this data is compared to similar research studies it can aid in expanding the body knowledge surrounding the phenomena.

This objective presentation of data and its expansion of knowledge is also evident in Phalen's (2015) autoethnographic vignette that displays the musical relationship between the researcher and the participant. Phalen acknowledges music's therapeutic qualities, but notes that the intention of the narrative is not to expound on those qualities, but to display music as a meaningful modality of expression and connection. However, as a reader who is also a music therapist, I saw, felt and heard the therapeutic benefits of Phalen's and the participant's musical interactions. Phalen's autoethnographic narrative not only re-enforced my assumption that music is a means of communication, but also unintentionally expanded my knowledge base of how music can initiate therapeutic rapport. This seemingly unintended occurrence is explained by Ellis and Bochner (2006),

who assert that autoethnographic text allows the reader to create meaning alongside the researcher, opening the text to multiple truths.

The parallel of storytelling present in autoethnography and music make autoethnography a suitable method to investigate and represent musical phenomena that may be elusive in quantitative investigations due to the subjective nature of music. The above studies suggest that autoethnography can shed light on musical phenomena while simultaneously impacting related occurrences. This is achieved by making use of the subjective narrative to create objective data that can be applied to the expansion of knowledge for the field directly under investigation, those engaged with it and those engaged with closely related fields.

Music Therapy and Autoethnography

Although autoethnography has recently begun to emerge in music therapy literature, music therapy researchers still relatively underutilize it. The sparseness of autoethnography in music therapy could be due to two reasons. Music therapy researchers are not utilizing autoethnography as a method due to the aforementioned criticisms and the dissonance these criticisms appear to create in relationship to evidenced based practice, or music therapist are making use of autoethnography and labeling it as something different. Music therapy literature is full of narratives, cases studies and vivid depictions of the power and efficacy of music therapy (Bruscia, 1991; Hadley, 2003; Meadows, 2011). These representations, which may make use of story, are typically evocative, causing us to reflect and analyze our own clinical practice and the theories that underpin it. The studies resemble autoethnography, but differ in regards to where the analytical lens is placed in an effort to gather and understand data. Non-autoethnographers may discuss personal thoughts and feelings surrounding the phenomena under investigation, but they are not taking the extra step required of autoethnography: reflexive examination of personal thoughts and interactions as a means of creating data to be analyzed.

If autoethnography has the capacity to investigate musical phenomena, then the method is also a potential fit to investigate and extend the knowledge base for music therapy (Baines, 2014; Bartleet & Ellis, 2009; Woodward, 2014; Schaafsma, 2012; Zhang, Shi, & Hsu; 2016). This is primarily because autoethnography has the capability of showing people in the “process of figuring out what to do, how to live, and the meaning of their struggles” (Ellis & Bochner, 2006, p. 111). The ability to explain the processes of music therapy is a goal of music therapy research (Aigen, 2015), which is partly defined as an evidenced based practice (Bruscia, 2014).

Blank (2016) explains that evidenced based practice is a combination of three tenets; “published literature, clinician judgment, and other contextual factors (culture, race, ethnicity, values, religion) of the therapist and client” (para. 2). However, music therapists can find themselves lacking the words or literature to explain how they arrived at a clinical choice, such as the selection of a particular song, intervention or instrument (Aigen, 1999; Blank, 2016). Blank explains that clinician judgment is often based in tacit knowledge or intuition, therefore making it subjective and susceptible to “faulty or oversimplified reasoning” (para. 3). Aigen (1999) suggests that tacit knowledge and intuition are cultivated and transferred through direct experience and clinical training.

When students participate in an experiential music therapy group, listen to Nordoff & Robbins' "Edward" tape, or . . . observe their supervisor work, they are internalizing the unverbalizable essentials of clinical process. They are learning things like how to discern levels of musical expression, how to perceive the individual meaning of their client's music, and how to best work with the affective nature of this expression on a musical, verbal, and bodily level (p. 92).

If tacit knowledge and intuition are a collection of tenets agreed upon by the profession this implies that they are not personally subjective, yet it does not eliminate the possibility of subjectivity held by the profession at large. If this is the case, in order to open up and extend the knowledge base of music therapy, tacit knowledge needs to become more explicit. This is a task that autoethnography can accomplish due to its requirement of reflexivity, which captures the internal experience of discovery and creation of meaning or purpose (Ellis & Bochner, 2006).

The concept of reflexivity to increase understanding is not foreign to music therapists. Bruscia (2014) defines music therapy as "a reflexive process..." (p. 36). Bruscia notes that the process of reflexivity is accomplished using "self-observation, self-inquiry, collaboration with clients, consultation with experts, and professional supervision (p. 36). A common practice of clinical training and supervision is the use of a reflexive journal to prompt self-observation, self-inquiry in order to uncover biases and reveal countertransference, understand contextual influences, and to connect theory and practice (Barry & O'Callaghan, 2012). Bruscia (2005) points out that the initial step of developing music therapy theory is "reflecting on personal experiences with a phenomenon" (p. 54). Baines (2014) asserts that music therapists must "explore, analyze, and incorporate the culture of the settings in which they work and reflect on their personal sense of culture and how they express their culture of music therapy" (p.176).

Therein lies the parallel of music therapy and autoethnography: the reflective introspection for deeper understanding—not only for self-improvement, but also for an improved relationship to the other. Like a music therapist making use of reflexive journaling, "autoethnographers are expected to treat their autobiographical data with a critical, analytical, and interpretive eye to detect cultural undertones of what is recalled, observed, and told of them" (Chang 2016, p. 48). Autoethnography offers insight into decision-making as it examines the process of understanding researchers and their interactions with participants. Aigen (1999) notes that the knowledge base of music therapy is potentially best transferred through research mediums that aim to describe the decision making process of music therapist without creating a definitive step by step guideline. Ellis and Bochner (2006) note that autoethnography accomplishes this by relating the phenomena through storytelling in an effort to draw the reader into the setting, thereby creating a vicarious experience in which the knowledge can be transferred either tacitly or explicitly. Autoethnography can potentially open a window into the culture of music therapy that allows the researcher as well as the reader the opportunity to investigate and understand the unconscious underpinnings of clinical decision-making. Of relevance to this study is the investigation of music therapy practices with people living with dementia.

To date there is one autoethnographic account of the experience of a music therapist working alongside people living with dementia. Baines' (2014) study holds strong relevance to the current study in its use of autoethnography as a method to provide music therapy services to older adults living with dementia. In an effort to explore anti-oppressive music therapy practices, which is a means of empowering and giving voice to service recipients, Baines used reflective journaling to investigate her personal ownership of power and control. Using grounded theory to investigate themes, Baines shapes a narrative that not only explores the perception of music therapy in the healthcare system but also the conventions of her academic training which informed her clinical decision making with residents.

It is important to note that a portion of Baines' music therapy training takes place in the United Kingdom (UK), and is improvisation based (W. Magee, personal communication, January 28, 2014; H. Shoemark, personal communication February 7, 2017; Wigram, 2004). In addition, the resident homes where Baines provides music therapy services are also in the UK. Baines' autoethnographic narrative lays out her struggles to implement her clinical training with residents who explicitly requested something else other than improvisation during their first session ("hand out those instruments and play some of our favourite songs") (2014, p. 117). Baines expresses that this instance of user preference for song-based methods occurred multiple times over her twenty years as a music therapy professional in settings in which her academic training suggested otherwise. This information not only challenges her personal training in music therapy, but also opens her to the possibility of another way of meeting the needs of those receiving services.

Due to the aforementioned similarities with the present study, the influence of autoethnography extends beyond Baines' personal experience. I found myself celebrating Baines' disclosure of figuring out what to do, as I was able to normalize my own experience by reading of the narrative depicting Baines' growth and work alongside the population, which may be seen as its own culture due to the nature of the disease progression of dementia.

Autoethnography and Dementia

The World Health Organization (2016) reports that dementia is one of the major causes of disability and dependence, affecting 47.5 million people worldwide with 7.7 million new cases every year. Dementia, a neurodegenerative disease in which the defining characteristic is memory loss, not only affects the person living with the disease, but also the people who surround the person, such as family and loved ones who often take the role of caregivers. It is therefore of little surprise that much of the autoethnographic work is generated by caregivers seeking to understand not only their loved one's decline, but also their personal feelings related to it.

Malthouse (2011) uses the shifting inner-outer evaluative lens of autoethnography to investigate her changing relationship with her mother, who is living with dementia. The narrative begins with her relationship with her mother before the diagnosis and takes the reader into Malthouse's personal feelings as she was coming to terms with her mother's diagnosis. Malthouse, who is a medical doctor specializing in palliative care, discloses her personal struggle with being able to practice patience and understanding with patients and being unable to use the same skills with her mother. Malthouse's experience as a caregiver is woven together with literature that not only informs

Malthouse, but also the reader, of the difficulty of being a caregiver of a loved one living with dementia.

When I recently read that Perrin (1997) spoke of difficulties of staff entering the metaphorical “bubble” around the person with dementia, I felt shame. I had so often watched my husband...show unrelenting patience as he was asked the same question again and again. He was entering her bubble right in front of my eyes, but I was too close to the situation with my mother to be able to untangle the way I felt. (p. 254)

Malthouse’s autoethnography exposes the reader to her vulnerabilities and in doing so challenges the existing medical view of dementia that refuses to accept the decline of the individual in search of a cure for the disease.

Even the Alzheimer’s Society website (www.alzheimers.org.uk) has headlines of “Leading the fight against dementia” and its commitment is given as “defeating dementia through research,” as if there was a battle to be fought against the neurodegenerative and downward trajectory of dementia. (p. 252)

Malthouse asserts that this fight took place physically, emotionally and mentally when engaging with her mother and prohibited her from engaging with her mother in a manner that focused on her mother’s strengths and instead focused on the areas of weakness which subsequently led to a deterioration of the relationship. Her autoethnography sheds light on the many challenges confronting caregivers of people living with dementia. In this way, Malthouse presents an alternative view to medical models that primarily focus on the disease rather than the person.

[With autoethnography] I have extracted meaning from experience, and I have held this critical mirror. Its reflections have helped me to disentangle the difficult personal experiences of my mother-with-dementia. Within the space of these reflections, I have been able to make distinctions between the relationships I have with my mother, and those I have with dementia. (Malthouse 2011, p. 255)

Getting Out of the Way

“Get out of your own way.” A phrase I may have heard too often. During my training as a music therapist it was a common phrase directed toward my colleagues and me. The phrase was meant to convey that we were interfering with the therapeutic process. Sears expresses that “eventually we must forget the fact, because so long as the fact is standing in front of us, we think of the fact and not the task at hand” (Sears, 2012, p. 2752). This could happen in many ways, overthinking an interaction before it has happened, limiting possibilities due to diagnosis, forcing an intervention, or over-evaluating the efficiency of the intervention while it is occurring. Essentially we are not in the moment and present with those receiving music therapy services and are instead focusing inwardly on

ourselves as the therapist and the decisions we are making. The action of “getting out of the way” is compounded when working alongside people living with dementia. During my experience as a music therapist working in a facility for people living with dementia and Alzheimer’s disease. I often found myself baffled and amazed at resident’s disclosure and engagement during music therapy, especially when the resident presented with low social functioning, poor reality orientation and was seemingly unaware or asleep. So clear were these moments that I began to label them as “moments of clarity” as their expression suggested that they were actually aware of not only what was happening in their surroundings, but were also engaging and interpreting their environment in diverse ways. These moments of clarity were characterized by a heightened level of arousal, either in body language or verbal disclosure, in which the resident took notice of the music, the music therapist, or their surroundings. To be clear, I am not suggesting that the symptoms of dementia ceased to exist during these moments, but that residents were more responsive, spontaneous and engaging in the moment. I wanted these moments to happen all the time, as it made my work as a music therapist extremely validating. My attempts to create a cause and effect relationship were futile as there were too many variables to control and I could find no consistent approach to generate these moments. These attempts made me think that I was over-interpreting, forcing, and ultimately not focusing on the resident; I was getting in the way. Thus the opposite feelings presented, I felt ashamed and inadequate. The cycle continued and the harder I tried the more difficult it became to engage with residents and the moments became almost non-existent. This was particularly upsetting for me, for I was certain that I had found an unexplored area to research in order to fulfill the requirements of my academic program. After relaying my frustrations to my research advisor she suggested that I look into autoethnography as a research method to examine my experience as a music therapist working with people living with dementia.

After researching autoethnography and its use with music therapy and dementia, I realized its potential for positively impacting the therapeutic process by increasing the occurrence of therapist reflexivity. It was through the methods early stages that I came to recognize (with the help of supervision) that the moments of clarity were not the residents, at least not solely, but my own “ah ha” moments as a therapist fully orienting myself to the resident through understanding and acting on their disclosure in a manner that increased our connectivity and thereby propelling and enhancing the therapeutic process.

Bruscia defines reflexivity (2014) as “the therapist’s efforts to continually bring into awareness, evaluate, and when necessary, modify one’s work with a client — before, during, and after each session, as well as at various stages of the therapy process” (p. 54). Bruscia elaborates on how to obtain reflexivity by suggesting that therapist pay attention to numerous aspects of the therapeutic relationship. Of importance to this study and the population served are, method and goal integrity, resident progress and preferences, self-awareness, responsibility, power, emotional reactivity, directiveness, and situating the residents and the therapist for well-informed ethical practice.

This reflexive awareness is of great importance for people living with dementia as the symptoms impair traditional therapeutic roles. Normally the therapeutic relationship and the pre-mentioned areas of concern are held by both the therapist and the resident, although the therapist is ethically responsible for the overall health of the relationship,

each person brings their memory of feelings, disclosures, aspects of transference and resistance to subsequent sessions, thus creating “grist for the therapeutic mill.” This makes it possible for the goals of therapy to be created and agreed on by both parties. However those living with dementia may not be capable of engaging in this process as their symptoms impair the majority of the aforementioned areas of concern. Therefore the therapist, consciously or unconsciously takes on more responsibility for the therapeutic relationship’s course and meaning. This increase of responsibility requires greater understanding of the self in order to engage in therapeutic decision-making with people living with dementia that is not unconsciously meeting the therapist needs.

My desire to understand what underpins my therapeutic choices, and my desire to provide the best service possible for residents, constantly put me in my own way. Autoethnography, also a reflexive process, appears to be an optimum research methodology to examine and effectively capture both my inner processes with those living with dementia without getting in the way. By requiring me to recreate the process as I remember it in story form, I am granted a window in to vicariously relive the moment and to focus inwardly without it interfering with the therapeutic process.

This project will demonstrate how a novice music therapist uses disclosure from dementia patients to inform the therapeutic process. This is of importance in terms of the “self” of the music therapist working alongside dementia, as disclosure and interactions are often given value and meaning through the inner lens of the music therapist due to the fact that people living with dementia are often unable to effectively translate their own accounts. (Hibbard, 2002; Quinn, 2013).

An autoethnographic research study meeting the goals and features outlined by Adams, Jones, Ellis (2015) and Anderson (2006), while avoiding the pitfalls listed by Chang (2008), will offer a greater understanding of “ therapist moments of clarity” and the use of them to inform clinical processes of working alongside older adults living with dementia. A closer look at those processes may reveal the need for greater competency, provide a therapeutic model for engagement, or offer insight into the life of those living with dementia, which would improve music therapy services offered to them.

There are multiple vantage points that call for the preservation of the self in dementia patients (Kitwood, 1990; Kitwood & Bredin, 1992; Summa, 2013; Summa & Fuchs, 2015). An autoethnographic account may be able to achieve this, as it is our self-narratives of what we deliver to others that contains the very essence of who we are. Summa (2013) notes that the ability to convey a narrative for someone living with dementia is “inevitably and irreversibly damaged, due to the disturbances in explicit (autobiographical and semantic) memory” (p. 480). The disease process impairs self-expression, yet the human need and right to self-expression and narrative remain. McMillan (2006), Radden and Fordyce (2006), Ricour (1990), and Summa (2013) suggest that when we as caregivers, clinicians or researchers take part in the lives of persons living with dementia, we have the ability to continue and preserve the narrative and the self of the person living with dementia by weaving and intertwining them with our own narratives.

I hope to explain music therapist’s moments of clarity in a way that captures the essence of the experience of older adults living with dementia suddenly becoming lucid and coherent due to both the awareness of self and other on part of the therapist. This choice to orient ourselves towards the residents’ clarity and not our own may offer

validation of resident self and increased emotional expression and support.

METHOD

Characters and Confidentiality

The characters in this autoethnographic narrative are an African-American male, from Southern North Carolina, who has been a board-certified music therapist for two years; and residents from diverse backgrounds residing at an assisted living home located in the Mid-Atlantic region of the United States. Residents have a primary diagnosis of a Neurocognitive Disorder (of the dementia type) or consistently present with symptoms of a major or minor neurocognitive disorder.

Anderson (2006) makes reference to “complete member researcher status” as a standard for analytical autoethnography. This author acknowledges that he is not a “complete member” in terms of medical diagnosis, generation or ethnicity. However, Anderson heuristically points out that a complete member is someone who is:

...considered a legitimate participant in the group’s conversations and activities through which (potentially multiple and contradictory) first-order constructs are contested and sustained...the autoethnographer is someone who helps to form and reform the constructs under study and is a more analytic and self-conscious participant in the conversation than is the typical group member. The autoethnographer’s understandings, both as a member and as a researcher, emerge not from detached discovery but from engaged dialogue. (2006, p. 381)

Therefore, in regard to interactions between music therapists and those living with dementia, the researcher is a complete member and therefore permitted to write and analyze the personal experience and interactions in order to create knowledge and theory specifically for the field of music therapy, but potentially for other care providers of those living with dementia.

Having complete member researcher status presents a potential ethical dilemma, as it is not the researcher’s story alone (Delamont, 2007; Jago, 2002). Residents are still characters in the narrative and their privacy calls for protection. Jago (2002) states “one cannot do ‘good’ autoethnographic work without constantly questioning the ethics of your pursuit. As soon as you put that “I” on the page, you can’t avoid asking if your revelations might be harmful to you or anyone else” (p. 753). Given these parameters, to avoid ethical dilemma, the research focus is on the therapist’s clinical and personal interaction in the therapeutic relationship as it unfolds. Therefore, this narrative, although including others reactions, belongs to the music therapist.

To further ensure ethical considerations of the residents, all efforts to create confidentiality and protection of participants are considered. This includes removal of, or changing, any major identifying characteristics and relaying only information pertinent to the reader for the understanding of the phenomenon from the perspective of the narrator.

Data Collection

The data for this study come from interactions between the music therapist and the residents, resident-observation, self-observation, reflexive journaling that documented resident responses, and historical and current information given by family members. These data sources were selected to reduce focus on myself, include participant voices and reduce subjectivity, as suggested by Adams, Jones, and Ellis (2015) and Anderson (2006). The artifacts were collected across a four-week period.

Participant-observation refers to the act of the researcher participating in the lives of their informants while observing their behaviors (Bruscia, 2005). In a similar fashion to this, autoethnographers can observe their own behaviors and document their thoughts while living them. Rodriguez and Ryave (2002) argue that self-observation as a data collection technique is useful because it gives access to “covert, elusive, and/or personal experiences like cognitive processes, emotions, motives, concealed actions, omitted actions, and socially restricted activities” (p. 3) and brings to the surface what is the “taken-for-granted, habituated, and/or unconscious manner that was formally unavailable for recall” (p. 4).

For this investigation, self-observation and reflection were recorded using pen and pad, or voice recording software after interactions with residents. These interactions largely took place within a music therapy group held at least two times per week in an open day room. Data was also collected from bi-weekly individual sessions with residents, a spontaneous encounter initiated by a resident, or per request from staff (PRN). Data given by family members was only solicited by the music therapist in response to resident interactions that were incomprehensible, or in spontaneous sharing initiated by the family member. Because this disclosure, or perspectives of residents was not analyzed for meaning Institutional Review Board approval was not so pursued.

Analysis and Presentation of the Story Narrative

The data was presented within a personal and experiential autoethnographic story, thereby evocative ethnography (Adams, Jones, & Ellis, 2015). In addition, data will include analytic components, derived by dialoguing with informants beyond the self and by drawing in theoretical stances and literature pertinent to the area of investigation (Anderson, 2006).

Analysis of data will be conducted using recommendations by Chang (2008) found in Table 1 below.

Table 1

Chang (2008) recommendations for analyzing autoethnography data

Search for recurring topics	Analyze relationships between self and others
Search for cultural themes	Compare cases
Identification of exceptional occurrences	Contextualize broadly
Analyze inclusion and omission	Compare with social science constructs
Connect present with past	Frame with theories

The autoethnographic narrative will include two font types, normal and *italics*, as well as footnotes. This variation of font is to help the reader distinguish between the narrative and dialogue happening in the moment with residents from the *inner dialogue of the music therapist*. It is worth noting that content of *italics* was produced quickly and it is the translation to written language that creates length. The use of footnotes, as suggested by Adams, Holman, Stacy, and Ellis (2015) will be used to incorporate analytic components into the text in order to “provide explanations, make connections, and provide supplemental or counter narratives in addition or juxtaposition to the primary personal narrative” (p. 91) without distracting the reader or interrupting the flow of the narrative.

MOMENTS OF CLARITY AND CRITICISM

What follows is an account of the daily life of this researcher at a residential treatment facility. Throughout the paper, I weave my interactions with clients who provided me with those moments of clarity in my work. This paper does not follow the typical case study in that as I encounter each client, I reflect on that encounter. A brief history is provided on each client.

I arrive to the facility midday to accommodate an after dinner group. I walk through the rehabilitation wing and approach the memory care wing doors. They open freely on going in but require a numerical code to exit. I quickly peek through the glass to see if anyone is on the other side. I’d rather avoid closing the door behind me while standing in front of a resident who wants to get out. It is painful looking into the eyes of a person who has been pulling on locked doors, which suddenly opened thanks to me, only to be closed by me with some made up excuse as to why they should not go on the other side. Thankfully this day the only person I see is a resident named Jenny. She is normally the first person anyone sees as they enter the memory care unit. Sitting in her normal spot, against the wall where she has a clear view of two out of the three hallways.

When Jenny first moved in Jenny presented with high anxiety and a labile affect ranging from tearfulness to physical aggression. Medication was successful in relieving some of her anxiety, but Jenny was still distressed about her surroundings and not being in her home. So the staff “hired” her and gave her a job: she would watch the halls.

Equipped with an ID card and lanyard like other personnel, Jenny rarely leaves her post, except for the restroom or occasionally to stop in the day room at the end of the hallway to observe what's going on. She never stays long, expressing her need to return to work. If Jenny is not present, people will ask questions.

To her left is the hallway containing the entrance and a smaller day room for family visits; straight ahead is the nurse's station and the second hallway leading to the day room. Behind her is the third, which has an emergency exit, also controlled by a numerical code. The hallways make an uppercase T. *Why she doesn't sit facing the entrance, giving her a view of all three hallways?*

I speak to her as I get closer, "Good afternoon Jenny." Slowing down, and looking her in the eyes before passing her. *I want her to know that my greeting is sincere and that I'm interested in how she is doing.*

"Good afternoon."

"How's your day?"

"It's ok, just watching... you got a handful." she comments on my occupied hands which hold plastic department store bag containing a salad, an evening meal and my guitar, which is secured in a hard case."

"Yeah I do!" I reply chuckling.

I pass her and approach the open office door. From the entrance one can see straight into the office, which houses 5 activity specialists and room for 2 creative arts therapists, myself and Jewelie, my supervisor.

After greeting and engaging briefly with the others, Sarah and I begin our supervision session by discussing residents. Of particular interest this day is Howie, a gentleman with blue eyes and rare smile that brightens and awes those he comes in contact with.

"He's a wanderer and sometimes pulls on the doors." Sarah reports. "He's sweet, really nice guy and family. The previous Music Therapist would sometimes walk beside him with her guitar and try to engage him that way. Really short sessions I believe, 5 minutes here and there. How are things going with you two?"

"Umm, they are going I guess." I disclose. *Inwardly I feel this pressure to relay some sort of good news or reason for not having any so that I avoid being reprimand because I currently feel inadequate.* ¹*When in fact she is genuinely interested in how it's going.*

He rarely comes down to group and when he does it's in and out. Our 1:1's feel kind of forced, interpersonal engagement is difficult for him. He either outright declines my invitation to music or he doesn't have a reaction to the music that I thought he would. *Is this some fantasy, music activates the resident and they "come to life" like the people in the documentary Alive in the inside?),* maybe he is just listening. I haven't figured out what he likes or how to engage him musically. We just aren't clicking yet.

¹ Roberts (2011) illustrates that engagement in leisure correlates to well-being. If the barriers associated with dementia can be addressed, then leisure activities, such as music therapy, have the potential to positively impact individual well-being.

My eyebrows are furrowed in thought, *why has the relationship not developed between him and me?*

A “hmm” from Sarah encourages me to keep trying to figure it out. I reach into my plastic bag and pull out a small salad. “I wish I could just ask him. Our conversations are word salads with a tangential dressing.” I share with Sarah. I begin eating my salad and create my own tangent in an unconscious attempt to stir away from my feelings of musical inadequacy.² “To a person not quite within hearing range, it would appear that Howie and I were in deep conversation. I match our body language and even though he isn’t looking at me, we are looking in the same direction, and standing in similar positions conveying that I’m actively listening to him. Howie speaks then I respond, in turn he continues to engage, either agreeing or re-explaining his point of view.³ Which feels about 90% tangential.”

“Sounds like you are creating a dialogue?” She asks.

I guess so, but if that same person were to move directly into hearing range they would...

“Hear you supporting him?” Sarah interjects.

“Yeah...” My affect is tense, my brow furrows deeper. “Yeah, hope so.” *I’m really beginning to get down on myself for not doing more with Howie, for not having a stronger musical relationship.*

“I know Howie is talking with purpose,” I continue. “But his dementia has affected his language center.”

“Aphasia.”

“Yeah, but I can’t recall what type. Broca’s affects the ability to speak fluently and he can do that. It’s just nonsensical.” I pull out my iphone and Google aphasia. According to www.aphasia.com, it’s anomic aphasia; he can speak fluently, but he can’t find the words he wants to use, which in turn affects interpersonal conversation. He still understands me, so it isn’t global or Wernicke’s. I can tell by his tone, his hand gestures, and the occasional brief eye contact that he is attempting to deliver a message.”

“Mmm hmm.”

“Sometimes it’s hard to follow and I refuse to force music on him, why won’t he speak about music!” I say with a chuckle.⁴ “I don’t want to force music on him. Nothing in his disclosure has touched on anything music related. I could argue improvisation always leaves room, yet his tangential nature would more than likely leave me standing there with my guitar watching him walk away. It has happened before.” “It can be difficult to connect with people living with dementia,” she gently asserts and continues, “It can make us feel inadequate especially when we are getting paid to do it.” “Yes! I feel like I need to fix him, like people have to see him engaging with music in order to create my value. This not only happens with him, but with everyone.”

² It was after reflection that I realized I stirred away from my feelings of musical inadequacy with Howie and highlighted what I was doing well instead. Deep down I felt that my musical abilities were to blame for his disinterest.

³ Knapp, Hall, and Horgan, (2014); Ridder, (2003)

⁴ Reflecting during the writing process I came to realize that I was placing the directness and responsibility of the musical aspects of the relationship on Howie and not taking full responsibility as the music therapist to generate the musical relationship (Bruscia, 2014).

“You’re doing good work. We all struggle with this.”

I sheepishly reply “thanks.” It doesn’t feel that way.

I retreat into my thoughts and take some solace in the notion that Howie can still clearly assert his autonomy. He initiated the close of a session once by walking me to his room door saying “Ok, you gotta go now” closing the door behind him. Or the fact that he won’t/cannot be forced to attend or remain in a group. For these reasons I know that when he does engage its truly because he is interested.

“I have a group this evening,” I disclose closing up my literal and figurative tangential salad. “Hopefully I’ll get him to come down and we’ll see what happens.”

“That sounds good, let me know how it goes. Who else are you seeing today?”

“I have a few individuals, 2 on the rehabilitation wing and then I’m going to stop by the assisted living side to meet with Carol. Things are going good there.” I report.

“I like Carol, she comes to my group as well. Her amnesia is severe though.”

“Yeah, she repeats herself constantly. She knows who she is and her family history is still intact. She is what I like to call pleasantly confused.”

Sarah reflects, “Yeah! She is aware that her memory is going and she kind of goes with the flow. Must be a testament to how she lived her life.”

“Even though her short term memory is fading, Carol can still play the piano! I mean really play. All those melodies live inside her. It’s amazing and it balances out when the group gets frustrated with her verbal repetition.”

“I bet they enjoy hearing her play.”

“Yeah, I think they do for the most part. However, I can tell that even then they may get annoyed. When the more cognizant members get brought back to song they already sang, or if we are getting ready to engage in improvisation and Carol wants to play the piano. Currently she is unable to break out of her training or conditioning rather. She’ll remind me often “All I know is Gospel.” That’s all her mother allowed.”

“The mind is amazing isn’t it?”

“Yeah, she remembers a massive amount of songs, the majority of them she isn’t aware that she knows. I’m thinking about creating a repertoire list with her. I think it would enhance her interpersonal relationships and increase her quality of life. She loves playing piano and sometimes can’t remember songs, which results in her playing the same song. I don’t know if she remembers that much.”

It’s 3:45pm when I knock on Carol’s door.

“Come in” she replies from the other side.

Carol is sitting on her sofa; her television is off along with her room light. She is still covered by the light of the sun shining through her window. “Oh Hey!” she beams at me. “Hi Carol! It’s me Demeko, the music therapist!” I state with her memory impairments in mind. “Oh, I recognize you!” she replies.

I do not doubt that she recognizes me, but I wonder if she remembers why. Summa’s 2013 article flashes quickly in my mind highlighting that although cognitively impaired, dementia patients can recognize familiar places, situations and faces although unable to explicitly reflect why. In a different context if I were to walk into Carol’s room and she began to spontaneously reflect on our musical relationship that would signal to me that she would not only recognize my face, but she could also recall why.

“How’s it going today Carol?”

“It’s going well, just sitting here doing nothing, thinking. I just ate lunch not too long ago, so I came back here and sat down to let my food digest.”

I wonder if she took a nap or sat awake for the 2-3 hours since lunch finished. People living with dementia can experience a time crunch, where large periods of time are perceived as the opposite. 2-3 hours is described as a few minutes. I’m worried she sat idle, as disengagement is believed to exacerbate dementia symptoms⁵. I briefly imagine her in conversation with God. It’s very fitting how the sun is shining on her. “Alright, well I came by to see if you wanted play the piano?” Her eyes and face begin to shine as if they have changed places with the sun. “Oh yes! I would love that!” Then with a bit of uncertainty, “I only play Gospel though, that’s all my mother would allow us to play in the house. She didn’t allow anything else; if she heard it she’d yell “turn that mess off in my house!” She was a gospel singer and we grew up in the church...”

There is a strong possibility I could finish at least the next 2 sentences. It’s a part of her narrative, I don’t want to dismiss it but I worry that we will not actually make it to the piano if I let it continue.

I politely interject, “That’s perfectly fine, I enjoy gospel music.” *It reminds me of my youth. Growing up with a Reverend for a grandfather hearing him preach and spending summers with my Aunt and Uncle who loved to sing Gospel. I can remember the days those three got together.*

“Alright then.” She states standing up, looking for her cane “lets go!” During the short journey to the dining room, Carol picks up where I redirected her before leaving the room, telling me about her upbringing, and her relationship to music. We arrive to the main dining room where upon entering the first thing one sees is a black baby grand piano.

“Oh this is a nice piano! It has to be new. I’m so excited, I cannot remember the last time I touched a piano!” she exclaims as we approach the piano situated to the side of the dining hall.

I recall it being the day before, a different piano during a weekly sing-a-long group, and before that 2 weeks prior at the same piano. I’m not going to correct her, she is telling the truth.

Carol begins by playing the refrain of “Everybody ought to been there.” The sound is distinctly Gospel, octaves in the lower register, the upper register incorporating dominant 7ths and outlining the melody. Her first few notes call on the attention of

⁵ After meeting with my academic supervisor, I realize how literature influenced my view of her idle time. Innes, Page, and Cutler (2015) discuss the barriers to leisure that occur with dementia, suggesting due diligence when attempting to uncover them “in effort to shift dementia from a marginalized and stigmatized position to one where they are part of mainstream society” (p. 3). My own personal takeaway was that people living with dementia should not have alone time or large amounts of idle time as it could exacerbate the symptoms of dementia. A use or lose it mentality that is a part of western culture. My supervisor, who studies eastern medicine philosophies, pointed out the benefits of quiet time, which can also be rejuvenating.

listeners imploring them, “If you know it, sing it.” I smile at Carol, and respond to her playing by singing the answer “when he set me free!” Carol laughs while exclaiming,

“He knows it!” Almost as if speaking to someone else.

I feel a little guilty. I only know it because of her. It’s usually the first song she plays, and according to her it was her mother’s favorite song. I still don’t know all the words and use my phone to pull up the lyrics.

The next 20 plus minutes are spent with me calling out and writing down songs. Carol plays them while I sing along. Depending on how well she knows the song, Carol goes back and forth between praising herself “Man these fingers still got it!” Or acknowledging her decline “I’m rusty, I can’t remember the last time I touched a piano.” I choose to affirm her playing with either response, drawing her attention to people who stop to listen and praising her ability to recall the selections from memory. At one point we are again talking about her playing for church when a nurse’s aide walks up and compliments Carol, “Sounds good!” “Oh thank you!” Carol replies, “I’m just sitting here with…” Carol looks over at me and draws a blank, before I can step in she continues, “this young man from my church, we’re just playing and singing some Gospel music. So you like it?” “Yeah it sounds good, keep it up!” the aide replies as she reaches down and pushes the button on a call pendent that Carol’s is wearing around her neck. As she begins to walk off she quickly and quietly says, “I was looking for her everywhere.” My mind is racing “*Carol does not recall where she is at, nor me. We’ve been here talking about her memories and we’ve (I’ve) lost our (her) place in time.*” Carol looks at me with curiosity holding her call pendent in one hand, “What’s this?” *Tell her the truth, she may need to use it one day and hopefully she will remember.* “It’s a call button, if you need help or if you’re turned around or lost you can press it and someone will come help you.”

Carol’s face switches from curiosity to shock, “I’m that bad huh? I knew I had some trouble with my memory” she expresses, gently patting the side of her head, “but I didn’t think I was that bad.”

“It’s not,” I reply, attempting to lessen the blow I just dealt her, “all the residents who live here have one.” Her eyes rise in curiosity again, “I live here?”

My heart churns.

“Yep, this is Red Oaks. You have a nice room here picked out by your family who always come by.”

“Yeah, I remember seeing my daughter. You live here too?”

“No, I work here. I’m the music therapist. You and I get together to play and sing gospel music, to keep your fingers up.”

Carol looks around the room and appearing to resign states “How bout that? Well, I do appreciate you bringing me to this piano. I can’t remember the last time I played.”

“How about His Eye Is On The Sparrow” *I suggest hoping to reground and reassure Carol in her faith.*

For the first time during the session I begin to place Carol in the lyrics, replacing “I sing because I’m happy” with “Carol plays because she’s happy, she plays because she’s free.”

She looks over at me with an acknowledging smile, and joins in “his eye is on the sparrow and I know he watches me.”

We continue for another 15 minutes or so, Carol casually asking questions about her stay at Red Oaks, some of them the same, some new.

I feel a slight tinge of annoyance at having to answer the same thing continuously. But her questions have lost the tone of shock and seem to be more about gathering information.

We end with “This Little Light of Mine” and me again making Carol the main character of the song,

“Carol’s got a gift from God, She’s gonna let it shine. Red Oaks is blessed to have her here, She lets her light shine.”

As we wrap up, Carol compliments the piano once more and thanks me. “Now, I don’t know how I got over here, will you help me back to my room?” “Sure. Well, it is actually close to dinner, do you want to go the café instead?” “Oh really? Wow, seems like I just ate. Well, guess I am feeling kinda hungry. Let’s go there.”

On our walk back Carol begins to reflect on how long she has been residing at Red Oaks, “I guess I’ve been here for about a month or so now.” I agree, while counting the actual time in my head. *Actually about 5 months, but that’s ok.*

She then asks my name, stating, “I can’t remember it, my memory has been acting up, I remember your face though.”

I tell her my name with a smile and joke “Don’t worry, ask anytime. I have some family members who still mix my name up!”

She repeats it a few times and then looks me in the eyes and with a smile of her own expresses, “Got it!”

As we approach her dining hall I continue to reorient her by casually naming the people at her table and talking about her relationship with them. They greet her with smiling faces. I give brief hellos and say goodbye to Carol before heading back over to the memory care unit.

“Good evening Jenny”

“Good Evening. It’s almost time for dinner right?” She asks.

“Yeah, dinner will be here soon.”

“Good. Cause I’m starving and didn’t bring anything. Do you know what they are having?”

“No, Sorry I don’t. Let me see if there is a menu around.”

I don’t really feel like helping her but I feel that a little bit of care goes a long ways. I’m hungry and feeling a little zapped and still thinking about Carol. I look around the nurse’s station for the clear plastic stand holding the menu insert.

“Salisbury steak with Garlic Mashed Potatoes, Peas and Carrots and Apple Pie for dessert.”

I relay the menu to Jenny, who in turn scrunches up her nose. “I think I’d rather have a sandwich.” She replies.

“Ok, that’s fine. We all have our preferences. I’ll let them know.” I tell her walking away in search for a nurse. I don’t get far before Rita pops her head out from the medicine room and quickly relays with a smile,

“I heard it. Thanks.”

“No problem.”

After dinner I push my cart down for the group. *Man, I hope this goes smooth. These evening groups are tough, sundowning, overall restlessness from sitting the majority of the day, and just being tired. We have a good plan tonight. It's gonna be ok. You'll do fine.*

I set up the group of 12 residents facing me with the television directly behind me. I plan on creating an evening variety show interspersing live music with clips from some of the old television shows from their past to elicit resident experiences for reminisce and socialization. The video segments would also grant me individual 1:1 time for behavior that could not be addressed by music and the group dynamic or just a chance to connect and listen to a resident who may want to share in the moment⁶.

Before the music therapy program began I noticed Cat is presenting with symptoms of sundowning, she is tearful, anxious, restless and aggressive. As the music begins Cat initially engages singing along to our opening song. Due to the size of the group, this did not last much longer than the first two songs and she became preoccupied with attempting to get up numerous times while asking for her father and to go home. *My body heats up. I know this to be a sign that I'm getting nervous and feeling a strong inner pressure to do something. It's almost like a code red and during these moments I feel judged as inept by everyone including myself. I also feel bad for her. She is so confused and is just working herself up more.*

I walk over to Cat with a small smile, hoping to console her once again with music.

"Don't you look at me like that! Don't don't don't!" Oh man.

"And don't you come over here with that! I want to go home! Then GO! Shut up!" A peer yells out to her. Oh man, the others are getting escalated. This isn't good. Come on Cat, calm down please, I want you to stay.

"Get away from me!" she snaps.

I look over to an aide, who is already looking me in the eyes. I nod my head yes, slightly tilting it to the side signaling that Cat should be removed. *Ugh. Damn Cat. It is better for the group. It is better for the group. It is better for the group.*

She walks over and moves Cat from the semi-circle and repositions her next to a table away from the group. She dims the lights above her head and rubs her back until she appears to fall asleep before walking away to attend others. For the rest of the group Cat would intermittently vocalize distress, but I was able to attend to her needs by vocal or physical (back rub) reassurances.

The group continues and a different aide wheels Jean into the common room and into the space that Cat occupied. She is in a wheelchair, opposed to her normal geri-chair.

"Hello Jean."...are you going to respond? "... Well, you appear to be looking at me.

"We are singing some songs and watching some clips of Sinatra, Lawrence Welk, and I Love Lucy." "... Nothing huh?

I smile. *"Hope you enjoy it."*

⁶ When this happens I bring it back to the group afterwards. I want to hear it in the moment because their symptoms may not allow residents to hold onto their thoughts until the end of the clip.

I shift my attention back to my computer screen to queue up the next clip when a chair alarm goes off.

“SIT DOWN JEAN!” The aide yells from across the room.

I walk and stand in front of her. “Have a seat Jean.” I plead looking her in the eyes. *Jean, please sit down. “I don’t want you to fall.”*

“I want to stand,” she replies. *What?! Sit down Jean!!!*

“Ok, But I don’t want you to fall.”

“I’m not going to fall.” *Right, because I’m standing here. Sit down! Dang you’re being difficult. But you have been sitting all day. Give me your hands.* “Let’s dance Jean.” Jean allows me to hold her hands and stand still while I move my legs in place. After a few moments she smiles and then spontaneously sits down. *Wow. That was cool. Anyone else see that? Because that’s how it is done!!* I turn around and begin to walk across the room towards my guitar. BEEEP! BEEEEEP! BEEEEEP!

“Jean!! Sit back down!” The aide yells out getting out of her chair and walking over towards her.

“What if we just ask her to dance?” I ask innocently.

The aide gives me a half smile with a gaze I cannot interpret. *Is that a no, a yes, a “you must be crazy?”*

“It worked for me just now, try it. Or just stand in front of her. She’s been in that chair for a while. She’s going to keep getting up.”

“I don’t want her legs to get tired and then she falls,” the aide logically replies. “I know, but you’ll be there right!? Just one song, see what happens.” She lightly rolls her eyes with a smile, “Come Jean, lets dance” she implores. “I don’t want to dance.” Jean replies rather coldly. *JEAN!!!!*

“She said she doesn’t want to dance. Sit down Jean.”

“I don’t want to sit down.”

I place my guitar back down and press play on a video of Nat Cole singing “Unforgettable” then take the aide’s place. *Maybe if you actually wanted to dance with her she would’ve said yes. Maybe it was me. Maybe Jean doesn’t want to dance with another woman.*

“Come on Jean, dance with me.”

Jean allows me to hold her hand while I softly sing along, scanning the room to see who else is engaged. I notice Margie singing along and a few others looking at the television. Cat has her appears asleep with her head down. Jean spontaneously sits down, only to stand again in a few seconds later. I know the song is ending and nothing else is queued up to play. “Jean?” I state looking her in the eyes, “I need you to sit down for a moment please. I’ll be right back. Just for a moment. Then you can stand again. Ok?” “Alright.” Jean sits back down. *I can’t believe this. She agreed. She’s going to stand up before you get back.*

I quickly move to my computer.

“I bet everyone knows who that was!”

There is a small moment of silence before Margie speaks up. “That was Nat King Cole. He was a good singer. He had a lot of hits.”

“You got it Margie, he sure was. Ray Charles says that Nat was his favorite pianist. Who else do you like, Margie?”

“...Eddy Arnold, was big back then” she replies.

“Who?”

“Eddy Ar...”

“BEEEP BEEEEP BEEEEP”

“Jean sit down!” the aide calls out.

“Jean, have a seat please.” I beg, walking over to her. “Jean, please sit down. I’ll be right back then we can stand together ok?”

Jean continues to stand for a little while longer and then sits back down into her chair. *She is awfully agreeable tonight. Is it because I’m empowering her do what she wants?*

“I’m sorry, Margie—Eddy who?”

“Eddy Arnold, he was a country singer. He had a lot of hits. I can’t think of any of them now. Look through your book (my ipad) and see if you have anything.” A Google search gives me a list of songs, a few of which are named out loud, “There’s Cattle Call, Red Roses for a Blue Lady...”

“Yeah, that’s a good one.” She states.

“Red Roses for a Blue Lady?”

“Yeah.”

During the playback of a recording “Red Roses for a Blue Lady” I walk over to Jean.

“Jean, want to stand?”

“What?”

“Do you want to stand up?”

“No.” *WTF*

“Do you want to dance?”

“No, my legs hurt.”

“Ok then. *I am so confused.* Well let me know if you want to try.”

I scan the room and see Howie walk in with his wife. *All right, Howie is here. What can I do? I have to do something. I’m heating up. Oh man. I don’t know, maybe... IDK*

The mysteries of life will never cease to amaze me as in this moment I am unexpectedly oriented to Howie’s past.⁷

Howie appears to be processing the room and indifferent to the music. His wife has a different reaction.

“Is that Eddy Arnold? She asks.

“Why yes it is! Per request of Margie; am I the only one who hasn’t heard of him,” I ask rhetorically while feeling a little novice on the inside.

She looks at Howie, “Hey Howard, it’s Eddy Arnold!” Howie says something, which is inaudible to me. She looks back at me, “Howard used to love Eddy Arnold.”

⁷ I was under the assumption that Howie’s musical preferences would be located in the late 30’s-40s, where he would be a young adult, as he was born in the 20’s. Maybe is this just word of mouth knowledge between therapist. However, big band, swing and wartime music that appealed to his peers was not having the same effect for Howie.

I wonder if he actually likes Eddy Arnold as I don't see any physical changes or hear what he says. Sometimes loved ones actually place songs they like on the other, because it was a song they shared or their loved one would listen to their preference with them (Iglar, 2012).

“What was the name of that song?” She ponders aloud. “He used to sing it all the time.” Her eyes shift upward and to one side, scanning her brain. I call out a few more from the list hoping to hit on something. “No,” she replies, “Sorry, I can't remember it right now but let me think on it.”

A few days later, it had almost slipped my mind when I pass her leaving the unit. “That song,” she spontaneously engages, “the name of it was ‘Anytime.’” I think he pretty much would enjoy anything by Eddy Arnold but the name of the one I couldn't remember was ‘Anytime.’”

“Anytime. Got it! Anything Eddy Arnold huh? Why is that?” “Well when Howard was young, he was bed ridden with rheumatoid fever. He told me he would stay up all night listening to country music. When we were dating he would always sing those old songs to me.”

“Ahh, so that's his music!?” I exclaim. *An inside feeling of duh washes over me. His music is still located in the late 30's-40's but it's a different genre!*

“Yeah, I'd say so. I'd forgot all about that until hearing that music the other day.” “Well, I don't know what kept me from asking you sooner, that helps out a lot.” I start including Eddy Arnold into my listening and get an interesting realization. The “old folks” were right. Their music is better than ours.⁸ About a week passes by after learning about Howie's enjoyment of Eddy Arnold. During which time I've worked on some of the music on guitar and I'm curious to how/if Howie will respond. A little after breakfast I enter through the memory unit.

On this day as I enter I choose to see Howie first. He is sitting in a chair underneath a silent radio, preoccupied with something in his lap. *What is he doing? This is perfect for a 1:1. I'm going to play some Eddy Arnold for him and see what happens.* Little did I know our 1:1 would spontaneously become a group.

“Good Morning Jenny.” *Can't chit chat today.*

“Good Morning.”

“Hey Howie,” I call out passing Jenny and walking closer to him. He is holding the drawstring of his pants, which is tied in numerous knots. Goodness. *What is going on there? Is he tying or untying.*

He looks up unhurriedly, blue eyes briefly locking with my brown, “Oh hey” he replies before gradually returning his attention back to his pants. *He acknowledged me! Good. He knows I'm here.*

His voice sounds like a firm and audible whisper. I don't have to strain to hear him there is a raspiness to his voice that reminds me of whispering. I sit down beside him and across from Jenny. “How are you doing today Howie?” He stops fiddling for a moment, “I'm alright, just...” looking back down at his pants and as he pulls the string and trails off. *Are you going to finish? No. He lost his place.*

⁸ This is actually me creating my own connections to the music, which in turn helps me be present with residents and their preferences.

I pull up Eddy Arnold's Cattle Call on my player in an effort to be more direct with my approach but I'm still indecisive how to go about it. *Just play it, no give it context, it is the context.*

"Howie? Tell me about Eddy Arnold." *Wait before pressing play.* Howie gives a sly smile, bobs his head slightly in my direction, his attention and gaze remaining fixed on his pants. "He's a nice guy. Has a great obituary." "HAHA!! Oh yeah? *What a classy response!*"

"Let's hear some of his music," I state while simultaneously pressing play. "oooo, oooo, yodel lay do oo..." Eddy's voice projects out of my tiny Bluetooth speaker and into the space.

Howie picks his head up fixes his gaze across the room and joins in yodeling. Jenny looks over at him and a nurse pops her head up from behind the station. *WOW! Oh my God, he knows it. Wow. Other people see it as well.*

As the verse starts Howie appears to be listening, as he is no longer occupied with his pant's string, yet he isn't actively singing. I scan his body in vain for the rhythmic movement I see in Jenny's foot. *I begin to feel pressure to do something else, to get in his face, call his name, engage him differently. Are you done? What happened?*

I silently unpack my guitar. *Maybe live music would be better, I've learned two Eddy songs.* Eddy yodels once again and Howie again joins in. *So it's the yodeling huh? I wish I knew a lot about yodeling.* I silently deride myself while simultaneously moving away from the moment with Howie.

The nurse once again raises her head, she's smiling and makes a gesture to an aide to look in our direction. *Maybe this is enough?* I begin to scan my .mp3 catalog for another Eddy song. I decide on "Just a little lovin' (will go a long way)." *Hmm, sounds like a message for me.*

As the intro guitar starts, Howie's affect brightens up. A couple of lines in Howie spontaneously stands up and begins to move in a slow shuffle, his hands gently pumping at his hips. "Go Howie!" I yelp standing up beside him.⁹ I watch Howie and shuffle alongside him moving my arms similar to his own. My steps are wider than his but that doesn't seem to stop him from moving. He begins to strum an air guitar; Howie isn't singing the words but responds with his own vocalization each time Eddy's voice does its signature melodic leap. I don't try to get him to follow me, although I'm not sure why.¹⁰ If he does follow me then that potentially re-affirms our therapeutic triangle between him, the music, and me.

The next song starts without my choosing. It's still Eddy but it is significantly slower than the previous two. Howie doesn't change to a slow step and is staring into the gap, *a space that I cannot define, his head is cocked to the side as if he really isn't*

⁹ This reminded me of a fieldwork experience in a children's hospital. My supervisor was playing an audio recording of Daddy Yankee and dancing with client. "Just try and matching his motions and movements and then try some of your own, to see if he'll follow you" was the recommendation.

¹⁰ Reflection leads me to believe that I was fearful of him not following and how I would be impacted by it as I was already critical of myself. By not venturing out, I avoid "rejection" but I also avoid potential.

looking at anything but listening intently, if he were to close his eyes it would be more congruent in my mind. Is he just listening?

Suddenly, "I'll be back." He straightens up and looks at me. *A little panic sets off inside me, Crap! I want to extend this moment.* "Howie, you're leaving?" I ask *Say no Howie*, say no. "Yeah, I'll be back." *Damn!*

I'm aware of his autonomy, I'm also aware of his diagnosis. It is evident in his facial expression and body language that Howie is benefiting from our session. He is smiling, strumming air guitar, small stepping around his personal space. Multiple staff have taken notice of his shift of energy. This is good, or was good. I'm worried he will not return, not because he doesn't want to but because he will forget. "One second Howie, I'd like to play a song for you."¹¹ I quip while quickly grabbing my guitar and sitting down. From the two Eddy songs I've learned, only one is fitting "Anytime."

I begin to pluck the strings while Howie looks on intently. *"Here we go, you can play this song. What are you gonna do Howie?"*

I begin to sing and Howie initially vocalizes the melodic line alongside me singing the lyrics then falls silent. He moves over and takes a seat beside me. *Awesome he likes it and is going to stay.* He remains sitting for a moment then bends over and begins to unstrap and remove his tennis shoes. *Why are you taking off your shoes?*

I continue playing and Howie does not join in again. *I begin to feel nervous and wonder what has occurred.*¹² who steadily rocks himself out of his chair and begins to walk to his room.

I continue plucking the song for a few more measures, *are your shoes collateral or? What just happened?*

Anne

As Howie disappears into his room, I look over at Jenny, whose gaze is still fixed in the direction Howie left. On second glance I notice Anne walking up the hall towards us. *Multiple feelings and memories flash Reorienting as I begin thinking about all the experiences we've had. I know Anne is going to approach me and I wonder what I'll do if Howie comes back? Should I redirect her or should I leave before she arrives to avoid rejecting her in favor of Howie?*

Anne's outgoing nature has created a love-hate relationship with staff. She has an engaging sense of humor equipped with a handful of "dirty jokes" and nicknames for the staff that resemble their real names. Some staff even started to refer to each other by their appointed nicknames. It's hard to know if Anne is actually joking or not with her nicknames or if her humor is a cover for symptoms of dementia such as short term memory loss, but is the inability to remember a "new" person's name a dementia marker?

Anne's dementia is complex. It is a mild dementia, that is present to staff and myself but seemingly not to Anne. On multiple occasions she has misplaced (or hidden) a personal artifact and forcefully asserted that someone must have stolen it. When it was found, it was because the thief got afraid and returned it, not that it was misplaced. Yet

¹¹ Attempting to be more direct although it is against his wishes.

¹² The feeling begins drawing my attention inward and away from the present possibilities to continue connecting with Howie. I am officially in the way.

Anne consistently demonstrates an awareness of where she is, and differentiates her past from her present. She is very attuned to social cues and becomes offended when she feels that she is being belittled, dismissed, or ignored.

The juxtaposition of different levels of awareness creates multiple mood states for Anne, however the one that is most present is depression. A major difficulty for Anne is her loss of autonomy and loved ones.

One night after dinner I sat with Anne as she cried, expressing between her tears, “I used to have a really active life, I used to go places, see things, I had friends you know? Now this, look at this place, look at her she doesn’t even know her own name. I don’t belong here. There is nothing to do here. I have no value here... You know I just want to be involved in something worthwhile. Not sitting around all day doing nothing. That’s not me. That’s not how I lived my life.” *I want to grab and hold her, to tell her that it's okay, but it's not ok. She is right, she doesn't "belong" here on this unit. Maybe assisted living, we tried that though and it didn't work. She became anxious, there was no nurses station, no one to engage her at any given hour. How can I show her she is still of value? How do I ease her tears without belittling her or carelessly reinforcing she doesn't belong here?*

Knowing that Anne enjoyed singing I walked her off the unit and to the empty dining hall where I played a few standards on the piano. Her tears subsided, she softly sang along to “My Way” and although she was still in a low mood, she expressed her gratitude for my listening to her and playing music she loved. It felt good to see some impact, but it still felt like a small band-aid.

I watch Anne deliberately steering her walker towards me. *Let's see what happens.* “Hey, it’s the musician” she calls out matter-of-factly. “Hello Anne” I reply warmly. “Looks like somebody lost their shoes,” she states with a chuckle turning her walker around and easing down into Howie’s former seat.

“So what are you doing here? Why aren’t you out entertaining?”

“I’m here today, Jenny’s here and Howie *was* here.” I state looking down at his shoes.

“Hey Anne, maybe you can help me out?” *Maybe I can empower her through reminiscing about her musical past, create a need and therefore a value in her knowledge (Cooney, et al 2014)..*

She looks over at me “With what?”

“I remember once you saying that you loved music, maybe you could teach me a few songs.”

She chuckles “I guess, if I can remember any! I used to sing all the time, people would tell me come up on stage and I sing a song or two. Nothing professional just singing for fun.”

“You do have a nice voice.” I reply.

Anne looks off in the distance for a few moments, *what is she doing? Thinking or reminiscing?*

“I’m sorry, I can’t think of any.”

“That’s okay. I know a couple. Do you know this one?” I ask while beginning to strum the turn around to “All of Me.” Anne looks curiously in my direction, waiting for some type of cue.

“All of me...” I begin to sing. Her eyebrows raise, “Oh, that’s a nice one” she exclaims, immediately adding “why not take all of me” She sings, while looking in Jenny’s direction, who remains facing the direction from which Howie departed. Jenny’s foot is tapping and her lips are moving, but I can’t hear her because of our distance. “Take my...?” Anne pauses...

“Lips” I continue.

That was her only mix up, one in which I often erred while learning “All of Me,” substituting arms instead of lips and throwing the song for a loop. Again I don’t really see that as a memory problem, if a person with an “intact memory” has difficulty remembering.

After completing the song Anne pauses for a moment before prompting me, “Ooo how bout this one? ‘You made me loooooove you’,” she sings out. I don’t know it and I listen intently while gently tapping time on the side of my guitar. As I listen I inwardly fight the feelings to do more. *Just listen to her sing and pick up a few words. You asked her for this.*

Although I wasn’t aware of it at that moment, I later realized Anne recalled the lyrics in their entirety.

“Wow, I’ve never heard that one. I like it! You used to sing that one?”

“Oh yeah,” Anne expresses before beginning to reminisce. Jenny glances over a few times during Anne’s disclosure then fixes her gaze down the hall.

Anne

B

I join her gaze and see a second Anne, looking around the hall and glancing into the rooms as she walks towards us. She is here for respite and I wonder how she is adjusting. When she gets closer Anne A calls out with enthusiasm,

“Hey! Look a there! It’s Anne! Her and I have the same name you know?”

Anne B smiles in our direction, “Popular name.”

“You should join us, he’s playing some old songs on his guitar and I’m trying to sing them. Not like I used to, I loved singing. What about you?” “Oh yeah” Anne B adds.

“I bet you’d know them. What have we played?” Anne A asks turning her attention towards me.

I’m caught off guard, as in my mind I’m realizing that an impromptu group has formed and if Howie comes back there won’t be enough chairs. “Umm, All of me,” I reply stumbling between my thoughts “and you just sang, umm... You made me love you? Was that the name of it?”

“Yeah that’s it!” Anne A starts singing the song as if it were the first time. Anne B stares at her singing, but does not join her, a slight smile on her face. I join in on the lines I remember, snapping my fingers while looking in Anne B’s direction.

Anne B remains standing, which makes me feel uncomfortable because I’m still sitting. I’m afraid I’m alienating her not inviting her in, although Anne has. *I need to get more chairs.*

“Here Anne, take this seat, I’m going to grab another. Keep singing Anne, it sounds good,” I request hopping up to grab a chair from our office.

Our office is directly next to our new group location, so I don't feel weird about leaving. It takes me no more than 10 seconds to grab a folding chair and when I come back out Anne A is still singing. I unfold the chair but I'm not able to sit down. I see Howie standing in his doorway looking straight ahead. My heart skips a little. *Howie!? Is he gonna come back? What is he looking at?*

"You knoooooww you maaade mee... loooove youuu!" Anne canaries out signaling the end of the song.

Anne B begins to clap which draws Howie's attention. "I remember that one," She relates to Anne A.

"I've only heard that one twice in my whole life!" I add with humor. "I like it, y'all had some good music."

"Yep, sure did." Jenny spontaneously replies.

"Let's see" Anne A ponders "what were some other ones?"

Howie has begun walking our way. I duck back into the room without explanation to grab a second chair.

I can hear Anne A start singing another song, "Babyface, you've got the cutest little babyface. Another one I don't know. *Does she remember my prompt from before? She is nailing it!*

When I come out I observe Howie, now with a different pair of shoes on, staring at Anne A, who is stuck in the song trying to recall the next phrase. He too is wearing a look of confusion.

Does he want his seat back? Is it his shoes? What is happening? It could be embarrassing to give him his shoes in front of his peers...especially Anne.

"Here you go Howie, here have a seat."

"No thanks." He replies with his wry smile.

Ouch. Okay... At least he is smiling.

"I can't remember how it goes other than that first bit. It's been so long." Anne says in form between disappointment and apathy.

"Here's one I think people know." I announce and begin to strum and sing 5'2, Eyes of Blue. *This generally is able to get people singing and moving.*

The ladies perk up, "There's an old one!" Anne A calls out. All three ladies join in singing at random points during the song. I can hear both Anne's but still cannot tell if Jenny is vocalizing or just moving her mouth as she is further away. Howie isn't singing, or moving and just appears to be watching and listening. I start leaving spaces in the music for the group to finish the lines. This creates more engagement with me and the song and allows me the chance to hear Jenny who is fact vocalizing.

At one point I begin to rock my guitar up and down in effort to create some engagement with Howie to no avail. *What gives Howie?* It doesn't cross my mind till later that maybe I should've stood up beside him.

I end the song to a small applause, Howie is smiling "that's nice" he says softly. "Thanks" I reply sheepishly. *Aww man, he is connecting.*

"I know one" Anne A makes known, "how bout 'Please don't talk about me when I'm gone?'"

"I don't know that one, can you sing it?"

Anne begins singing in an upbeat manner. She is holding the melody but she isn't full on singing. It's more like Anne is speaking melodically; her peers do not join in. I begin to scat a baseline and snap my fingers in effort to give her some support. She looks in my direction and begins to deliver the lines while looking me in the eyes. "Just remember! Please don't talk about me when I'm gone!" She ends pointedly. "Nice one Anne! Anyone else know that one?" I ask while looking around. Jenny nods her head and Anne B expresses "I think I've heard that one." Howie doesn't reply. He appears to be getting restless, as he is starting to move around looking in different directions.

I shift my attention slightly "Here's one I think Howie knows. Do y'all know Eddy Arnold?"

"Who?!" Anne A asks.

"Eddy Arnold."

"I don't think so."

I begin to play "Bouquet of Roses."

Howie looks in my direction but doesn't have nearly the same reaction as earlier. *I wonder if he knows this one. It's one that Margie knew. Is it my version of it? Is he listening? No one is singing with me. Ugh. OK. Just finish the song.*

Jean

Towards the middle of the song a sharp "NOOOOOOOOO!" abruptly cuts through the music. It seems like everybody was jarred by it. *What the hell was that? It's Jean. Ah man.*

I continue playing the song pretending as if nothing happened. *Never stop the music. Especially now. If you stop then what? I'm the only one who knows the root of the sound, maybe Jenny does, she hears it at least once a day. Oh man please don't come... I'm not sure how to handle it. Ok, just focus on the group. No one knows this song! Finish this song and move on.*

"Has anyone heard that one before?"

"Can't say that I have. It's a nice heartbreak song though." Anne replies. Howie is looking down towards the common room. *He is thinking about leaving. Would he stay for Anytime, maybe vocalize again. The group might know this one. Call his name.*

"No! No! Noooo!"

My body tenses as the beginning stage of fight or flight kicks in. Anne A and I look in the direction of the sound, coming from the room a few feet behind Jenny, who is shaking her head with a scrunched face.

Confusion and concern flashes over the others, myself included. *I can't go. What is going on? Should I say something to the group? They haven't verbally acknowledged it.*

I begin to pluck the chords to "Anytime once again."

It's in triple meter. I can use this to address the shock to our nervous system. I know this works, but I missed that entrainment class. Can I do this with a group?

Moments later Jean's aide Sherrie brings her out of the room. *Here we go.* Jean is seated in a wheelchair, her eyes closed, head propped up by her right arm. A quick image of "why me" pops into my head, *Jean is not happy. I wonder if her aide asked her*

if she wanted to come for the music and she said no? The lack of decision making might be the source of her dejection. She looks so sad. Sherrie looks so tired. I'll try. The others look, but say nothing. Their faces scan Jean, possibly creating their own perceptions of her body language.

I lightly smile at Sherrie, looking her in the eyes. She silently mouths "Can she?" I nod my head in to the space directly beside me. *Put her next to me. That's the best place. I won't be disturbed by her.*

Sherrie follows my clue and places Jean on my right with a soft "Thank you." Jean remains quite during the song. *Ok. She is cool. The group is...? They seem ok. No one left. Is anyone singing? No. Are they nervous? Can I repeat anything for them to latch onto? Ah man! There is no chorus. I guess I'll play and sing it three times through. I don't want them to check out.* I end the song after the third pass and scan the group.

"Will you please stop?" *I'm not doing anything.*

Silence. I'm not sure if she is talking to me.

"Stop what Jean?"

"Playing music. I don't want it."

Jean's aide interjects "Stop Jean, they are having a good time. Come on. Listen to the music."

I wonder what she actually needs, but I dare not ask. For one, she has already said it. She wants the music to stop. I don't plan on stopping because the rest of the group is engaged.

Another layer is that her aide has just brought her out of her room, where Jean spends an enormous amount of time...so I feel an unspoken dynamic from her aid, one that says "Help me out here, or Jean needs to do something to beside sit in the room, maybe music will cheer her up." My body is warming up.

"Sorry Jean, I think the others are enjoying the music right now. We'll be here for another 15 minutes or so. How bout we slow it down a little bit. Here is one that I think you and the group will know and enjoy."

I switch to a 3/4 finger pick and begin to play "Let Me Call You Sweetheart." Before I arrive to the second line Jean jars the group "No no nooooo!" I look over to her aide with concern, but continue to play. "STOOOOOP!" Jean exclaims. I stop. I feel a sense of rejection for both her aide and myself. She walks over and wheels Jean away from the group and down the hall towards the common room.

"Somebody doesn't like music." Anne A quips. Anne B makes an inaudible agreement. "Well, that's ok. Sometimes we have bad days," I reply trying to smooth over the rough patch. "Yeah," Anne A agrees "She's like that all the time, you know. Yelling and carrying on. Some people..." "have a lot of bad days" I interject, trying to stir up some empathy but it seems futile. *Why didn't that work? What happened?*

"Did folks know that one? 'Let Me Call You Sweetheart.'" I ask in attempt to stir us back to the music.

Anne A begins to sing the first line, but with less enthusiasm than before. I join in on the guitar and soon Anne B is mouthing the words. Jenny continues looking down the hallway, prompting me to take a glance. I'm actually checking to see if Jean is on her way back. Thankfully she is not. Howie isn't singing or engaging rhythmically, yet he hasn't left. In fact, he is standing slightly closer than he was on his arrival. When the melody ends I continue to play the rhythm and segue way into the Tennessee

Waltz. I immediately look over at Howie. He is looking at my guitar. The other group members are either singing or tapping their foot. I feel satisfaction and dissatisfaction at the same time. I really want to see him sing and dance again like he was before. I play through the song twice, changing the gender of the “dear friend.” Nothing changes for anyone. I begin to wrap up the song, but continue the rhythmic feel alternating the finger pick.

“Last one, folks” I announce and I begin to sing “Que Sera.” I put a little more pep in my voice while singing the verses and step it up one more notch as I reach the chorus at which point I glance up at Howie. His mouth makes a motion as if he going to sing, but it stops. The other group members are singing, tapping their feet. It’s a nice moment, I repeat the chorus twice each time I come to it. The final chorus I repeat three times, dropping the guitar out entirely while continuing to sing. The ladies continue with their engagement. Howie looks at me briefly in the eyes. I smile at him while I sing the lines rocking side to side. He breaks eye contact but continues to stare in my direction. “That’s all I have to for today folks. I hope you enjoyed it.” “Yeah, that was nice. I like hearing those old songs. I forgot about some of them.” Anne answers. I notice her peers nodding their heads. I glance over at Howie who is already turned around and slowly walking down the hallway. I let him go and clean up the area, saying goodbye to Jenny and the Anne’s when I see Howie’s shoes. I knock on his door and turn the knob. Howie is sitting on a chair looking out and doesn’t turn his head as I enter.

“Hey Howie, I have something of yours.”

He looks in my direction at the pair of shoes I’m holding up.

“Here ya go” I state as I place them beside his other shoes.

“Thank you.” He says, making eye contact with a slight smile. He then begins to talk, but I cannot keep track of what he is saying. It’s still the same type of verbal communication/word salad mentioned earlier.

I reply using his facial expressions and tone of voice on whether not it’s a statement or a question.

I decided not to ask him if he enjoyed the music.

About three days later I’m sitting at my desk when I hear, “HEEEEEELLLLLLLP MEEEEEEEE!!!! OH GOD! SOMEBODY! SOMEBODY HEEELLLLP MEEEEEEEEEEEEEE!”

My heart drops and I am overcome by a sense of dread.

Jean’s plea carries down the hallway and enters any open door and ear along the way. Everyone hears and no one comes. No one is responding...and it's not because they don’t care, it is because it is Jean and there isn’t anything that can “actually” be done. Or is there?

Hearing another human call for help, whether they have dementia or not, seems to vicariously place us in the same vulnerable position. My soul is vexed and my mind peppered with questions, “What if I cannot help her? What if she tells me off? What can I do? What is even going on?” I’m still sitting at my desk. Somebody help me to help her.

As I approach Jean, I have a personal sense of vulnerability. The previous questions are still running through my mind and even though it’s only the two of us in the hallway at this moment, I feel as if everyone is watching.

Jean is sitting in her Geri-chair, which reminds me of a lazy boy recliner without all the thick cushioning – almost as if it were streamlined to become a bed. She is reclined with her feet up, slightly below my knees. She can't get up, but it wouldn't be for lack of desire. *She looks trapped to me. I hope she doesn't ask me to help her get up. I really don't want to tell her no. That would only make me feel useless to her.* Her mouth is open and slightly contorted. Her eyes are closed and she does not see me approaching and wails, "HEEEEEELLLLLLP MEEEEEE!!!!"

I deliberately use a gentle voice, to convey my concern. "Hey Jean, what's going on?"

She opens her eyes and looks up at me. They have a unique character about them; their blue color is moistened with tears that haven't fallen, in combination with her eyebrows and gaze that display both confusion and curiosity. Her eyelids are a little droopy and give her facial expression a constant touch of sadness.

"Who are you? Can you help me?"

I kneel, down to be eye to eye with her. I introduce myself.

"WHO?" I reintroduce myself.

"I don't know you."

"I know." I reply feeling slightly rejected but I understand. *You don't remember me.*

"Ok. Can you help me?"

"Maybe, *please don't ask to leave again.* What's going on?"

"They're going to be coming soon and I don't have anything ready!" she laments.

"Oh no..."

"Can you help me?"

"What do you need?"

"I was going to make an egg salad...and I have some stuff for sandwiches," she discloses while counting on her fingers, her face scrunched in contemplation. "I think I do. Oh, I don't have ANYTHING! I don't have enough."

"How much do you need?"

"I'm not sure how many people are coming. A lot I suppose, it's a wake and they'll need something to eat. I was thinking I could mix something up real quick and maybe that would help but I don't know...there's a lot to be done."

Ok. What? She wants food... She is at a funeral. Where? Her house maybe... Who...not important right now. Why not? Well, She needs help. She doesn't seem to be grieving the loss...just the fact that people are coming and she doesn't have anything. How do I help? Music? No. not yet. I can get the food. FROM WHERE! Role Play.

"I'm go talk with someone about the food. You shouldn't have to worry about it all by yourself. I'll be right back ok?" *I need more time to think about what to do.* "Oh thank you!"

I walk towards the nurse station and turn the corner out of her sight. There is no one there. I stand for a while talking to myself. *Gosh this feels wrong. I'm about to lie to this woman, tell her that the food is coming and that she doesn't have to pay or worry about it. Then what? The food never comes and she gets anxious again.*

Music. I'm the music therapist. Music. It's a funeral wake, so spirituals or hymns. I need my guitar.

I flash back to Jean's response earlier in the week when she insisted that I stop playing music, I still haven't figured out what went "wrong." Almost immediately a separate memory jogs my mind.

Jean and I are sitting outside on a late summer's evening. We had moved from spot to spot after I overheard her calling from her room "HELLLP! Someone get me out of here! Heelllp me!" At one point I was just pushing her around and around, going somewhere and nowhere at the same time. "*How did I get myself into this?*" I recall how relieved her aide looked when I offered to take her out the room, the tension leaving her face instantly. I thought Jean and I would just go over to a day room, I'd pull out my guitar and boom; music therapy! Jean did not want to just get out of her room...she wanted to get out of the facility entirely.

Finally, after much commotion, she agrees on a place between two trees. There is a light breeze and there isn't any foot traffic. Her eyes are closed and I gently open the case to my classical guitar. Within four measures she asks me to stop playing. Her eyes are still closed.

My fingers drum lightly on the nurse's station. *She's been unresponsive to the guitar. Is it my playing? Or is it just the sound of the guitar? Can she even hear? There was that one time when...well no. Her hearing isn't good. Well, she heard me play guitar...she heard me ask her questions.*

A nurse approaches the station, bringing me out of my thoughts and to the moment.

"What's up?" She asks.

I'm going to need two pair of headphones and a splitter. I'll play some instrumental piano spirituals. I wish I were better at piano. I don't feel confident enough to hold this space. The main dining hall has a piano...people are in there now though.

"Oh, just ordering a sandwich platter," I reply.

The nurse's eyebrows tighten in confusion. I smile and turn away, "it's for Jean."

Jean has closed her eyes. *Is she is sleeping? Maybe she has forgotten. I could slink away and wait. She doesn't remember. Please...*

"Hey Jean, I'm back. I talked to some people. It's all taken care of. Folks put together some money to get a large platter to make sandwiches. You don't have to worry about a thing, I promise. It's all taken care of. Food, drink and music."

Jean looks me directly in the eyes. I stare back raising my eyebrows and face into a small smile. "Oh thank you!" she exhales.

"You're welcome" I reply, smiling slightly larger simultaneously exhaling. I feel that I have relieved her from her presenting problem of anxiety, yet I feel this isn't enough.

Here Jean, try these headphones on. I'm going to play some music while we wait. Jean begins talking generally, about the room and people arriving. She doesn't seem to notice or care that I'm placing headphones on her ears. This makes me feel a little weird, yet, its part of the scene I'm trying to co-create with her. Certainly there is soft background music at the wake.

As the music begins she falls silent for a few moments. Then picks up the conversation about the funeral wake again. *Whose funeral are we at?*

Her speech is calm. *She is engaging me. I try to talk back will she even hear me, I would have to take the headphones off, the experience would go awry. Am I really just gonna sit*

here with headphones on as she talks!?! A brief panic sets in and my body warms up... Then I remember.

“I can’t hear you! What did you say?!” Speaking loudly in her ear for at least the fourth time.

“MY NAME IS DEMEKO!” It’s my first time meeting Jean. Her face is still perplexed. She has no idea what I just said.

I walk away. *Gosh. I wonder if she feels as embarrassed as I do. She may forget this ever happened in 2 minutes, but I won't.*

I return a few minutes later with a different approach. *I'm not going to say anything at all. I'll just use my facial expressions.*¹³

Jean interpreted every one of my facial expressions and body gestures correctly.

I don't have to speak to communicate.

Jean is currently looking and speaking in my direction. I flip one side of my headphones up to expose my ear. Her disclosure sounds tangential...*I think we are still talking about the wake...no we are talking about her mother...recipes?*

I engage Jean with my eyes. Using my eyebrows to ask for clarity, and my smile and head nods for understanding. Jean continues talking on and off for about what felt like 10 minutes. Then somewhat randomly, she interjects:

“I hear a piano.” I flash a thumb up and a smile as Jean falls silent for a few moments. Suddenly Jean begins talking intimately with clarity and purpose of thought. She begins to discuss being in a nursing home and why she is here. Her daughter-in-law, with whom she never got along, has placed her here. “She says I can’t come home. I understand. Its hard taking care of someone when you have kids already. I just didn’t think I would end up here.”

Oh my God. She is clear. Where did this come from? She isn't talking about a funeral anymore she is talking about her life as she recalls it. Wow, I cannot believe this is happening right now.

Jean is looking at my face, wide eyed and full of disbelief and awe. Luckily it correlates to her disclosure, but it doesn’t reflect her own feelings and doesn’t convey that I heard her disclosure.

I furrow my eyebrows slightly, my eyes droop, my bottom lip pushes upward creating a small upside-down smile... I point to and press my heart a few times before pointing my finger in her direction, nodding my head as I do so. *I'm sorry Jean that you have to be here. For whatever it's worth, I'm honored by the opportunity to be in your life. I can't imagine the difficulty of being here. Just know there are some people here who care about you.* She continues to look back at me, the moisture has fallen from her eyes.

¹³ Another piece of tacit knowledge gained during a hospice fieldwork. My supervisor highlighted my facial expressions during fieldwork. Challenging me to be aware of if they are congruent with my intentions and to use them as a means of matching and leading residents. “They may be confident in what they are saying, even if it’s incorrect and your facial expression will either affirm them or make them question themselves.”

Jean's behavior doesn't change...yet my feelings towards her do. I can empathize with her more readily with the understanding that her autonomy has been removed and sometimes she is aware of it. A week or so later I've realized that receptive music therapy methods work well with Jean. I can adjust the volume and she treats it like background music freely expressing what's on her mind.

We are sitting hand in hand listening to ballads when Jean spontaneously expresses,

"You don't have to, you know?"

I cock my head to the side, raising my eyebrows and creating eye contact. "Have to what?"

"Stay with me. You're young and have your whole life ahead of you. I'm old, I can't do anything for you."

"Aww Jean! You don't have to do anything for me! I just enjoy being in your company, listening to music."

Going Home

Later on that evening I after packing up my things, I stop to reflect and write on some of the experiences I have had over the weeks, the population I work with, and how our interactions are influencing the therapeutic process and me.

What do we really mean when we speak of reality orientation? Reality is a subjective and collective construct. It constitutes whatever people decide to agree on. Is consistently orienting those living with dementia to the reality of those living without it the best practice? I don't know, but I doubt it is.¹⁴ A decision to orient to reality should be decided based on the needs of the individual. With Carol reality orientation felt necessary compared with Jean. Carol lives independently and is free to walk out of the building anytime. If she is not oriented to her current living situation, then she may gain the desire to go back home after church, resulting in anxiety, confusion, or possibly leaving the facility without staff knowing. Not good.

It's interesting that no specific time did I feel a desire to re-orient Jean and instead sought to validate her by orienting myself to her reality. Jean was in fact disoriented and experiencing a different reality, which was very real and stressful to her. What is gained by approaching her and informing her there was no funeral? How do you tell someone, who is oriented or not, that there is no funeral. Furthermore, that underlying anxiety and stress never gets addressed! That was...validating for both of us. The experience makes me think of that lady who validating people living with dementia.¹⁵ Validation can occur manifest in numerous avenues before, during, and after music therapy, verbal and non-verbal body language, selection of music, encouragement of abilities, or inclusion in a group.

By engaging with and validating Jean's reality, a door was opened that created space for the music, which then allowed her to relax and express deeper concerns. While I'll never truly know what combination of music, context, or validation made the moment possible for Jean, I am certain that it does not occur without validation. Validation

¹⁴ Kitwood, 1993; Harding and Palfrey, 1997; Higgs and Gilleard, 2017.

¹⁵ (Feil, 2012)

through verbal and nonverbal communication as well as music must be an essential component of the therapeutic process, as it is the gateway for empathy, rapport, and relationship.

Howie, Jean, Carol, and Anne serve as reminders that I cannot always go straight into the music. Context needs to be established through gathering of information followed by a validation that acknowledges their reality or experience. Only then can integration of music occur organically.

For Howie, context was gathered from his wife, who I doubted largely due to my own inability to assess Howie, when in fact she was the very person I should sought after assessing that Howie would not be able clearly communicate with me using words! I feel some sense of embarrassment about not turning to her and asking her, the expert, for information about her husband. I still don't understand my resistant ego there.

Jean gives me the context that sends me on a path effectively validate her reality. Just agreeing with her did not seem like enough, there needed be action. Afterwards I was able to integrate music. I recall a resident in distress expressing, "I like music. I really do. But I cannot listen to it right now, I wouldn't enjoy it, I have too much to think about."

Ahh and what about being able to say "no!" I always thought of myself as therapist who honored the desires of the resident. With Howie I believe I was so excited to see him engage by singing and dancing that I wanted my need to remain met. I therein limited his autonomy and potentially stifled the process that I so desired! I could have asked him if I could go along instead of him staying. There has to be a balance between not being direct enough, my initial way of engaging Howie and later on being too direct and denying his choice. "We [music therapists] walk a constant tightrope between expecting too much and expecting too little from our clients."¹⁶ A good example of this is with Anne and the group when I prompt them to recall songs, more so with Anne, who I ask to teach me a song. In this case I think I was curious and took a risk, being armed with songs I knew that Anne remembered. I was surprised later on when she began spontaneously singing songs I hadn't heard of before. I wonder if the same thing would occur over time with Carol? Offering her a prompt after recreating a series of songs to "prime her memory." It's possible.

My feelings got the best of me sometimes, resistance, doubt, inadequacy, doing more v/s being enough. Maybe my not seeking information from Howie's significant other was my way of trying to hide my feelings of inadequacy. Yet by trying to hide them, they continued to manifest. I guess that's the crutch of "being in the way." Instead of just embracing what is going on, whether that be the anticipation of the encounter, the actual encounter, of the feelings produced, I sought to hide from them or fix them immediately it was only through embracing the process each time that therapy took place.

What will my life be like if I live to be their age? Will I be angry, pleasantly confused, sad? Will I have family or will I be alone? What if I end up in a skilled nursing facility? What if I'm just catching a glimpse of what my future looks like? Gosh, I hope I'll be a pleasant person to be around. If I'm not, I hope there is someone who understands me. I guess that what I do here, try to understand, to make sense of and

¹⁶ Bright 1988, as cited in Jessops, 2014, p. 9

validate them using music or presence. It certainly isn't psychotherapy like I envisioned but components of it are there, specifically holding the space for emotional disclosure.

The hardest part of the human experience may be surrounding death and feelings towards our own mortality. How much more difficult is that when you can't find the words to articulate it. I would probably cry, yell, be angry, or anxious as well. I pray what I do today, for others as well as myself, brings me peace later on in my life, I really do.

“Goodnight Jenny, See you later.”

“You leaving?”

“Yeah, I'm headed home.”

“Alright. I think I'm going to stay here tonight.”

“That sounds good. Have a good night Jenny.”

“You too.”

1946*

POSTLUDE

The goal of this study was to use a method that helped me understand the clients I work with, to understand my motivation behind my interactions with those clients, and to understand my music choices. The method I selected was autoethnography, a research tool designed to vicariously recreate the experience for the reader through the eyes of the researcher, who exposes personal vulnerabilities and processes via story in an effort to better understand the self interacting with the phenomena, people living with dementia.

Reflexivity and self-awareness are of significant concern for music therapy clinicians working with people living with dementia. Its symptoms impair social functioning, decision making, and reality orientation creating a vacuum of engagement that may make those unaffected by the disease biased, controlling, or belittling in an attempt to uncover barriers to engagement. Music therapists must be certain they are responding to resident needs and not unconsciously asking the person to continue to integrate into our definition of reality when they are cognitively impaired.

Describing and analyzing personal experience and perception within the culture of interest and then retelling that experience through story, vulnerable researchers are given the opportunity to step back and reveal fragments of subconscious thought patterns, such as decision making, stereotypes, and methods of processing and interpreting. All of which can then be valuated for efficiency, thereby increasing clinician reflexivity and competency, which is in the best interest of those served.

The autoethnographic account was a useful tool for increasing my reflexivity as a music therapist. If the stories we tell (or do not tell) are our presentation of how we see and interact with the world, as well as how the world sees and interacts with us, then the autoethnographic story, which is an academic story, offers great possibility for revealing biases, blocks, self-discovery, and learning about others. Major areas of discovery for me were:

- Understanding the creation of reality with those living with dementia as form of power that can be unconsciously abused or consciously manipulated for therapeutic intent.
- The value of embracing the learner role by suspending therapist expectations of resident response, engagement, preference, or behavior.
- How to “get out of the way” by acknowledging and bracketing feelings vulnerability, helplessness, doubt and inadequacy.
- The benefit of orienting myself to their reality after evaluating risk for harm, instead of generally requesting someone with cognitive impairments to orient to society’s definition of reality.
- The gift of responding in the moment with an understanding of the previous areas.

Writing the account was not an easy a task as I thought it would be. If there is such a thing as self-supervision, I think autoethnography is close. Specifically staying true to the narrative and acknowledging your role in its creation. After finishing a section and re-reading it I had to resist the urge to change details to make it seem more favorable. Asking myself, “Why do you want to change this?” often revealed my inner conflict, which was often blocking the therapeutic process, or me wanting to cover up erroneous ways of engaging. I also had to recognize whom I decided to include or not include in the account. There are residents that only after my writing of this account and seeing them left out, completely or in dialogue, have shifted the therapeutic relationship in a manner that encourages a greater level of health for residents.

Owning these moments is integral to reflexive thinking. From this vantage point the autoethnographic account could be twice as powerful in offering growth when being co-created or re-told to other professional, functioning as a supervisory tool, and even more so, having co-created the account with the population being served. In both instances the story provides a greater means of communication and clarity of perspectives between parties and allows the audience to also see their own behaviors and perceptions in the researcher, granting the opportunity to reflect and improve how they engage with others.

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