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# Caregivers' Experiences of how Music facilitates Communication for People with Dementia

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# Caregivers' Experiences of how Music facilitates Communication for People with Dementia

by

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## Abstract

The purpose of this study was to explore caregivers' experiences of how music facilitates communication for people with dementia. One major effect of dementia is that language abilities become increasingly compromised and disordered, leading to a decrease in quality of life. Music is used in dementia care as a conduit to facilitate communication, even in late stages of dementia. A constructivist grounded theory methodology informed this study. Purposeful sampling was used to recruit nine formal and four informal caregivers for a total of 13 participants. Sixteen interviews and a focus group were conducted. Charmaz's analytical steps were used to guide the analysis. Three main categories emerged: (a) *Relating with Others*, (b) *Memories through Music*, and (c) *Being in the Moment*. These categories provided the theoretical framework for the present grounded theory of *Communication through Emotional Connectedness*. This study provides new insights into the dynamic interplay of *relating*, *remembering*, and *being* that provides impetus towards communication from people with dementia. The result of this study indicates that music can facilitate communication, resulting in the potential to improve quality of life and maintain/build relationships with caregivers. This study, as explorative, may also provide the foundation for concatenated research including, for example, interprofessional approaches.



*Keywords:* music and communication, dementia, grounded theory, person-centred care

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**Dedication**

To my parents, Józef and Antoinette

*in memoriam*

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## List of Abbreviations

| Abbreviation | |
|---|---|
| ADL | Activities of Daily Living |
| BPSD | Behavioural and Psychological Symptoms of Dementia |
| CGT | Constructivist Grounded Theory |
| GT | Grounded Theory |
| MTC | Music Therapeutic Caring |
| PwD | Person/People with Dementia |
| QoL | Quality of Life |

## Definition of Key Terms

Activities of Daily Living (ADL) – daily, routine behaviours, basic ADLs: eating, bathing, getting dressed, toileting, transferring, and continence.

Behavioural and Psychological Symptoms of Dementia (BPSD) – behavioural expressions of need and psychological symptoms displayed in people with dementia.

Constructivist Grounded Theory (CGT) – a version of grounded theory informed by the constructivist view that experience and reality within the research itself is subjectively perceived and constructed.

Long Term Care (LTC) – When applied to a facility, a home providing 24/7 services and care for people who cannot live independently and require onsite health care.

Music Therapeutic Caring (MTC) – an intervention that involves the caregiving singing familiar songs during ADL.

Person/People with Dementia (PwD) – A person/people who has/have received the medical diagnosis of dementia.

Quality of Life (QoL) – the state of the person's perception of life including physical, mental, and social well-being.

# CHAPTER ONE: INTRODUCTION TO THE STUDY

Communication (verbal and nonverbal) is a vital part of quality of life (QoL) for persons living with dementia (Clare et al., 2020; Gaugler, 2005; Marmstål Hammar, Emami et al., 2011). Central to QoL is the provision of quality care provided by caregivers, both formal and informal. Whilst providing care, caregivers often find it challenging to achieve and/or maintain meaningful communication with this population, resulting in an impact on QoL (and quality of care provided by the caregiver), which in turn affects the caregiving relationship (Dassa et al., 2020; Ridder & Wheeler, 2015).

Music, due to its wide neurological distribution enabling it to bypass the communication barriers of spoken language, has been identified as a mode of communication that can still be accessed by people with dementia, even in advanced stages (Babikian et al., 2013; Blackburn & Bradshaw, 2014; Tomaino, 2015). Though considerable literature exists about the effects of using music to foster communication with people with dementia (PwD), most studies have been on its behavioural, physiological, and psychological effects, rather than on qualitative aspects of the *how* and *why* of the effects of music on communication (Beer, 2017; Dowson et al., 2019; McDermott et al., 2014). However, in recent years, there has been an emergence of interest in the subjective experience of living with dementia (Baird & Thomson, 2019; McDermott et al., 2014).

In this study, I sought to add to this emerging interest, but from the perspectives and experiences of caregivers, the most important interlocutors with PwD. As such, efforts were made to recruit from amongst music therapists, nurses, recreation therapists, occupational therapists, and unregulated health care workers for formal caregivers, and from amongst families of PwD for informal caregivers. Music therapists for dementia care use combinations of

rhythmical activity, singing, or other synchronized musical cues, such as mirroring, matching, and extemporizing to establish communication within a dialogical context (Hiller, 2015; Ridder, 2005; Zentner et al., 2008). Nurses also have a long involvement in the use of music for healing, and specific for dementia care, the use of individualized music (Gerdner, 1997, 2013; McCaffery, 2008; Parr Vijinski et al., 2018). Recreation therapists, occupational therapists, and unregulated health care workers (under a health professional's supervision) include musical interventions within programs in long-term care (LTC) facilities, such as sing-a-longs and music listening groups (Foster, 2009). Finally, most families wish to remain involved in the life of their loved one as informal caregivers (Dassa, 2018, 2020; Gaugler, 2005; Whitaker, 2008). It is within the family that the PwD can not only express and exchange meaningful communication, and maintain relationships, but do so based on shared life-long experiences (Baker et al., 2012; Dassa, 2018; Duggleby et al., 2013).

Dementia is a daily lived experience for over half a million Canadians (Alzheimer's Society of Canada, 2016). The number of Canadians diagnosed with dementia is estimated at 25000 *per annum*, with the total number of Canadians with some form of dementia estimated to be more than 564,000 (Alzheimer's Association, 2020). The annual care costs exceed $10.4 billion CAD and are predicted to double over the next 15 years (Alzheimer's Society of Canada, 2016). It is estimated that within 25 years there will be 1.5 million cases of dementia, and annual health care costs exceeding $135 billion CAD (Alzheimer's Society of Canada, 2016; Chertkow, 2008; Rockwood & Keren, 2010).

People with dementia live in a variety of settings, from LTC facilities with 24/7 care to living alone in the community. In Ontario, over 50% of long-term care residents are over 85 years of age and nearly two-thirds have a form of dementia, one-third of which have serious

cognitive impairment (Canadian Institute for Health Information, 2016). In Alberta, by comparison, 54% are over 85, of which 59% have a form of dementia (Government of Alberta, 2019). However, most Canadians who have dementia still live outside of an institution (61%); of those living in the community, about one-fifth are estimated to have serious cognitive impairment (Canadian Institute for Health Information, 2016). For those living in the community, about 90% of care is provided by family caregivers (Tam-Tham et al., 2016).

In this chapter, I introduce the key concepts of communication, music, and dementia care, followed by the statement of the problem, the purpose of the study, and the significance of the study. Next, I briefly present the methodology chosen and reflexively present my rationale for doing so. A conclusion to the chapter follows.

## Communication, Music, and Dementia Care

The etymological roots of the English word "communication" is derived from the Latin *communicatio*, which means message, and *communicare*, which means to share (Ridder & Gummesen, 2015). Aldridge (2005a) referred to communication as a dialogue, which is derived from the Greek διά (trans. through) and λόγος (trans. speech). Human communication is the exchange of "meaningful information between two or more participants" (Thaut, 2005, p. 1), entailing the establishment and maintenance of relationships, imbued with personal, emotional, and social content (Aldridge, 1989; Haberstroh et al., 2011). The final objective of communication is, according to Aldridge (2005b), the sharing of "our stories" as "our identities", of which "we mutually understand each other" (p. 47).

Communication consists of sound (language and paralinguistics), silence, and gesture (Aldridge, 2005a; Ridder & Gummesen, 2015). Nonverbal communication emphasizes interaction and emotion, rather than semantic context, and includes body language (e.g., gestures,

body angle, eye contact), proxemics (bodily distance and the use of space), the use of clothing, object language (reactions to objects), and metacommunication (reaction to nonverbal interactions) (Chew, 2014; Silverman, 2008).

Spoken communication includes similarities to music, with prosodics such as tone, pitch, rhythm, duration, timbre, dynamics, volume or intensity, and inflection (Aldridge, 2005a; Hald, et al., 2017; Higgins, 2012). Utterance or vocal expression of non-speech sound is communication in *how* and not *what* was said (Ridder & Gummesen, 2015). For example, was the uttered sound loud or quiet in volume, and what emotion(s) did it convey? Music has two fundamental elements: sound and time (Stravinsky, 1947). As a series of sequential sounds, music is an arrangement of pitch, tone, timbre, melody, and harmony (Herkenrauth, 2005; Pavlicevic, 2013). Music, irrespective of style, genre, or performance, is expressed through shared emotions, and cultural and social manifestations (Aldridge, 2005b; Cross, 2014), in a process that has been referred to as *entrainment* (Clayton, 2007), which involves people sharing, dialoguing through music, leading to a "collective convergence" (Cross, 2014, p. 813).

For health care, music is used in intervention strategies for disorders that have some form of language and/or communication difficulty symptoms, such as acquired brain injuries, traumatic brain injuries, autism spectrum disorder, and neurodegenerative diseases (Aldridge, 2005a; Gilbertson, 2005; Hurksman et al, 2012; Jungblut, 2005; Ridder, 2005; Whipple, 2004). For such disorders, "music can serve as a bridge across communicative restrictions and may function as a powerful treatment modality in treating clients with communication deficits" (Silverman, 2008, p. 7).

Music has a long history of use for dementia care (Foster et al., 2016; McCaffery, 2008; Parr Vijinski et al., 2018). It can be used live, recorded, and with instruments, including the

voice. Interventions can involve passive listening or active participation (Hiller, 2015; Ridder & Wheeler, 2015). Music offers the person with dementia the ability to communicate in means other than spoken language, such as through nonverbal communication in gesture, body language, facial expressions, paralinguistics (Hiller, 2015), as well as to reconnect them with a greater sense of self-awareness and life (Baird & Thompson, 2018; Sacks, 2007).

In therapeutic interventions, communication is typically manifested through appropriate social reciprocity, mirroring, shared attention, and emotional attunement (Guerrero & Turry, 2013; Hiller, 2015; Watson, 2014). Music has been noted for its positive impact upon both the PwD and formal and informal caregivers, where the ability to communicate and socially engage through music mutually improves their relationship (Baker et al., 2012; Dassa, 2018; McDermott et al., 2014; Skaalvik et al., 2016).

The use of music, with its association with personal meaning, experiences, and memories is an approach that sees the person as unique, with experiences and desires (Dassa et al., 2020; Garabedian & Kelly, 2018). McDermott and colleagues (2014) stated that using music with an emphasis on personhood sees the value of each person's autobiography. This can be achieved through the use of familiar music, where memories can be triggered that can reattach the person to an awareness of self, and create, through the generation of a shared experience, the opportunity for building connectedness with the caregiver (McDermott et al., 2014). In dementia care, when music is familiar, linked to aspects of the PwD's life, it becomes not just an activity, but a meaningful, desired activity (Dassa et al., 2020; Gerdner, 2013; McDermott et al., 2012). Benefits of familiar music include increased reminiscence, positive emotional responses, and the reawakening of self-awareness (de Vries, 2013; Sacks, 2007; Schoenfelder & Gerdner, 2010). Wall and Duffy (2009) wrote that the function of music in such interventions is to create ways to

"connect and understand people with dementia who appear incoherent and unable to communicate" (p. 111).

I discovered as I undertook my literature review, music is more than merely utilitarian, but impacts on the whole person – on emotions, cultural identity, memory, and psycho-social needs – and connects the PwD to the caregiver (Baker et al., 2012; Ridder & Gummesen, 2015). This is reflected in music as a tool for memory (Baird & Thompson, 2019; Dassa, 2018), for emotion (Clare et al., 2020; Götell et al., 2009; Söderman & Rosendahl, 2016) and reflecting understanding (Engström et al., 2011a; Marmstål Hammar et al., 2010b; Ridder & Gummesen, 2015), where it was identified as creating meaningful interactions with the caregiver, facilitating aspects of communication that were not just content, but relational (Baker et al., 20102; Götell et al., 2009; Sixsmith & Gibson, 2006).

## Statement of the Problem

It has been said that "difficulty in communication is a core effect of dementia" (Riachi, 2018, p. 304). With the progress of dementia, language abilities become increasingly compromised, resulting in "interrupted and disordered" communication (Aldridge, 1989, p. 276). Dementia may be defined as a clinical syndrome for a group of diseases that has as its main feature progressive deterioration in multiple domains of cognitive functioning leading to progressive loss of language skills, memory impairment, and a decreasing ability for perception and cognitive functioning (Chertkow, 2008; Knebel, et al., 2016; Qui et al., 2007; Vink et al., 2004). Comprehension of spoken communication involves understanding different levels of complexity, syntax, and subtleties of language. The effect of losing language skills can undermine identity, increase loneliness, and precipitate a general decline in QoL (Bergman et al., 2007; de Vries 2013; Hill et al., 2010; Hirst & Le Navenec, 2007; Wiersma & Pedlar, 2008).

Many symptoms of dementia (such as agitation, depression) can be driven by unmet needs, one of which is communication (Clare, 2014; Jonas-Simpson & Mitchell, 2005; Kuosa et al., 2015; Thuerer et al., 2015). To compensate for loss of language skills, PwD become more dependent on nonverbal relational aspects of communication such as gestures, proxemics, and the use of paralinguistics and vocal dynamics (Aldridge, 2005a; Haberstroh et al., 2011; Kuemmel et al., 2014).

Maintaining, perhaps even improving communication is essential to good dementia care. However, many times caregivers struggle to have meaningful communication with PwD. Institutional based care has become increasingly complex, with many in LTC facilities having chronic conditions and diseases which further exacerbates frailty and vulnerability (Estabrooks et al., 2015; Hirdes et al., 2011; Registered Nurses' Association of Ontario, 2016). In addition to physical diseases and disabilities, many have behavioural and psychological symptoms, especially agitation and anxiety, much of this due to the breakdown of communication (Kuosa et al., 2015; Matthews, 2015). In such contexts, music has been identified as a meaningful activity in which the caregiver can engage the PwD to facilitate communication and lessen negative psychological symptoms caused by isolation, loneliness, and unmet needs for communication (Garabedian & Kelly, 2018; Sacks, 2007; Smetanin et al., 2016).

For informal family caregivers, dementia care can impact deleteriously upon family relations, leading to stress for the immediate family, and economic hardship on those who take time off work to care for loved ones. Primary caregivers can be placed under immense psychological stress as they not only attend to daily health needs, but also must take on multiple daily tasks, such as shopping, and paying bills (Dassa et al., 2020). The duration and intensity of dementia care can also affect primary caregivers' physical and psychological wellbeing (Cox,

2013; Rockwood & Keren, 2010).

As such, the effects of dementia upon the person have spillover effects on family and friends, as well as on those who take care of the PwD on a professional level within health care, making dementia a major health and social challenge requiring proactive and creative initiatives to deliver the highest possible care (Alzheimer's Society of Canada, 2016; McDermott et al., 2014; Pitkala, 2016). The challenge is for formal and informal caregivers to use a conduit that might facilitate paths of communication, that might not be accessible through spoken language. Music is one such pathway. This study explores how music facilitates communication for PwD based upon the lived experiences of their caregivers, formal and informal.

## Purpose of the Study

The formation of a good research question is driven by the research objective (Holloway & Todres, 2003). The primary objective of my study was to develop a grounded theory of how music may facilitate communication for people with dementia from the perspective and experiences of formal and informal caregivers. My overarching primary question was: *does, and if so, how does music facilitate communication for the PwD?* This study had a number of purposes including: (1) to understand caregivers' experiences when using music to try to communicate with people with dementia; (2) to use this understanding to explore how this may increase our knowledge of the value of the caregiving relationship between caregiver and the care recipient; (3) to help families understand their experiences and vital role as informal caregivers; (4) to contribute to the research field a new grounded theory for a little studied phenomenon; (5) to generate new knowledge that may be used by formal caregivers for developing new approaches for a higher quality of care for people with dementia.

## Significance of the Study

This study is significant from several perspectives. Canada is an aging society, with dementia a major health issue requiring a dynamic response to this societal change and challenge (Alzheimer's Society of Canada, 2016). Whether in community or LTC settings, this study may provide new knowledge on how music facilitates communication for people with dementia, and by extension the promotion of their quality of life.

Most research into the use of music for dementia is quantitative (Dowson et al., 2019; O'Callaghan, 2012). Beard (2011) suggested that research is focused on emphasizing a "quantitative, product-oriented emphasis" (p. 637). In contrast, my study offers the potential of a new grounded theory that focuses on the uniqueness of human experiences as situational (community and LTC) relational, meaningful, and part of a person-centred approach of which communication plays a vital role. The new knowledge generated exploring contextual real-life experiences may help formal caregivers and other allied health care professionals to understand the effect of music on communication for people with dementia, and may also help them in developing new approaches for care in their practice.

In the community, music use by people with dementia is common, and not only through passive listening (such as listening to the radio), but actively, such as in song and experienced within the social contexts of community life, in the home being engaged by a family member or friend, or within a day program (Sixsmith & Gibson, 2006). The use of music in the community with family caregivers has been documented to have positive emotional and social effects on not only the PwD, but also on the family (Brotons, 2003; Hanser et al., 2011). It has been noted in the literature that in comparison to formal caregivers, there is a paucity of research conducted amongst informal caregivers on how they impact dementia care (Hanser et al., 2011; Lethin et

al., 2016). My research is an effort to contribute towards this new trend in research that includes the contributions of informal caregivers in dementia care.

In contrast to life in the community, living in a LTC facility involves a disruption of familiar social networks, which can undermine already compromised communication abilities, making the PwD in LTC institutional settings particularly vulnerable to loneliness (Moyle et al., 2016; Williams et al., 2017). The exploration of communication within this context may provide new knowledge as to how the lived environment, may be a factor in the facilitating of communication through music.

Whitaker (2008) has noted there exists in institution-based care an ambiguity as to the role of the family; either as on the outside as visitors or as part of integral care. This ambiguity tragically played out during the COVID-19 pandemic where, in many jurisdictions, family members were excluded for consideration as ‘essential’ caregivers (Kent et al., 2020; Government of Ontario, 2020). This study is therefore timely in highlighting the value of informal caregivers as an essential part of a dementia care team.

Music is recommended as a non-pharmacological first-line intervention for dementia care, including behavioural and psychological symptoms of dementia (BPSD) (Blackburn & Bradshaw, 2014; Elliot & Gardner, 2018; Kales et al., 2014; Legere et al., 2018; Matthews, 2015). My study has the potential to contribute to the call for greater awareness of non-pharmacological interventions as part of best practices for dementia care.

## Rationale for Constructivist Grounded Theory: An Initial Reflexive Positioning

A constructivist grounded theory (CGT) methodology was selected to explore the experiences, interpretations, and meanings expressed by the caregivers. Music and communication, I propose, are both interactive, subjective phenomena whose meaning and

understanding is constructed by people. This reflects a constructivist position (Charmaz, 2014). As such, I regarded a constructivist approach as an appropriate fit for exploring contextual and subjective experiences of how and why the communicative act transpired, and how the act might have been influenced by music. In my approach, I was cognizant of Stebbins' (2001) encouragement for the researcher to engage in the "exploration of discovery" (p. 3) when encountering a little researched area (of which mine is). As exploratory, this study is a first step which "typically produces *some* grounded theory - it is not wholly and descriptively idiographic - but not (yet) *a* grounded theory, which can only come with further exploratory research, with several more studies in the same area" (Stebbins, 2006, p. 493).

My selection of CGT methodology was also influenced by a confluence of a life's experience of music and reflecting on the meaning of music. I did not approach my methodological selection with a *tabla rasa*, but rather with due consideration for my *a priori* experiences and reflections, that found resolution in a methodology that would reflect my belief that music is a subjective experience. A comprehensive discussion of my philosophical positioning will be discussed in Chapter Three.

Reflection, as well as personal experience, led me to concur with the observations of the drummer and percussionist William Bruford (2015), who wrote that music is both science and art, "…on the one hand, measurable and knowable in its physical properties and on the other, mysterious and ineffable" (Bruford, 2015, p. 14). Accepting Bruford's (2015) proposition that music is both knowable, yet mysterious and personal, I considered a qualitative and inductive approach, as a fit for the interactive subjective phenomenon of music and communication, as well as the contextual experiences of the caregivers participating in the study. Exploring caregiver experiences called for, on my part, "understanding meanings and actions and how

people construct them" (Charmaz, 2014, p. 31). Being open to their unique experiential worlds in my study reflected the constructivist approach of "the creation of a sense of reciprocity in the process of interaction between participants and the researcher when co-constructing meaning" (El Hussein et al., 2014, p. 9).

## Conclusion

Communication is a vital part of human life and impacts directly upon QoL. For good dementia care the ability to communicate between caregivers and people with dementia (both formal and informal) is essential (Dassa, 2018; McDermott et al., 2014; Ridder & Gummesen, 2015). Music, as a conduit for communication, can enable caregivers to establish or even strengthen communication (Baird &Thompson, 2019; Engström et al., 2011a). Exploring how caregivers experience music facilitating communication for people with dementia is, therefore, one area of research that can generate new knowledge in how music is manifested as communication for PwD. Developing a constructivist grounded theory provides greater understanding and insights for formal caregivers in their practices, but also generate an awareness of the value and contribution informal caregivers bring to the dementia care team.

# CHAPTER TWO: THE LITERATURE REVIEW

This chapter commences with an overview of the place that the literature review holds within grounded theory, and where I position myself on this issue. Explicating my position helped form my reflexive road map before actual data gathering and analysis. An overview of salient literature served the reflexive process of recognizing the potential influence of pre-existing knowledge, assumptions, and views on my approach to my research and theoretical perspectives (Charmaz, 2014; Strauss & Corbin, 1998; Thornberg, 2012).

Next will follow the main body of the chapter, with a review of studies that have a focus on research findings on the use of music for communication for people with dementia. The purpose of this review was to identify relevant research as well as identify knowledge gaps that served as the justification for this study, and for potential future research that may evolve from this study. I conclude this chapter with a brief summation of the findings, and an overview of my research question positioned within the context of the literature review.

## The Literature Review in Grounded Theory

The use of a literature review is a debated topic amongst grounded theorists with no resolution as to a definitive approach (Dunne, 2011; El Hussein et al., 2014; El Hussein et al., 2017; Hall et al., 2013; Kenny & Fourie, 2015). El Hussein and colleagues (2017) put it succinctly: “over three decades of discourse among grounded theorists has done little to quell the controversy related to the literature review” (p. 1200). In the original classical iteration of GT, Glaser and Strauss (1967) recommended the researcher be cognizant of the literature, but to conduct the review after the study. Their concern, influenced by objectivism, was that the researcher might be unduly influenced by the literature, as well as any existing theory/theories *a prior* to the actual research (Dunne, 2011; El Hussein et al., 2017; Glaser, 2005). Glaser still

retains this position, holding that general awareness and reading on the problem area are sufficient for gaining prior understandings (Hall et al., 2013; Kenny & Fourie, 2015).

In contrast to the original classical GT iteration, Strauss with his colleague Corbin, (Strauss & Corbin, 1998) proposed a nuanced position, where knowledge and experiences of the phenomenon prior to its investigation can be of use to the researcher. Strauss and Corbin suggested that an awareness of the literature may be of value in identifying knowledge gaps and in developing and providing new ideas for theoretical sampling. However, they nuanced their stance by proposing the literature be not exhaustively reviewed. Rather, they advised that the literature review should be an overview that informs, provides knowledge, but does not inhibit the researcher's abilities to generate knowledge and engage in new discoveries. They recommended a balance between familiarity with the literature and openness to creativity, as an "analytical tool" (Strauss & Corbin, 1998, p. 53).

Charmaz (2014) suggested that the literature review should be to "clarify ideas" and make "intriguing comparisons" (p. 309) as well as be a place where the researcher explores critically relevant literature to see where the proposed study may fit. She recommended the researcher use the literature to "set the stage" (p. 308) for the developing grounded theory.

The iterative and inductive nature of grounded theory has given rise to debate on the question of how a researcher who has substantive knowledge or personal experience of the phenomenon under study can hold this same knowledge in abeyance and approach research inductively (Dunne, 2011). Awareness of the literature calls on the researcher to engage in a reflexive and sensitizing process (Dunne, 2011). Incumbent on the researcher is to openly acknowledge any pre-existing knowledge, personal experiences, views, assumptions, and to engage reflexively throughout the entire research process to ensure a naturally evolving,

unforced iterative and inductive process (Lempert, 2007; Strübing, 2007).

Considering the place of the literature review in my study helped me to form a reflexive road map of my understanding of the pertinent literature to my research interests, prior to and during data gathering and analysis. Being aware of my views on music and communication, (which I explicate in Chapter Three), I strove to be reflexive and avoided forcing the literature, which would have sacrificed the iterative and inductive nature of GT. Conducting a literature review challenged me to be opened to the extant literature's, themes, and ideas and to note its influence in my iterative journey of exploration. As Cutcliffe (2000) stated, it is incumbent on the GT researcher to acknowledge pre-existing knowledge, views, and assumptions, and to engage in a reflexive process throughout the entire study.

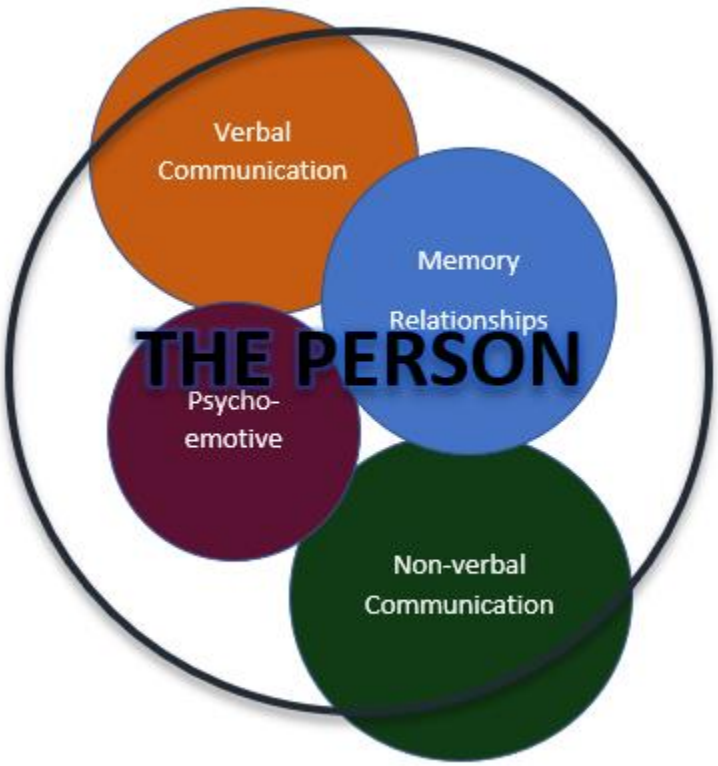
Finally, the exploratory study, which mine was, should, according to Stebbins (2001), have a literature review that can demonstrate a paucity of knowledge and research in the area under study, and lead to "an open-ended approach to data" (p. 42). The literature review in an exploratory study should, as Stebbins has noted, be short and focused on the centrality of discovery, which is inductive "rather than within established theory and a set of hypotheses deduced from it" (p. 7).

**Positioning the Literature Review**

My positioning follows both Charmaz (2014) to clarify and compare ideas, and Strauss and Corbin's (1998) proposal that the literature review be a balance between familiarity and creativity. After reflection, I organized the literature under the two main modes of human communication: verbal and nonverbal. My first step in reviewing the literature was an overview and exploration of various indicators of such communication as precipitated by music. However, human communication is directed towards the expression of the self, in other words, it is

relational and not just utilitarian and content laden (Aldridge, 2005a; Dassa et al., 2020). To reflect this relational aspect, I explored and reviewed the literature creatively with an emphasis on the psycho-emotive, and memory and relationships components of communication. This division does not imply a separation between the psycho-emotive and memory and relationships, but to reflect the various influences of music. I conceptualized this as mutually interconnected interplay flowing out from the inner person to be expressed by the outer person. This is reflected in Figure 1, where "verbal communication" and "non-verbal communication" project outside of the "The Person" to signify that these are externalized manifestations of communication reaching outside of the person that are perceived by others. Further, the asymmetry in size and placement of the indicators and influences of and on communication are meant to indicate the uniqueness of each person.

Figure 1



For example, when memory/relationships are triggered, the other elements will be triggered in various and differing degrees, such as improved verbal speech, gesture, and emotional responses (Davidson & Fedele, 2011; Götell et al., 2009). Music, as subjective, means that it triggers each of these elements in a personal way, not in a linear way, but rather dynamically, reflecting the effects of music on the act of communication (Aldridge, 2005a; Garabedian & Kelly, 2018; Ridder & Gummesen, 2015; Schall et al., 2015).

## Music and Verbal Communication

Verbal communication is a common and universal human response to music (Aldridge, 1989; Ridder & Gummesen, 2015). Vocal expression, through speech, song, or utterances, include within them, not just what is conveyed through sound, but *how* the sound is conveyed (prosody) (Ridder & Gummesen, 2015). The importance of the human voice not only in speech, but as a conduit of music should not be overlooked. As Pavlicevic (2013) noted "human communication is essentially musical in character" (p. 78). The human voice, as a musical instrument is used to "invite people into shared communicative and expressive communication" (Pavlicevic, 2013, p. 78). The effect of music upon verbal communication indicates that music has been found to precipitate an increase in speech, from an individual tone, to the singing of lyrics, and using music to put together phrases (Brown et al., 2003; Engström et al., 2011b; Marmstål Hammar et al., 2010a). Even individual sounds, however small, can be indicative of communication. The utterance within a musical context is not "meaningless" (Aldridge, 2005a, p. 32), but a "meaningful" (p. 32) response to music, reflecting attention, understanding, thus indicating communication (Kuemmel et al., 2014). The linking of utterances can lead to the creation of phrases, melodies, or tones that are signs of further cognition and communication (Aldridge, 2005a; Brown et al., 2001; Götell et al., 2009).

**Indicators of Verbal Communication**

Verbal communication is manifested in various musical responses, including matching (singing along) and mirroring (imitating the vocal of another) through singing, humming, or even brief vocally produced tones (either melodically, or rhythmically) (Ridder & Gummesen, 2015). Unadkat and colleagues (2017) in a study of 17 couples (one partner having a diagnosis of dementia) gave the example of an otherwise silent PwD joining in the singing of a song. Garabedian and Kelly's (2018) ethnographic study on 12 dyads (each dyad consisting of a PwD with severe dementia paired with family, friend, or staff) used familiar music as a means of triggering memory recall of the songs, resulting in PwD responding using occasional appropriate words. Ridder and Gummesen (2015) in a hermeneutic case study with a 64-year-old male subject who had dementia and global aphasia, used an explorative and improvisational music therapy technique to facilitate verbal communication. His situational appropriate responses (e.g., singing, humming to incoming musical cues) indicated a communicative response. Mirroring and matching in this study was a key indicator of appropriately responding to not just matching a melodic phrase, but also the rhythm, indicating a cognitive abstraction (Ridder & Gummesen, 2015). Brotons and Koger (2000) in a within-subjects (where all residents participated in non-music and music sessions) study that focused on verbal communication, identified an improvement in cognition as compared to non-music sessions reflected in improved verbal communication. Rylatt (2012) in a preliminary study of two comparison groups (both consisting of PwD who receive day and inpatient care) to evaluate a creative arts intervention for dementia (which also included music) identified staff recorded observations that included improved verbal communication amongst the effects of the intervention. Even in late-stage dementia, such verbalization and singing can be expressed. For example, Dassa and Amir (2014) in a study

involving six participants, noted indicators of short verbal exclamations and singing at the awareness of the familiar songs.

Verbal communication was also identified in a number of studies that used a singing music intervention called *Music Therapeutic Caregiving* (MTC). MTC involves the caregivers singing familiar songs to or with the PwD during caregiving. In an ethnographic study of 48 participants living in a LTC facility, Götell and colleagues (2000) noted verbal indicators such as singing along to songs using appropriate words, verbal expressions of joy and improved attention, and an increase in talkativeness following the completion of the MTC session. Brown and colleagues (2001) in a single case study of an 85-year-old female compared baseline caregiving with no music to MTC interventions. All sessions were videoed and analyzed following a phenomenological-hermeneutic approach. Results of verbal communication included "increased cognitive sharpness in her verbal statements, and more of a sense of conversing during the time that the caregiver spoke to her (or even sang to her)" (p. 127). In a study involving seven women and two men (median age = 84) Götell and colleagues (2002) noted that the participants not only improved in their use of words, but also had a decrease in negative verbal manifestations (such as screaming), indicating emotional responses. These decreases in negative verbal communication may indicate music meeting an unmet need (such as the desire to communicate, which is innate in the person) (Götell et al., 2002). A reduction in negative responses were also identified in other studies (Götell et al., 2003; Marmstål Hammar, Götell et al., 2011).

Using qualitative content analysis, Marmstål Hammar and colleagues (2010a), in an MTC study of nine dyads of caregivers and people with severe dementia during morning care noted that PwD began to initiate verbal communication, replying to caregivers, and engaging in

singing. Caregivers noticed an improvement in speech usage from single to multiple words, improvising words to songs, appropriate paralinguistic use of laughter, and even, occasionally sentences. Residents were able "to remember song texts and sing songs even when they experience severe impairment of communication" (p.18). Similar findings were found in a follow-up pre-post study that showed improved verbal communication leading to increased cooperation (Marmstål Hammar et al., 2010b).

Studies were also identified that included findings of a decrease of negative verbal communication whilst positive communication improved. For example, Marmstål Hammar, Götell and colleagues (2011) in a study of two women with dementia noted that in four MTC sessions compared to four without MTC baseline sessions, music lowered negative verbal manifestations such as shouting and crying, and improved verbal communication. Engström et al (2011a) in a case study of an 86-year-old female that consisted of eight sessions, compared four baseline sessions with no MTC to four with MTC and noted that enhanced appropriate verbal communication followed MTC and reflected in more active cooperation. In a follow-up study to the single case study, Engström and colleagues (2011b) conducted an observational study on 10 persons with dementia, paired with caregivers. Findings included improved verbal communication and a reduction in negative communication behaviours.

## Music and Nonverbal Communication

Nonverbal communication can express a range of emotion and thought, albeit more ambiguously than spoken language (Robinson, 2005). Anger, sadness, tenderness, love, and happiness are just a few emotions that can be conveyed with gesture and facial expressions. As embodied beings, we humans are constantly using the body to interact and communicate with others. The importance of communicating with the body cannot be underestimated, as Aldridge

(2005b) wrote, "…it is gesture that is pre-verbal and promotes thought" (p. 47). Pavlicevic (2013) suggested that music is in a sense, "embedded in our bodies" (p. 71), as part of daily human existence and experience.

Nonverbal communication, with the advance of dementia, begins to supplant verbal communication, and takes on a primary position in communicating for PwD (Allison et al., 2019; Chew, 2014; Schall et al., 2015). A major implication of this is that communication becomes more relational and less content reliant, and the focus of communication is to facilitate relationships and maintain bonding between the PwD and the caregiver (Allison et al., 2019).

**Indicators of Nonverbal Communication**

Nonverbal communication takes on greater importance as compared to verbal for those with dementia, and can be manifested by facial and eye movements, as well as bodily responses to music and its rhythm through tapping in time or moving a leg, indicating an understanding and appropriate response Götell et al., 2003; Marmstål Hammar et al., 2011; Ridder & Gummesen, 2015; van der Vleuten et al., 2012).

In a quasi-experimental study with a focus on QoL of 54 subjects living in LTC, van der Vleuten and colleagues (2012) noticed that live music delivered by a musician created a positive effect on nonverbal communication expressed with improved body language. Music, they theorized, not only can improve emotional wellbeing through facilitating communication, but also the way these same emotions are experienced and then communicated to others. They further identified that music in improving communication "…contributes to a person's ability to make contact" (p. 487). Allison et al (2019), in a two-year longitudinal ethnographic study on the effect of music and arts in everyday life of 40 late-stage dementia residents living in LTC, identified that music as part of daily activities facilitated nonverbal communication, built

relationships, and created situations reflective of bonding (such as handholding). Data included activity and caregiving observation, and interviews with staff, family, and volunteers.

Amongst MTC studies, nonverbal communication was identified as an effect of music. Götell and colleagues (2000) noticed that those who were normally serious or even confused would smile during singing when engaging in requested behaviours, such as ADL in contrast to being withdrawn or resistive to requests from the caregiver when MTC was not used. Other nonverbal communication identified in a follow-up study included positive nonverbal communicative actions and responses such as more appropriate bodily posture, the use of facial expressions, and alertness and completion of tasks (Götell et al., 2003). MTC sessions resulted in greater communication, such as nodding to music, having stronger and more symmetrical movements, being more alert such that there was "…improved gestural communication between patient and caregiver leading to a mutuality of their interaction" (Götell et al., 2003, p. 428), as compared to noncompliance and less or even no communication without MTC.

Marmstål Hammar and colleagues in two studies (2010a, 2010b), identified that from a caregiver perspective, the use of singing was positive in building nonverbal communication as reflected in increased cooperation resulting in a sense of relaxation during ADL. Other indicators of nonverbal communication included eye contact and appropriate body and head motion, where residents engaged in more indirect face-to-face positioning, and no longer turn the body away from the caregiver during MTC. Similarly, Marmstål Hammar, Emami and colleagues (2011), noted that MTC could impact negative nonverbal communication (such as less restiveness to ADL, which included pulling the body away, and the clenching of teeth) in a positive manner where the PwD bodily and facial gestures became receptive to the caregiver through the turning of the body towards the caregiver, and the diminishment of negative facial indicators.

Engström and colleagues (2011a) in a single case study of an 86-year-old woman living in a LTC facility, using video analysis compared four baseline non-music sessions to four using MTC noticed that the subject had improved nonverbal communication, including smiling, and appropriate bodily responsive gestures during caregiving. In a follow-up, Engström and colleagues (2011b) noted improved nonverbal communication (including body movement and eye contact), and a reduction in negative communication behaviours, such as being resistive to ADL.

## Communication and Music: Psycho-emotive Expressions

In this section, I discuss some of the findings that link both verbal and nonverbal communication within a musical context to specifically psycho-emotive expressions. Acts of communication involve "a content and a relationship aspect" (Kuemmel et al., 2014, p. 24), because humans not only exchange content, but in the process of relating content, exchange and convey emotional meanings to each other. Cross (2014) emphasized that music communicates affective states or emotions. Verbal indicators of psychological or emotive content can include volume, dynamics, and repetition. Indicators of nonverbal communicative expression, many emotionally imbued, can include facial expression, gesture, and body language (Aldridge, 2005a). Psycho-emotive aspects identify the usefulness of music as benefiting both the PwD and the caregiver, for the caregiver also benefits from positive communication, be it simply in successful ADL, or entering a more emotionally connected relationship through a shared musical experience (Brown et al., 2001; Dassa 2018). The facility of music to elicit positive psychological and emotional state can lead to mutual interaction and bonding, benefiting the caregiving relationship beyond that of mere utilitarian usage, such as for ADL, and can become a positive shared experience (Brown et al., 2001; Clare et al, 2020; Dassa et al., 2018).

Familiarity with pieces of music seems to be the predominant conduit of facilitating positive psycho-emotive responses. It has been suggested that this may be because the music has an emotional link to past meaningful experiences, and that it can invoke recollection of past experiences, aspects of the person's self and identity, thus reawakening within the person something that is not so much lost, but obscured (Baird & Thompson, 2019; Dassa, 2018, 2020; Genoe, 2009; Hiller, 2015). In an interview, Sacks (2008) noted that "personal memories are embedded, to some extent, in things like music, and especially in songs which one knew or which one learnt." (Sacks, 2008). Tomaino (2015) suggested that "the more emotionally charged the musical experience, the more likely a strong memory is connected with it" (p. 47). Familiar music plays a central role in communication (Mandzuk et al., 2018), triggering memories and reconnecting the PwD to others (especially family members) (Dassa & Amir, 2014; Dassa et al., 2020), and offering the potential to re-establish relationships through sharing a meaningful musical experience (Garabedian & Kelly, 2018; Götell et al., 2000; Harmer & Orrell, 2008).

Verbal indicators of psycho-emotive acts of communication can be reflected in individual words selected by the PwD, the dynamic delivery of the word or words, the repetition of a word or phrase that might convey its meaningfulness or importance to the PwD, and the desire to verbally express this to the caregiver. For example, from a positive communication perspective, this may be reflected in the repetition of a sung phrase or spoken word (Dassa et al., 2020), or negatively as in a vocal tone and dynamics that conveys emotions indicative of anger or confusion (Götell et al., 2009).

The emotive aspect of the human voice singing is reflected in not just the sound, the lyrical content, but *how* that sound is conveyed, which impacts ultimately how it is perceived and interpreted by the hearer (Götell et al., 2009; Ridder & Gummesen, 2015). The human voice

elevates the emotional nature of music in that the singing voice can be said to manifest intense emotional inflection and intent, incorporating such musical paralinguistics as pitch, tone, dynamics, tempo, and vibrato (Götell et al., 2009; Ridder & Gummesen, 2015). As a singing instrument, to facilitate verbal and nonverbal communication, the voice can increase positive emotions and lessens negative ones (Götell et al. 2000, 2009; Marmstål Hammar, Emami et al., 2011).

Singing, due to its intimacy and personal involvement, may facilitate an atmosphere of caring which can precipitate attachment and bonding as reflected in both verbal (such as the participant joining in singing) and nonverbal (such as smiling and bodily gestures) communication (Götell et al., 2000). For example, Bannan and Montgomery-Smith (2008) in a pilot study of group singing between PwD and their carers, identified improved interaction both verbally and non-verbally as PwD became more socially acclimatized to sing when using familiar song over a series of group sessions with other PwD. Brown and colleagues (2001) noted that "individualized singing can be enormously soothing and can create a great feeling of security and bonding" (p. 130). Using MTC, they also noticed the human voice itself as a conveyer of expressiveness whereby "elderly people may in fact be more responsive to the sound of the human voice and the act of singing than to a particular song or its instrumental arrangement" (p. 131).

Illustrative of the effect of the singing voice is Götell and colleagues' (2003) observation that during MTC sessions (as compared to no MTC baseline sessions) emotional manifestations changed from unresponsiveness, muteness, and flat emotional affect, to positive emotional responses, and with these appropriate responses and emotions continuing without any verbal instructions from the caregivers. This may indicate that PwD retain a latent cognitive effect of

emotion and that it is not transient.

Götell and colleagues (2009) noted that, unlike speech, singing amplifies paralinguistics (e.g., tempo, dynamics, tone) and resultantly manifests an innate emotional inflection and intensity. They identified that PwD also expressed emotion and moods through vocalization such as delight (expressed in happiness while dressing), or uncertainty (such as being aware of the challenge of a task in dressing). They noted that the effect of singing led in turn to "a sense of sincerity and calm seemed to permeate the interaction with singing" (p. 428).

Dassa (2018) using familiar music combined with photographs, for sessions involving three men with dementia and their spouses, noticed that meaningful music led to positive emotions and expressions of togetherness, which in turn triggered improved communication and relationship building. She theorized that it was musical familiarity within the context of shared experiences and memories that led to shared positive emotions between spouses.

Laughter can be both a vocalized relational communicative act related to paralinguistics and expressing emotion. For example, Dassa and colleagues (2020) in a study of two couples noted that music triggered situational appropriate laughter, which in turn, facilitated greater connectivity and relationships between the couples, as the non-dementia spouse would also engage in laughter in response. The ability of music to trigger laughter as an indicator of communication was also found to be a common vocal occurrence in other studies (Garabedian & Kelly, 2018; Marmstål Hammar et al., 2010a; Raglio et al., 2008; van der Vlueten et al., 2012). Clare and colleagues (2020) in a GT study of seven PwD, noted laughter as an observable behaviour that was coded as social interaction, "laughing together" (p. 1120). Similar findings exist in other studies that indicate emotive paralinguistic vocal and verbal communication facilitated similar responses towards the PwD from the caregiver (Brown et al., 2001; Dassa et

al., 2020; Marmstål Hammar, Götell et al., 2011).

Psycho-emotive communication can also be manifested through nonverbal communication. For example, Garabedian and Kelly (2018) in their ethnographic study noticed that the communicative actions flowed from improved cognition and memory and included such nonverbal actions such as gestures, facial expressions (e.g. smiling). Similarly, within an MTC context, Götell et al (2000) noted that musical engagement also elicited emotionally driven communicative interaction with caregivers with situational appropriate facial gestures such as smiles, noting that residents "who normally seemed to be serious or confused could smile warmly during the singing and instrument playing" (p. 121).

Schall et al. (2015) in their pre-posttest analysis of video-graphed music therapy sessions, identified wellbeing and the expression of positive emotion. Interventions using improvisation and familiar music were structured within a psychotherapeutic context. In this study, analysis was based on video observation which allowed the authors to access "sensitive and differentiated assessment of music-induced changes in behavior and emotional well-being" (p. 120). They noted that video observation may be beneficial as music is a constant changing temporal reality, where multiple subtle responses can be documented and reviewed which cannot always be done during *in vivo* observation.

Raglio et al (2008) in an experimental study (control n = 29; experimental n = 30) used music over 19 weeks to access its efficacy to reduce BPSD. Though secondarily focused on communication, their findings indicated nonverbal communication improvements in facial expressions (such as smiling), as well as bodily movement in synchronicity with music and responding with appropriate singing behaviours which, according to Raglio and colleagues, indicated improved mutual relationships during therapy and an overall improvement in

participation.

It should be noted that the psycho-emotive is usually an integration of both verbal and nonverbal communication. Illustrative of this is, for example, is Marmstål Hammar, Götell and colleagues (2011) identification of emotive communication when engaging PwD with MTC resulting in an increase in appropriate and positive emotional expressions (such as manifestations of pleasure, smiling), and a decrease in negative emotions, such as shouting, or gestures reflecting anger. Söderman and Rosendahl (2016) in a study of 27 nurses' experiences with residents in LTC identified that familiar music facilitated emotional communication responses in later stages of dementia. Their findings also included the importance of body language for communication, particularly facial and eye contact. Further, they identified that even when spoken language is lost, communication using the resident's native language (as compared to a second language) resulted in more positive communicative results, indicating a latent ability to respond. This was reflected in positive emotional responses and mnemonic triggering from songs native to the resident as compared to not so favourable findings when using a second language. Fischer-Terworth and Probst (2011), in a two-group (n = 26 intervention group, n = 23 control group), pre-post design study, identified music as a successful intervention for communication and positive emotional responses. Participants had mild to moderate dementia in both groups. Results showed significant effects for social communication, social interaction with caregivers, and with fellow residents. Post-study interviews with staff included observed improved communication, such as improved emotional affect, increased interaction, and increased positive emotional responses expressed both verbally and nonverbally.

## Communication and Music: Expressions of Memory and Relationships

When music is familiar, meaningful, and shared, expressions of communication (verbal and nonverbal) can deepen to include an interplay of psycho-emotive and mnemonic triggers that can then lead to a greater sense of connectedness and relationship with the caregiver (Dassa et al., 2020; McDermott et al., 2014; Osman et al., 2016; Thuerer et al., 2014). Nonverbal communication was found, as with verbal communication, to precipitate experiences that were relational, such as bodily and facial expressions communicating what caregivers identified as positive emotion (Götell et al., 2003; Söderman & Rosendahl, 2016), to nonverbal expressions that were interpreted as acts of bonding and mutuality (Allison et al., 2019; van der Vleuten et al., 2012). According to Sacks (2006), music can precipitate a "cognitive focus…especially familiar music, that may evoke for them memories of earlier events, encounters or states of mind" (p. 2529). Familiar music can then have its desired effect (shared memories and emotions), and through the sharing of these mutual experiences, can then lead to relationship building. It is here that the raison d'etre of communication is reflected, where communication is taken to the level of identity, the dialogic and mutual expression (Aldridge, 2005b; Ridder & Gummesen, 2015; McDermott et al., 2014). Where the joy of music can trigger laughter, the singing voice becomes a conduit of shared emotion and the establishment of connectedness and the building up of reciprocity (Clare et al., 2020; Garabedian & Kelly, 2018).

Familiar music involves the use of music that is known by the person and has personal meaning, being embedded in past, positive life experiences (Gerdner, 1997, 2013). Its efficacy is well documented in the literature, with familiar music being used extensively in dementia care (Baker et al., 20102; Götell et al., 2002; Sloboda & O'Neill, 2001). All of us can relate to past memories that were linked to emotional experiences (Levitin, 2007). Conceptually, this theory

places primacy on previously experienced music being able to trigger a mnemonic recall. It has been said that “familiar music becomes a blanket for the soul that remains and becomes an opportunity for interpersonal and intrapersonal connection and communication” (Foster, 2009, p, 44). The role of emotion as a type of memory enhancer has been suggested as playing a part in the ability to retain memory. For example, in a study on the use of familiar music by a recreation therapist in an acute care facility to assess social engagement and relaxation for 10 people with dementia (mean age = 81), the findings indicated an increase in attention and nonverbal activity, as indicated by appropriate eye contact, emotional expressions, humming to the music, as well as reminiscing (Mandzuk et al., 2018).

Studies that focused on families, and especially spousal relationships reflected the ability of familiar music, as a shared long-term memory, to facilitate relationship building through, for example, the sharing of not only emotions (e.g., appropriate eye contact, mutual exchanges of smiles, holding hands), but the recall of meaningful incidents from earlier in life. Baird and Thompson (2019) conducted a case study on the use of music for communication between a married couple, in which the wife had advanced dementia, though her musical skills were relatively preserved compared to her deteriorated language skills. This was reflected in retrospective interviews with her husband who identified music as facilitating reminiscence, relationship, and identity. Music in this study showed its social activity potential, as responses were also attributable to the social dimensions of music, such as familiar music and dancing.

Osman and colleagues (2016) using a combination of reminiscence therapy and familiar music within a group setting of ten dyads (seven spousal dyads and three mother-daughter dyads) noted that music was able to facilitate relationships through improved communication. Using qualitative analysis, they identified themes such as improved mutuality through positive

emotional expression and reminiscing leading to verbal and nonverbal interaction. The strength of their findings Osman and colleagues suggested, is that PwD respond with meaning such that music can provide benefits beyond that of outcome-based studies focused on ADL.

Clair and Ebberts (1997) in a study of 12 dyads (consisting of spouses and a PwD) divided up into groups of two and four couples received music therapy sessions over four weeks. Besides verbal and nonverbal communication indicators (such as increased speech, and rhythmical responses to music), the effect of music on relationship was significant in that touch was found to be a positive and intimate gesture between the couple. Similar intimate gestures were also identified by Götell et al (2000), such as the PwD kissing, hugging, and placing the arm around the shoulder of a non-spousal formal caregiver.

Dassa and Amir (2014) identified familiar songs as a stimulus for improved conversation and communication. The study involved twice weekly, (over four weeks) music therapist-led sessions involving familiar songs for six participants with late-stage dementia (median age 78) living in LTC. The communicative effects of the songs were the triggering of family memories, and more extended social memories, as well as increased spontaneity in interacting. Other indicators included short verbal exclamations of knowing the songs and expressing happiness and belonging.

Dassa (2018) in her familiar music with three spousal dyads also noticed that the music elicited positive emotions, which also led to the triggering of memory. For example, Dassa quoted one spouse as commenting that music "…illuminated memory fragments so we could do some fun things together (p. 5). Improved communication opened new possibilities for relationships and created the possibility for negative psychological variables to be lessened. Such findings also show that self-identity is activated and maintained by memory, thereby recreating

the ability to maintain a relationship through (even for a short period) a rediscovered self-awareness. With awareness of the self comes the ability to share mutual experiences.

Baker and colleagues (2012) explored the effect of music on communication for five couples living in the community. Each couple consisted of a spouse caregiver and a spouse with dementia. Caregivers were trained by a music therapist. Included were recorded music, singing familiar songs, movement to music, and music for downtime. Two themes that emerged were an enhanced sense of togetherness (such as listening to music together) and strengthened reciprocity (such as sharing memories). This togetherness was reflected in listening, dancing, and/or talking. The ability of music to trigger identity can lead to, as this study showed, the ability to communicate with the other, and re-establish a relationship through what Baker and colleagues called the "common ground" (p. 130). Strengthened reciprocity was reflected in "the sharing and purposeful act of being in the moment with her partner…to share some time with us" (p. 14). Another aspect of reciprocity was the ability of music to precipitate shared memories of their life and relationships. This study reflects the importance of music as a conduit for self-awareness leading to an awakening of identity.

Two studies were identified that focused on the everyday impact of music. McDermott and colleagues (2014) using interviews and focus groups explored the perspectives of music of 53 participants, including 16 with dementia (moderate and severe dementia), four informal caregivers, 15 staff, and eight music therapists. They concluded that music was a valuable intervention that not only triggered communication but, in turn, triggered identity and facilitated relationships with the caregivers. Familiar music was identified as a trigger for emotion and the recall of memories. Indicative of the effect of music on communication was one music therapist quoted as saying that music could make her client "…much stiller (than how she was on the

ward), she would look at me, would attempt to communicate with me, she would engage with songs and instruments" (p .712). A strength of this study is that McDermott and colleagues identified that music as a meaningful shared experience can facilitate shared emotions, which can lead to a connectedness between a PwD and a caregiver.

The second study on the impact of music on everyday life for people with dementia was a GT study by Sixsmith and Gibson (2007) of 26 people in various stages of dementia, where they explored music across a range of personal attributes, life contexts, and environments. The study included four persons living alone, 14 with a caregiver, and eight in a LTC facility. Musical activities were diverse from active (singing with others, playing an instrument) to passive (such as listening to the radio, listening to music with other people). Reflected in their findings was the universal positive effect music had on emotion, and with it, on interaction.

## Conclusion

The effects of music are multiple (e.g., verbal, nonverbal, psychological, emotive, relational) and interrelated (Dassa, 2018; Götell et al., 2009; Mandzuk et al., 2018). Verbal (singing, humming) and nonverbal (bodily gesture, facial gesture, eye contact) acts, become purposeful indicators of comprehension and expression via a musical dialogue, suggesting that they are indeed communicative (Ridder & Gummesen, 2015; van der Vleuten et al., 2012). The studies reviewed are indicative of a wide spectrum of effects, as verbal reactions and facial and bodily gesture become interconnected with and trigger emotions, memory, and the building of relationships (Clare et al., 2020; Garabedian & Kelly, 2018; Götell et al., 2000; van der Vleuten et al, 2012).

The triggering of memory by music contributes to identity, self-awareness, of a realization of being in the world, of having experiences, of being able to ground oneself in past

meaningful life events, each of which contributes to the maintenance and building up of communication (Baker et al., 2012; Dassa, 2018; Fischer-Terworth & Probst, 2011). Familiar music especially may lead to the triggering of a specific memory (Garabedian & Kelly, 2018), which may result in positive emotions (Götell et al 2003) and improved dialogue (Marmstål Hammar et al., 2010a) which, as a shared musical experience can be relational building (Baker et al., 2012; Dassa & Amir, 2014; Söderman & Rosendahl, 2016). To conclude, the effects of music on communication seems dynamic, integrated, and multidirectional, rather than hierarchical.

## Positioning my Research Question within the Literature

Though incorporating aspects of both formal and informal caregivers' experiences (including those of spouses), such as emotional responses, bonding, and relationship building (Allison et al., 2019; Clair & Ebberts, 1997; Dassa et al., 2020; Dassa & Amir, 2014; Götell et al., 2001), were identified in this review, there were no studies with a *primary* emphasis on caregiver experience. McDermott and colleagues (2014) in their study on perspectives of the influence of music on PwD and caregivers commented on the paucity of research in this area, stating that theirs was "…the first in-depth study on the meaning and value of music for people with dementia from the perspectives of these four groups" (p. 715). My study's findings are a contribution to this growing interest in the perspectives of formal and informal caregivers.

Only two studies (Clare et al., 2020; Sixsmith & Gibson, 2007) used a GT approach. Further, a paucity of GT studies with a focus on music and communication has also been identified in the literature. O'Callaghan (2016) in a review of 30 GT music research projects, noted the lack of research on the contribution of music to communication. Wall and Duffy (2010), in a review of 13 studies identified one study by Götell et al (2003). Beard (2011), in a

systematic review of art therapy (including music therapy), did not identify any studies with a focus on music and communication, and those that used music were focused "on biomedical products, such as reducing and managing symptoms, rather than person-centered outcomes, such as enrichment" (p. 639). He recommended the inclusion of subjective experiences and personal history to move research forward. This openness to the subjective and experiential is reflected in research on relationships and the shift of the focus of research towards the person and experiences shared with the caregivers (Baker et al., 20102; Dassa 2018; Götell et al., 2009).

My GT study is, to my knowledge, the first that focused on music and communication for PwD from the perspective of the experiences of caregivers. Being a "first" it was explorative, and as Stebbins noted (2001, 2006) an explorative study has the potential to generate new knowledge.

The development of a theory may help formal caregivers in considering new approaches in their practice, as well as support them in the challenges of facilitating communication for people with dementia, leading to better care through enhanced understanding of how they respond and communicate through music. For informal caregivers such as families, it may help them understand the value of their voices in their vital role as an informal caregiver, as reflected in the literature (Baird & Thompson, 2019; Dassa, 2018). For health professionals, it may provide new knowledge of how music can precipitate social and emotional bonding with the caregiver, how music may trigger memory, leading to meaningful interaction (Allison et al., 2019; Dassa, 2018; Marmstål Hammar et al., 2010b; 2018; Ridder & Gummesen, 2015).

# CHAPTER THREE: PHILOSOPHICAL AND CONCEPTUAL FRAMEWORK

In this chapter, I explicate my philosophical and conceptual framework through which I viewed the research question and which informed my study. This chapter includes my foundational beliefs in how qualitative research should be informed by philosophy, my positioning regarding ontology and epistemology, constructivism, the appropriateness of constructivism for my study and the concepts of music and communication as viewed through a constructivist lens. A summary concludes the chapter.

## Questions of Philosophy in Qualitative Research

Prior to, and during my research in the field, my philosophical positions gradually became clarified, and provided me with a logical foundation for my explanations as I followed the data, through inductive analysis, towards an emerging substantive theory. Given that I have developed fundamental assumptions on the nature of music from real-life experience, as well as extensive reading on the subject, it became imperative that I explicate my philosophical stance, as it has influenced my approach to knowledge and research. By doing so, I maintained transparent reflexivity as I proceeded on my research journey. As has been pointed out by Bryant and Charmaz (2007), and applies in my case, the choice of a methodology implies an ontological and epistemological stance.

My approach to the value of philosophy within qualitative research was nuanced by Lohse's (2016) suggestion that ontology is not a foundation *per se* of qualitative research, but useful to clarify and examine any ontological "assumptions in explanations" (p. 22). He contrasted two conflicting schools of thought within social sciences, the first as *ontological foundationalism* (that is, the qualitative researcher must state an ontological position which is also congruent with any proposed research), the second as *anti-ontological pragmatism* (that is,

ontological perspectives must be excluded from the research). Lohse suggested striking a balance between ontological foundationalism and anti-ontological pragmatism, proposing firstly that there is no determinant reason that a philosophical ontology must determine scientific research. Ontology, according to Lohse (2016), can be of service not as a foundation for the "extension of social scientific knowledge and explanatory strategies" (p. 22), but that ontology can at times be very useful in research to clarify "the relationships between different explanatory frameworks in the social sciences" (p. 22). Hence my position follows Lohse's pragmatism regarding the use of philosophy in qualitative research, where I explored music and communication without an *a priori* ideological restriction, but rather settled on a philosophical stance that considered both external reality and subjective experience. Charmaz (2014) noted that CGT as pragmatic accommodates a pluralistic approach to philosophical perspectives as equally valid foundations for a methodological route for researchers "from other traditions".

As both objective and subjective (Bruford, 2015), the complex reality of music led me to consider how to position myself ontologically and epistemologically. Taking a moderate constructivist philosophical position, it has been argued, reconciles personal, subjective reality within an objective external world (Hammersley, 1992; Schwandt, 2003). This is what I did. My ontological position influenced my decision for the selection of a GT methodology, and my explanations of data flowed from a constructivist epistemology.

## Ontology at the Service of Research

My philosophical journey began by asking myself what is the nature of reality which led to my ontological position. I hold that reality and knowing reality must have some grounding in the external and objective. I reflected on epistemology, and by extension, my research approach. My initial self-questioning was asking whether reality is knowable and how it is known?

I hold that music and communication are both real, knowable, yet subjective and both dependent on interaction, for example between researcher and participant. I felt a constructivist philosophical position was logical. Music ontologically is an aural narrative, yet it is also a plurality and even an amalgamation of such narratives, being interpreted slightly differently by each person. An objective musical world cannot be known, as the sense data of the music is actively and subjectively ordered by the mind (Bruford, 2015; Kant, 1781/2013).

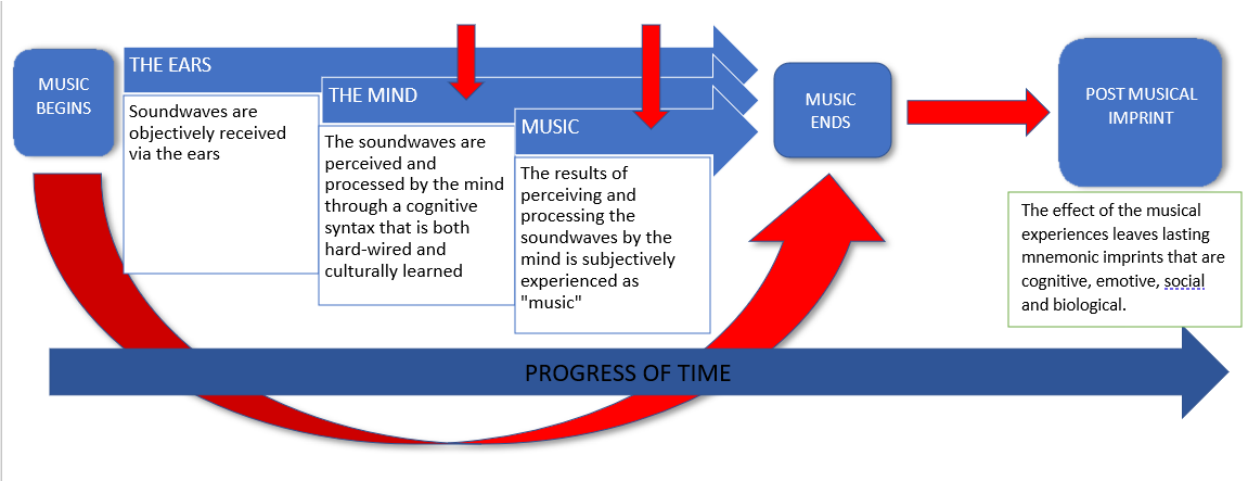
Ontologically music is a balance between what it is objectively (as ordered sound) heard in sequence, and how it is understood, emotively felt as it touches the human mind (Barenboim, 2016; Cross, 2014). The Russian composer Igor Stravinsky, in a reflection on the essence of music, wrote that "tonal elements become music only by virtue of their being organized, and that such organization presupposes a conscious human act" (Stravinsky, 1947, p. 34). Within this human act, each person determines what is beautiful and meaningful to them. As Sacks (2006) said, "all of us have had the experience of being transported by the sheer beauty of music" (p. 2529). This subjectivity emerges, as the human mind processes objective tonal elements into a personal language. As something of beauty, music becomes an aesthetic judgment and is therefore subjective (Kant, 1790/1987). Music being "everything" (PS Music Berlin, 2014) as the pianist and conductor Daniel Barenboim noted calls for an appropriate ontological and epistemological positioning by the researcher who wishes to explore it scientifically within GT (Holloway & Todres, 2003; Stebbins, 2001).

## Epistemology at the Service of Ontology

My second self-question was how do I come to know the reality that exists around me? The approach to epistemology determines the "bridge" between data and it being known by the researcher (Denzin & Lincoln, 2005). The considerations of Kant on this "bridge" between the

objective world and its subjective perception influenced my epistemological position. Kant (1781/2013) suggested knowledge is perceived and processed by the mind, via a hard-wired cognitive structure. Kantian epistemology was an approach to considering both empirical, external knowledge, with subjective, transcendental knowledge (Ameriks, 2005; Collin, 2001). From this perspective, the reality of music and how it is known is a fusion of both the external, the objective, and the internal, the subjective, via constructions of the mind (Armezzani & Chiari, 2014; Daniel Barenboim, 2016; Bruford, 2015). Sound is heard objectively through the ear and is subjectively experienced as music in the mind. (Figure 2).

Figure 2




## Constructivism

Constructivists hold that reality is perceived subjectively in the mind (Panterotto, 2005). Panterotto (2005), following Hansen (2004) defines constructivism as the philosophical position that "reality is constructed in the mind of the individual, rather than it being an externally singular entity" (Panterotto, 2005, p.129). Armezzani and Chiari (2014) contended that constructivism is not a radical rejection of external reality, but a philosophy that includes the following propositions: the retention of the real external world, the independence of the object

from the subject, and the acceptance that the object may be perceived in different, though equally legitimate ways by the thinking subject.

### Constructivism and Grounded Theory

Charmaz (2014) selected the term *constructivist* "to acknowledge subjectivity and the researchers' involvement in the construction and interpretation of data…" (p. 14), rather than being objectively discovered, with the researcher detached from the participants (Mills et al., 2006). A CGT approach regards the world of experience as knowledge that is co-created between the researcher and the participant (Bryant & Charmaz, 2007; Charmaz, 2014; Strauss & Corbin, 1994). Accordingly, reality "arises within a situation and includes what researchers and participants bring to it and do with it" (Charmaz, 2014, p. 13). Charmaz (2006) encouraged researchers to include in both data and analysis, "shared experiences and relationships with participants" (p. 130), where GT theory will be an "interpretive portrayal of the studied world, not an exact picture of it" (Charmaz, 2014, p.17).

In summary, my epistemological approach is congruent with the constructivist interaction that is sought between the researcher and the participants, and the primacy of the participants "voice" and "values" before "acts" and "facts" (Charmaz, 2014, p. 275), as the person becomes an active agent in the construction of the subjective reality from objective facts (Ameriks, 2005; Armezzani & Chiari, 2014; Panterotto, 2005).

## Appropriateness of a Constructivist Grounded Theory Approach

There is a rich history of research into music using GT, with partial and completed grounded theories ranging from the experiences of clients, music therapists, family members, and health care staff (O'Callaghan, 2012). My selection of a constructivist approach to GT was based on the evolution of my research question (Parr Vijinski, 2017), and an evolving

philosophical view of communication and music. Given the centrality of music in my research, I had to ensure that my method was congruent with my philosophy of music and communication. Music is not only an objective, external reality of ordered sound but also a profoundly personal experience (Aldridge, 2005a), and that this same experience in music is "an integral and necessary part of music" (Barenboim, 2006, para. 2). Barenboim's (2006) perspectives on what is music also helped clarify my understanding of music as essentially personal, always experienced subjectively.

> It is essential to understand that music is conceived of, and eventually delivered, point of view of one individual. As a result, subjectivity is an integral and necessary part of music. And therefore, the permanent relationship between subjectivity and objectivity is an essential aspect of music making, as it is of life (Barenboim, 2006, para. 2).

I selected an inductive, exploratory approach, as an appropriate method to explore my research question with an emphasis on what Charmaz (2014) calls "analyzing action and process" (p. 34). According to Charmaz (2014), CGT should "acknowledge subjectivity and the researchers' involvement in the construction and interpretation of data…" (p. 14). The unique experiences of caregivers in my study reflected the centrality of reality as subjective and interactive, a reality that in CGT is understood to be "within a situation and includes what researchers and participants bring to it and do within it" (Charmaz, 2014, p. 13). Also, as Lincoln and Guba (2000) noted, it is the research question that should drive the method selected of research. Both communication and music are temporal experiential realities that contain multiple actions and processes, such as: dialogue, gesture, utterances, speech (lyrics) that exist within time (Aldridge, 2005a; Pavlicevic, 2013). Barenboim's (2006) and Bruford's (2015) claims of

music's integral subjectivity confirmed my ontological position regarding music, as well as providing me with the key to realizing that a constructivist approach is more appropriate where theory is to emerge from data, driven by interactivity and subjectivity (Holloway & Todres, 2003). In contrast, a classical approach would entail the suspension of my ontological and epistemological stance for a detached, objective position and not constructed between researcher and participant (Glaser, 2005).

In my selection of CGT, I also considered two unique communicative aspects of music that reflect its subjective and constructed reality: "*floating intentionality"* and *"entrainment". "Floating intentionality*" is understood as music heard as similar to all listeners (we hear the same thing physical soundwaves) yet heard as a distinct personal sound (the idea that music provides a uniquely personal listening experience) (Cross, 2014). The intention of the music, so to speak *floats* before the listener, who responds subjectively to the external stimuli. The second aspect, *"entrainment"* may be defined as attention and behaviours of people becoming aligned with the music experienced. It is this aspect of music that is socially manifested. Cross (2014) referred to "*entrainment"* as "a sense of collective convergence" (p. 813) around the music. Both these concepts necessitate interaction between peoples and are therefore constructed realities. For example, in sharing the same musical experience leads to a shared emotional response, which can lead to further constructed interactions such as shared gestures, clapping, and nodding together.

**Music as an Inductive Experience**

It must be emphasized that music is primarily emotive and a lived experience (Aldridge, 2005a). Additionally, when experienced outside of solitary listening or performance, it is also communicative between persons (Aldridge, 2005a, 2005b; Ridder & Gummesen, 2015).

Considered in this manner, music with its own subjective and ambiguous syntax is open to inductive reasoning. A deductive approach to considering music would be prone to imposing meaning that would be heavy with quantitative considerations, such as tempo or structure. The logico-deductive harmonic analysis of music cannot be used alone to explore music which has "a unique power to express inner states and feelings" (Sacks, 2007, p. 300). Barenboim put it this way: "Music is everything at the same time...it always smiles and cries at the same time" (PS Music Berlin, 2014, 2:35). It is by being open to the "everything" of music, that a "tacked-on" explanation can be avoided, and "to forestall the opportunistic use of theories that have dubious fit" (Glaser & Strauss, 1967, p. 4).

## Conclusion

Taking account of my philosophical lens in approaching qualitative research and how philosophy should be used, as well as the objective, yet subjective experience of music, and the personal, dialogical nature of communication, a constructionist approach was a natural "fit" that followed the primacy of my research question and the evolution of my study. Communication and music are lived experiences within contexts, situations, relationships, and cannot be separated from subjective interpretation (Cross, 2014; PS Berlin Music, 2014; Sacks, 2007).

# CHAPTER FOUR: RESEARCH METHODOLOGY

This chapter provides a detailed description of my grounded theory methodology. I begin with a statement on my background and biases, in which I outline reflexively my role as a researcher, which informed how I conducted research. In my previous chapter, I explicated my philosophical positions and why I chose CGT. In this chapter, I outline and discuss the specific GT processes that provided the structure and direction of my research. This chapter will include descriptions and discussions of the setting, participants and sample, data collection, data analysis, ethics, and anonymity and confidentiality.

## My Role as a Researcher: Background and Biases

The use of GT, with its systematic approach to the collection and analysis of data (Charmaz, 2014), can provide the structure needed for a novice researcher, particularly a minimally studied phenomenon (El Hussein et al., 2014). This systematic structure enabled me to focus on the creative and interactive aspects of my research within a general guideline. I felt the iterative and inductive logic of a constructivist GT was a natural match for the subjective, inductive experience of music and communication as discussed in Chapter Three.

Before entering the field as a researcher and my PhD program, I was aware of my own biases and motivations, and came to an awareness of how I valued music and its influence on people's lives. My interest in how music might be used for communication for a PwD grew from my daily interactions with my mother, (who was diagnosed with semantic dementia) for whom I was her primary caregiver. I noticed that not only did music facilitate her communication and social engagement, but likewise her enjoyment of seeing the music performed. I discerned her fascination with the added stimuli of visual elements of watching a concert, rather than just listening to the music. These musical experiences became the genesis of an audio-visual

intervention called the *Audio Visual Musical Interaction* (AVMI). Initial findings, based on a preliminary case study, indicated that the AVMI warrants further exploration as an intervention for PwD (Le Navenec & Parr-Vijinski, 2015). This experience of using music for communication helped facilitate my journey towards exploring the use of a qualitative approach to music. In doing so, it also became part of my reflexive journey of being aware of personal biases and how they may inform research choices. Such awareness can ensure honesty with one's relationship to the research and audience (Tracy, 2010).

## Setting, Participants, and Sample

### The Setting of the Research

Participants were drawn from across Canada, primarily from the Greater Toronto Area (GTA), Ontario, and Calgary, Alberta. Due to COVID-19, the study was conducted online or using the telephone.

### The Participants

Participants consisted of formal caregivers and informal caregivers, both defined in the Selection Criteria section. I sought to explore the experiences of formal and informal caregivers in both institutional as well as in community settings. Amongst formal caregivers, a variety were sought who had the knowledge and practicum amongst PwD to provide a wide variety of experiences to best explore the research question. Amongst informal caregivers, I sought out family or friends.

### Selection Criteria

#### *Formal Caregiver*

1. Nurse (RN, LPN, RPN), certified music therapist (MTA, BC-MT), certified recreation therapist (CTRS), certified occupational therapist (CAOT), unregulated health care worker (e.g.,

Health Care Aide (HCA), Personal Support Worker (PSW).

2. The formal caregiver works with people with dementia using music.

***Informal Caregiver***

1. Family member or friend of a PwD (who has received a medical diagnosis of dementia).

2. 18 years of age or older.

3. English speaking.

4. Self-identified familiarity with the PwD's engagement with music.

5. Self-identified as having regular contact with the PwD (minimum one visit per month, pre-COVID-19). This applied only to informal caregivers of PwD in LTC facilities. In the community, informal caregivers self-identified as having regular monthly (at minimum) contact.

**Recruitment Strategies**

I recruited participants using purposive sampling. Professional organizations were identified whose members are involved in community and LTC settings and approached for recruitment support. Those who agreed were asked to distribute my contact information and a flyer to potential participants (Appendices A, B). Distribution strategies for flyers included an email "blast". I also engaged in "snowballing", which Bryman et al. (2009) described as involving using established contacts to establish contacts with others. I engaged in "snowballing" at the end of the interview, so as to separate "snowballing" from the dynamics of an interview, and ensure the participant was focused on the interview as well as removing any possibility that the participant felt pressured to help in recruitment.

I contacted potential participants by phone or email to explain the purpose, significance, method of the study, and to ensure inclusion criteria were met. If a potential participant still expressed interest in participating, a consent form (Appendices C, D) was emailed (or mailed if

the participant chose this option), and the appropriate Demographic Questionnaire(s) (Appendices, E, F). An additional questionnaire for PwD was also completed by a family member (Appendix G).

**Demographic Data of the Participants**

Table 1 contains information on the 13 participants who were involved in this study. The participants are documented in chronological order of their interviews. Nine participants were formal caregivers (six music therapists, three HCAs). Four music therapists were from Alberta, one from British Columbia, and one from Saskatchewan. Two HCAs were from Alberta, one from Ontario. Four participants were informal caregivers (three spouses and one daughter). The family members of the informal caregivers all lived in a LTC facility. Two facilities were in Ontario, one in Alberta, and one in the Yukon. The range of age of the participants was from 26 to 85. Work experience amongst music therapists ranged from 4 to 15 years, amongst HCAs from 3.5 to 16. The names were all anonymized.

**Table 1. Participant Information**

| Anonymized Name | Type of Setting/s | Formal Caregiver | Informal Caregiver | Focus Group |
|---|---|---|---|---|
| Johana | Community-LTC | Music Therapist | | |
| Northern Woman | Community-LTC | | Spouse | Yes |
| Tami | Community-LTC | Music Therapist | | Yes |
| Jen | Community-LTC | Music Therapist | | |
| Lena | LTC | Music Therapist | | Yes |
| Dinner | LTC | | Spouse | Yes |
| Ella | LTC | | Daughter | |
| Robyn | LTC | HCA | | Yes |
| Albina | Community-LTC | Music Therapist | | |
| Moira | Community-LTC | | Spouse | |
| Jane | Community-LTC | Music Therapist | | |
| Jay | LTC | HCA | | |
| Ava | LTC | HCA | | |

**Demographic Data of Family Members**

Table 2 contains data on the family members of the participants who were informal caregivers. The family members are documented in chronological order based on the date of the interview. With the exception of one family member who was diagnosed with early-onset Frontotemporal Dementia (FTD), all other family members had a diagnosis of Alzheimer's and were in their mid to late eighties. Interventions included sing-a-longs, live music, and music therapy within a group setting. All family members had access to music on a personal level in their room such as a CD player, iPad, or radio.

**Table 2. Family Member Information**

| Participant | Relationship to Participant | Age | Year of Diagnosis with Dementia | Type of Dementia | Current Residence | Types of Music Interventions in LTC* |
|---|---|---|---|---|---|---|
| Northern Woman | Spouse | 88 | 2019 | Alzheimer's | LTC | live music |
| Dinner | Spouse | 51 | 2013 | Frontotemporal | LTC | group singing |
| Ella | Daughter | 85 | 2015 | Alzheimer's | LTC | music therapy within group setting |
| Moira | Spouse | 88 | 2017 | Alzheimer's | LTC | group singing |

*As described by participants

## Data Collection

I collected data (due to the ongoing COVID-19 pandemic) from online or telephone interviews, and an online focus group. Hence direct person-to-person contact did not transpire. Though data collecting through a virtual setting (e,g. Zoom) does not generate the same quality as direct face-to-face contact, any limitations can be overcome with comparison to future direct contact research through concatenation (Stebbins, personal communication, October 17, 2020).

My data collection primarily flowed from the interviews and the focus group. Data was also collected from video observation, memoing, and field notes taken during and immediately upon concluding interviews and the focus group. Demographic Questionnaires also provided data.

**In Vivo Observation and Video Observation**

During interviews sessions that were conducted via Zoom, I engaged in observing the participant *in vivo*. The sessions captured the upper bodies and faces of the participants. In addition to observing nonverbal communication (e.g., body language such as movements of the head or arm, facial gestures indicating emotion). I observed for nuances and dynamics in verbal communication and how the two types of communication interconnected (e.g. increased vocal dynamics and emotion accompanied with words selected to reflect the emotive state of the participant). I*n vivo* observations were jotted in a notebook during the sessions and later transcribed as an electronic file. Any codes of the video reviews were entered into the video and replicated in the transcript along with the time of occurrence in the video. This allowed for reference between written data and visual data. Video coding followed was incident to incident, and I compared codes within videos and between videos, engaging in comparative analysis, for both similar as well as dissimilar incidents. Video reviewing allowed for a look at the data and transcript as it happened in time, providing me with new opportunities for memo taking.

**Field Notes**

Field notes consist of a written record of what has been observed: “a running description of settings, events, people, things heard and overheard, conversations among people, conversations with people” (Lofland et al., 2005, p. 112). They may be conjectures and reflections, but will remain part of the thinking process leading to emergent theory (Glaser & Strauss, 1967; Kenny & Fourie, 2015). Memos, analytical notes, and coding were undertaken as

data collection evolved. During sessions, I documented anything that I felt was significant, or an arising question, or any spontaneous idea in my notebook. They were then transcribed as electronic files. I developed the practice to ensure to have a notebook handy at all times to jot any ideas that I might be reflecting upon for further thought. A practice I developed from the outset was to engage the data initially by watching or listening (if only audio) to every interview in its entirety and take spontaneous field notes and jot memos. This enabled me to approach the data in an open manner and re-experiencing the real-time flow as each interview happened.

As I took field notes, I distinguished between what objectively happened and my reflections on what happened. My reflections and interpretive ideas became part of coding and memo writing during data analysis. During the process of conducting research, taking field notes were a source of inspiration for reflection and questioning myself as I developed memos and analytical notes.

**The Interview**

I approached the interview seeking the participant's reality and experiences, to be open to their assumptions and interpretations. The goal of a constructivist interview is to include not only the content of the transcript, but also the participant's tone, tempo, dynamics, flow, and responses (Charmaz, 2014).

Interviews were scheduled at the preference of the participant and took place from their home or office. I was in my home office. A total of 16 interviews (three follow-ups) were taken with average length ranging between 51:53 and 1:21:20 for initial interviews, and 17:18 and 38:33 for follow-up interviews. Fourteen interviews were via Zoom, two via telephone. Interviews were semi-structured, which according to Wuest (2007) usually involve "an overview question with some follow-up probes" (p. 251) to facilitate the participants to elaborate on their

answers. The *Interview Guide* (Appendix H) consisted of open-ended questions, following a structure recommended by Charmaz (2014, pp. 66-67), of three stages: initial, intermediate, and ending questions. For me, the interview guide provided consistency for questions across all participants. The formal process of each interview involved requesting permission to the interview and record it, reminding the participant of the voluntary nature of the study, the right to refuse and/or move to another question/s, and terminate the interview. I sought to avoid leading questions and to provide the opportunity for considered responses. This approach afforded me to remain open to the understandings and interpretations of the participants. My objective was to begin the interview in a broad manner (e.g. *what could make music a form of communication*?), to then move to the specific and contextual (e.g. *can you talk a bit about responses or non-responses to music*?), to the concluding, or drawing it all together question (e.g. *how might your views of music as communication be changed by your experiences?*). Upon completing each interview, I asked each participant if he or she had anything else to add or ask any questions. This, I felt created reciprocity and minimized any perceptions of a power structure.

My *Interview Guide* did not remain static, but as I gathered and analyzed data, I began to revise it, adding new questions that arose from emerging ideas, and from codes, concepts and categories that needed further exploration. As a result, I ended up with a "final" *Interview Guide*, that evolved dynamically, driven by the data (Appendix I). Additionally, the three follow-up interviews were driven by the data and analysis which called for elaboration or clarification.

Though an option existed for participants to have the interview divided into two 30 minutes segments, no participant choosing this option. Upon completing the interview, they were transcribed and checked with the audio/video recording for accuracy. I kept a notebook with me

during interviews to jot down any spontaneous ideas or questions that might arise. Upon completion of each interview, I noted any initial codes, wrote memos, and made reflexive journal entries. Further coding and memoing were undertaken during transcription, rather than at the end of a completely transcribed interview. This approach permitted my imagination to be free with a focus on creativity and discovery *at the moment* of analysis, rather than restricting myself to analysis after completing the full transcription.

**Online Focus Group**

A focus group is a form of qualitative data collection and analysis that involves an interview with a group of participants usually to discuss a central question or theme (Foyle & Timonen, 2015; Houser, 2012). Interaction amongst participants may contribute to new perspectives of how the participants see the issues (Foyle & Timonen, 2015). I decided upon the use of the focus group as it availed me the opportunity to seek data from a different perspective than the solitary interview, this time within the context of the dynamics of the exchanging of views between and with caregivers.

The focus group was conducted using Zoom, recorded, and transcribed for analysis. The video component was also reviewed as observational data and analyzed. I kept my notebook with me to jot any key ideas or impressions that emerged during the focus group. The focus group was one hour and twenty-three minutes in length, and the number of participants (see Table 1) was five. It followed a *Focus Group Interview Guide* (Appendix J) which consisted of open-ended questions. *A Focus Group Protocol* outlining its purpose and how it would be conducted was followed (Appendix K).

**Demographic Questionnaires**

Questionnaires were used to gain a basic understanding of the participants' backgrounds. A number of questions were designed specifically around exposure to, perception of, and usage of music. These questions were developed to provide an understanding of influences and experiences of music on the participant before my interviewing and/or engaging with them in the focus group. An additional questionnaire was used to obtain information on the family member of the informal caregiver. However, demographic client information was not requested of the clients of formal caregivers outside of the selection criteria. The reason was that, unlike informal caregivers, formal caregivers had multiple clients, and their experiences and reflections would reflect mostly that of the "collective client" which influenced my approach to the collection of demographic data.

**Theoretical Sampling and Saturation**

Theoretical sampling involves seeking data to achieve the properties for developing theoretical categories and emergent theory leading to theoretical saturation (Charmaz, 2014, 2015). Theoretical saturation is essential for a study to be both credible and rigorous (Tracy, 2010). Glaser and Strauss (1967) defined saturation as the "criterion for judging when to stop sampling the different groups pertinent to a category is the category's theoretical saturation" (p. 61). It emerges from theoretical sampling, which involves the simultaneous collection and analysis of data for the purpose of refining categories, and when no new ideas emerge to be added to the categories (Aldiabat & LeNavenec, 2011; Bryman et al., 2007). Theoretical sampling may involve seeking people, events, or information to develop and define categories. One guide in my approach to theoretical sampling was Corbin's (2017) suggestion to constantly question how concepts relate to each other, and what further data may be needed to develop a

category or concept.

I engaged in theoretical sampling through seeking fresh data to help me understand emerging categories and to answer questions that arose during data collection and analysis. As I began to identify that emerging theoretical concepts needed further qualification and exploration, theoretical sampling involved revising my *Interview Guide* to create new questions based on the emerging concepts that needed fine-tuning, clarification. In addition, three follow-up interviews were conducted with several participants where I thought new data was necessary to saturate categories. Finally, I continued to recruit participants until saturation was met. Saturation was achieved when I identified that no new theoretical insight was found in my data analysis.

**Triangulation**

Triangulation is "the use of multiple methods or data sources in qualitative research to develop a comprehensive understanding of phenomena" (Carter et al., 2014, p. 545). Its use increases the accuracy of the findings in a qualitative study as data is accessed from different sources. Charmaz (2014) suggested "data collection methods flow from the research question and where we go with it" (p. 27). I used method triangulation (interviews, a focus group, *in vivo* and video review observations), and data source triangulation (informal and formal caregivers).

When undertaking triangulation, I strove to be aware of how the different data are analyzed and weighted. I took care to identify similarities and differences in data analysis and synthesis, to see how different methods and sources impacted emerging theory. I avoided any arbitrary favouring of one finding over another, which would have led to inconsistencies and an obscuration of findings. As such, it is stressed in the literature that inconsistencies are to be re-examined, with the possibility that further research may be necessary for resolution (Bryman

et al., 2007).

## Data Analysis

### Constant Comparative Method

My role as researcher was to keep the participants integral to any emerging theory, as in CGT the participants are co-constructors of the theory (Charmaz, 2014). I strove to do this by being engaged in the open-ended interviews and the focus group. Central to grounded theory is the constant interactive process between data collection and analysis, which is a dynamic and cyclical process that encompasses all phases of GT, until the generation of a final emergent theory. As inductive and cyclical, it is an ongoing comparison of data to data, data to code, code to code, code to category, category to category, and category to concept (Charmaz, 2014). As data collection began, so did my analysis, which led me to review data, to the collection of new data and ongoing analysis, until I reached theoretical saturation.

### Coding: Initial, Focused, and Theoretical

Coding is the main method of analysis in GT, and, in the constructivist tradition is proposed as initial, focused, and theoretical. The first main phase of coding is open (Charmaz, 2014). This approach involves an initial engagement with the data in a quick manner, that is open to documenting action and participant perceptions and behaviours. Early open coding breaks the data up into segments for data-to-data comparisons. It is the initial stage of reflecting on process, the how, the why, the when, and the consequences. In this stage, I sought to be descriptive, seeking processes, patterns, actions that led to concepts and early emerging categories. I followed Charmaz's (2014) suggestion to go quickly through the data with a focus on the descriptive, noting actions, and processes. This helped to allow the data to inform me, rather than for me to try to read into the data my biases or assumptions. If anything stood out to me, or if I was reminded of another piece of data, I made memos that a potential concept or category might

be emerging. After interviews were transcribed, I would initially read them seeking any initial spontaneous codes.

The second main phase of coding is focused coding (Charmaz, 2014). This approach involved coding what I considered significant and frequent earlier initial codes. Likewise, my coding in this stage was linear but emergent, dynamic, and cyclical. As with initial coding, as I coded, I strove to be careful about not applying interpretations, motivations, unless supported by the data. With detailed observation (such as video observation) focused coding was used to analyze incidents, and incidents to incidents (both within and between interviews), looking for patterns that emerge within actions and settings. Focused coding helped me to delve deeper into the analyzed data leading from concepts to categories.

The third and final phase was theoretical coding, where theoretical relationships between categories emerge through analysis of the linkages between substantive codes (Charmaz, 2014). Mills and colleagues (2006), following Charmaz (2014), noted that constructivist coding, though analytical in written style should be "be evocative of the experiences of the participants" (p. 12). In doing so, the "visibility" (Mills et al., p. 12) of the participants is maintained in the emergent theory, thus reflecting the co-construction of the theory between researcher and participants. To realize this, I strove to reflect the voice of the participants by ensuring that my memo writing, journaling, field notes, and observations (*in vivo* and video review) were reflexive so to ensure clarity and truthfulness in coding. I sought throughout the entire constant comparative process of coding to seek any "ah" moment, in being open, flexible to participants' experiences and communication, and strived to create a fusion of voices between myself and the participants.

## Memo Writing

Memos are the pivotal core of analysis between data collection and drafting the research paper. “Memo writing encourages you to stop, focus, takes your codes and data apart, compare them, and define your links between them” (Charmaz, 2014, p. 164). Memoing became the process whereby I engaged with the data with thoughtful reflection, as well as spontaneity. Through memoing, I began the process of developing analytical notes and the filling out of categories. Memos served for comparing between data and data, data and codes, leading to codes and categories.

Charmaz (2014) emphasized that memo taking is both a record of the path taken during theory construction, as well as a type of intellectual map as to how this path was taken. I began memoing as I entered the field, jotting down ideas that came to me after each session; ideas from added reflections on sessions, or developing field notes I had written. I also jotted memos, as I reviewed videos and recordings of post-session. I ensured my memos were reflective by striving to ensure that participants’ voices were heard and to be transparent when interpreting the participants’ voices. During the transcription process, fresh ideas would come, which were added as new memos, complimenting the older ones. Memos were dated, to provide an audit timeline of how my exploration and discovery evolved and emerged.

## The Writing Process

The writing process, in GT, retains the iterative dynamic of inductive reasoning, hence it involves rewriting, rethinking, and revising throughout to reach a satisfactory outcome (Charmaz, 2014). The writing process became part of my analytical process. As Charmaz (2014) noted, “through writing and rewriting drafts, you can bring out implicit arguments, provide their context, make links with extant literature, critically examine your categories, present your analysis…” (p. 289). In my approach, I was aware that data analysis permeated the entire

process, including my drafts, which were reflected and revised towards the final iteration of my research.

## Ethical Considerations

Ethical approval for conducting research was obtained from the University of Calgary Conjoint Health Research Ethics Board (CHREB). Flyers were physically displayed at various locations, or distributed as an e-flyer received approval from a senior person of a LTC facility, private health employer, or professional association.

Participants after receiving information about the study (via a generic email) from a distribution list made initial contact with me either by email or telephone to discuss the study in detail and to determine if they wanted to participate. For those who agreed to participate, a consent form was emailed to them for electronic signature, or a hard copy mailed. Participants were made aware at initial contact that they could withdraw from the study at any time, and that their real names would not be used in any written materials. The right of withdrawal was reiterated verbally prior to every interview and the focus group. Participants also were informed that every answer to questions was valued and that they had the right to not answer a question.

I paid attention to reflexivity (such as journaling, memo-writing, and exploring personal biases and assumptions), transparency (such as an audit trail), and multivocality (seeking to hear all the voices of the participants). Documentation ensures a reliable audit trail that reveals how decisions and choices were made and is key to ensuring ethical qualitative research (Charmaz, 2015; McBrien, 2008; Tracy, 2010). I sought to reduce bias by journaling and not only during my research, but prior to it, through reflecting and writing about my views on music and communication in my academic writings, written doctoral exams, and in published work.

## Anonymity and Confidentiality

To assure anonymity participants selected a pseudonym. Their real names were only used on their Demographic Questionnaires, which are kept locked in a fireproof cabinet in a secure location at my home. All electronic devices (laptop and hard drive) were encrypted and password-protected, and when not in use kept locked in the cabinet. The University of Calgary Cloud server was used for all identifiable electronic data, other than interviews and the focus group recording, which were stored on my laptop and backed up onto an external hard drive. Data was made available to committee members upon request and sent in an encrypted format. A password to open encrypted data was sent either via a separate email or given by phone.

The Zoom focus group session did not have anonymity amongst participants, and they were able to see each other. Prior to the focus group beginning, all participants were reminded to keep confidential the identities of other participants and the content of the focus group. Upon completion of the study, University of Calgary guidelines will be followed that stipulate after a time frame of five years, all video and audio recordings will be erased, and field notes, memos, and any other writings destroyed by the researcher.

## Conclusion

In this chapter, I presented my background and a reflexive review of my biases, and the need for awareness of bias, particularly as I have been a primary informal caregiver. The remainder of the chapter contains details on the settings for my research, the population, recruitment, sampling, data collection, and analysis. I also integrated how a constructivist approach informed my data collection and analysis. A discussion of ensuring an ethical study, as well as reviewing issues of anonymity and confidentiality concluded the chapter.

# CHAPTER FIVE: FINDINGS

In this chapter, I present the substantive grounded theory that evolved from data collected from thirteen semi-structured interviews, three follow-up interviews, a focus group, and *in vivo* and video observation of the interviews and focus group. A constructivist interpretation suggested by Charmaz (2014) was followed to code and analyze the data. Data analysis was based on transcripts of the interviews, the focus group, memos, and any notes taken, such as field notes during *in vivo* observation. In addition to the traditional manner of reading the transcripts, video reviewing helped focus my coding, memos of the transcripts by allowing me to re-engage with the interviews and focus group as they happened in time. The findings have been categorized into one core category and three main categories.

The core category that emerged was *Communication through Emotional Connectedness* and its related categories of (a) *Relating with Others,* (b) *Memories through Music*, and (c) *Being in the Moment*. These findings addressed the primary question of this study: *how does music facilitate communication for the person with dementia (PwD)?* The findings also add rich details on the pathways of caregivers' journeys of understanding their experiences of the effect of music on communication.

This chapter consists of an introduction to the grounded theory, followed by the description of the findings. Quotations from the interviews and the focus group are used throughout the chapter to illuminate how the findings emerged. The chapter concludes with a review of video observation, serendipitous findings, and a short summary.

## Introduction to the Grounded Theory

My analysis of the data resulted in the conceptualization of a substantive grounded theory of how music facilitates communication for PwD. Data was gathered from the perspectives and experiences of formal and informal caregivers ("participants" as defined in chapter 4) who had engaged with music PwD in community and institutionalized long-term care (LTC) settings. To provide a general understanding of the substantive theory that emerged, a brief overview will be given of the core category, the main categories, and the relationships between them, which will be supported with excerpts from the data.

This grounded theory is conceptualized by one main core category and three main categories.

The categories are:

Main Category: *Communication through Emotional Connectedness*

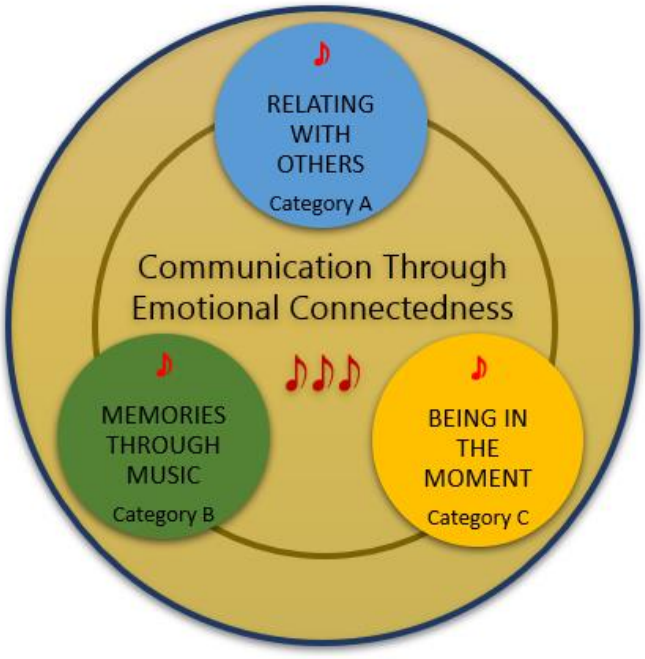
Category A: *Relating with Others*

Category B: *Memories through Music*

Category C: *Being in the Moment*

The relationship between the core category and the three main categories is presented in Figure 3.

Figure 3. *Communication through Emotional Connectedness*




The theoretical model as presented in Figure 3 reflects the centrality of the core category *Communication through Emotional Connectedness* and the integration of the three main categories. The diagram represents each main category within the core category, indicating that it contributes to the totality of the theoretical model. Additionally, the main categories are linked with a ring to indicate their interconnection, and that this interconnection reflects an aspect of the core category. For example, music being linked to reminiscing (*Memories through Music*) through familiar music (*Relating to Others*), bringing about a sense of awareness (*Being in the Moment*) leads to communication for a PwD. The core category is therefore the nexus of the main categories. The inclusion of musical notation for the quaver or crochet [♪] in the model represents the fact that music informs the categories, their interplay, and the resultant emerging theory.

The selection of "A", "B", and "C" to identify the main categories is not to be interpreted hierarchically or linearly; rather, the three categories are conceptual dynamics that emerged from

analysis, reflecting the unique way music can facilitate communication. For ease of interpretation (given that there are limitations to expressing a theory diagrammatically) for the visual reading of the diagram, I decided that each main category be of the same size, but this should not be interpreted as equal in importance. Human experience is unique, not reducible to one-size-fits-all; rather, each PwD would be influenced and experience aspects of the main categories in different ways in their journey into entering communication.

As reflected with my example above on reminiscing, each main category provided an essential underpinning for the emergent core category. I found that the process of making constant comparisons in constructing categories led through the three main categories to the emergent core category that tied them all together. The core category subsumes the main categories, providing them with an overarching conceptual understanding, whilst each main category, though related to the others and the core category, lacks the substantive conceptualization of the core category.

## Description of the Findings

A detailed presentation and synthesis of the findings is presented, following Charmaz's (2014) suggestion of providing a definition of the category, an explication of its properties, the conditions under which it arose, its consequences, and any changes. Its relationship to other categories will be presented after each category has been presented.

The findings of this study are that music facilitates communication for PwD through emotional connectedness emerging from an interrelated process of music facilitating communication that is built upon relating to others (Category A), the accessing of memories through music (Category B), and the PwD being in the moment (Category C). The main body of the chapter will be now presented, with each category defined and main findings from each

presented answering my primary question: "…how does music facilitate communication for the PwD"?

## Communicating through Emotional Connectedness

The core main category of "Communicating through Emotional Connectedness" is a dynamic concept that emerged as the substantive grounded theory. Being grounded in how music facilitates communication in PwD, it is a multi-faceted category. Fundamental to the core category is the emotive experience of music for PwD, which is the catalyst for acts of relating to others, to memories, and to being in the moment (as reflected in the main categories) enabling connectedness (both verbal and nonverbal) which facilitates their communication. As a product of an exploratory study, this grounded theory is amenable for concatenated research in a diversity of situations and circumstances.

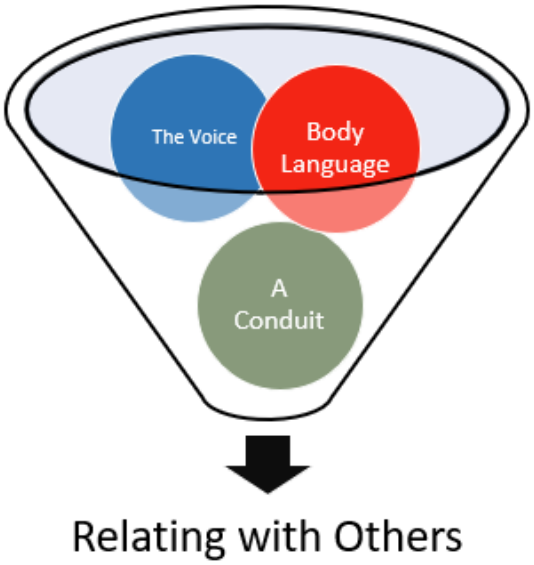
Emotion in the context of the findings means expressions of feelings, whilst connectedness means the process of connecting with another through the trigger of music. Both emotion and connectedness in various manifestations permeate the three main categories, as well as their subcategories. For example, emotion can be brought about through *Relating with Others* and *Memories through Music,* as illustrated in Jane's statement: "it brings about such emotion, which then is also tied to memories, which then brings on communication around different life experiences or different memories that came about…" Connectedness can be brought about by being *In the Moment,* which in turn is underpinned by the concept of connecting with another and entering the "moment," of making that communicative link. This is illustrated in PwD becoming much more communicative when being exposed to a musical experience: "And they'll talk and talk and talk. And the staff will say I've never heard that person speak that much in my life you know! But the music opens a door" (Johana). The core category emerged from, informs and is the nexus of the three main categories. The three main categories will be presented next.

## Category A: Relating with Others

### Definition

*Relating with Others* is the main category that is a conceptual synthesis of three subcategories reflecting some element that facilitated relating to the other and leading to communication by the PwD. The three subcategories are: *a conduit, the voice,* and *body language*. They emerged from either focused codes, or focused codes that were merged. Figure 4 illustrates the subcategories that informed the main category. The use of a funnel is to reflect the coming together of the subcategories to emerge as the main category of *Relating with Others.*

Figure Four. *Relating with Other*




### The Main Subcategories

Three main subcategories (see Table 2) emerged from the analysis: 1) *A Conduit,* or the use of music as a conduit for a variety of communicatively linked interactions, including shared experiences, 2) *The Voice,* or the centrality of the human voice in facilitating relationship, and 3) *Body Language,* or the use of the face and body as an indicator of non-verbal communication, including visual indicators and rhythmic reactions.

**Table 3. Relating with Others**

| Category A | Sub-Categories |
|---|---|
| Relating with Others | A Conduit<br>• Sharing Experiences<br>The Voice<br>Body Language<br>• Visual Indicators<br>• Rhythmic Reactions |

## A Conduit

*A Conduit* reflects that aspect of music that facilitates on the part of the PwD an aspect of relating to the other. Being a "conduit," or a type of bridge to and from the PwD was identified in the interviews and focus group. Ella noted, "It's a conduit. Something that can help us, as you were saying communicate, even though we're not saying much". During the focus group discussion, the idea of a conduit was raised as a 'kind of package.'" Lena observed that music "…comes in a kind of package. It deals with emotions. It deals with relationships and memories that are so deep-seated with the experiences of people." Responding to Lena, Tami said that using music was about "creating ways to communicate…families have to learn ways to build again some kind of bridge…and one of those ways to do that's through music."

The idea of a conduit was also identified as building a relationship through music leading to communication. The importance of being a conduit for such relational aspects generated rich data amongst caregivers who were also spouses. Moira viewed music as encouraging her husband to communicate with her: "Well, there's been times and in my relationship with my husband that music encouraged him to communicate with me. Because he would say 'Oh, I remember that. We went maybe to see a musical and that was the show.'" Dinner noted music as a conduit for "connection" with his wife Mona: "Our main connection is through music," and especially for emotions: "Music can touch like nothing else can." He then gives examples such

as: “It can pick you up. It can ramp you up. It can console…It’s allowed me to cry. Something that maybe I didn't permit myself to do…express my emotions that were bottled up.”

Northern Woman referred to music as central to being able to continue a relationship with her husband: “It’s fundamental.” She noted that when her husband listened to familiar John Denver songs that had lyrics that were relationship based, he was known to rub his thumb over a photograph of her that he carries with him. Northern Woman related: “So, he’d be looking at my picture like it’s on a piece of wood. And rubbing his thumb over it. Like over me kind of thing.” This rubbing “over” her, is meaningful for Northern Woman as an indication of an ongoing relationship that music plays a role in being a conduit for triggering his gesture of rubbing his thumb on her photo. The conduit, therefore, is very much an exchange of feelings and emotions.

Findings also included the idea of a conduit for emotional exchanges and continuing relationships and hence communication into late stages of dementia referred to as “the last thing,” up to “the end.” Robyn saw music, “being the last kind of one of the last things to be forgotten. So, I think that because they have this special access to music, it does allow them more communication than they might otherwise have.” Dinner noted: “…where I worry what will happen when she no longer can respond to the music. Where will that leave our; what will our relationship look like or the dynamic of that relationship?” He also saw music as being a “gift” and stated: “I think there will always be music, you know, right up to, to the end.” Northern Woman constantly expressed the belief that music was the connecting conduit that held her relationship together: “it almost feels like it’s the last thing we’ve got together with my husband. And the last way of connecting is through music. The last way of communicating, I guess.”

Music serves as a conduit to gain access to the PwD, where before communication was minimal or even nonexistent without music. For example, Robyn related an experience in which a client who was ambivalent about attending a music session began to open up to her after his experience:

> …well, I remember one time there was one gentleman, and it was like his first time at the day program for Alzheimer's society. And I came and performed. And afterwards he was really emotional, and he said, and he told me, "I didn't want to come to this and I didn't think it was a good idea I didn't want to be here, but I'm really glad that I did, because then I got to hear your music."

Familiar music, due to its being linked to long-term memory, can also function as a conduit for communication. One example of this was related by Jen who spoke of the experience of a client who not only began opening up to her, but linked his musical experience back to recalling his wife. The following passage documents her efforts to explore what her client liked, and then to use musical examples that eventually elicited more communication than she expected:

> So, I was trying to do an intake with this gentleman and the only thing he could say was "yes." Yes, yes, yes. I would ask questions: "Um, what kind of music do you like?" "Yes." "What kind of leisure activities you enjoy?" "Yes." That's all he would say. And I was like, well clearly this isn't working because he can't remember anything. He has no idea where he is, he has no idea what I'm asking him, so I was like, well out with the intake. We will have to call his family. Um, but I just started singing a couple of songs. I was like, he's going to start singing along to something and whatever he responds to that will give me an indicator of what his musical taste is. And it just so happened that he

> responded to like the country and western music that I was singing. I was singing a couple of pop songs, he wasn't really engaging. And then I started singing "Home on the Range" and he was right there with me, he was singing every single word. He knew all of them. And, at the end of the song he said, "my wife". And he said her name. "My wife so-and-so used to sing that song with me".

***Sharing Experiences***

*Sharing Experiences* emerged from the emphasis on music as a conduit for the sharing of experiences by PwD with their caregivers, thereby triggering communication. Sharing experiences that emerged from analysis would be more than just utilitarian experiences, but activities, exchanges, and interactions via music, that were seen by the PwD as meaningful. The interpretation of a shared experience as meaningful is identified by the indicators that the PwD conveyed to the caregiver. According to Jen, she looked for indicators such as "being expressive in your body language, facial expressions…encourage participation and communication from their end." Albina looked to see if any particular music they may enjoy is triggering a positive response that they share. Once she builds up trust, she will look for them to communicate "…a little more of 'Yes, this is good. No, I don't like this.'" Her objective being a relationship where "…they feel a little safer saying those things or communicating those things." The interpretation of a shared experience could be based on facial expression. According to Dinner, "But how do I know it's meaningful? When I see the joy on her face and I see you're kind of lit up and, and start singing, right?" He developed his perception of the meaningful sharing of the experience of "joy" brought on by music in the following terms:

> You know what? I don't need to converse with Mona. We communicate nonverbally. The hand holding, the singing, uh dancing, the being able to see her smile. That, that, that is to

> your question, that is communication. Because then that joy radiates. And I see that. And seeing that I would say absolutely that joy is a form of communication because she is telling me by her facial expressions, by her singing, by being able to recite the lyrics that it's meaningful.

Shared experiences as social engagement were noted within the context of groups settings. Albina gave the example of the response and increased interaction amongst PwD to "The Hockey Song" by Stompin' Tom Connors:

> I was doing a group of seniors; this was a number of years ago and it was that same situation I thought it was going be a really tired, lazy morning. And someone asked for "The Hockey Song" by Stoppin' Tom. And so, they kept pushing the tempo faster. Like they were stomping their feet; they were clapping their hands.

Such was the energy and reaction in her group that Albina said it nearly became out of hand due to various men recalling team hockey rivalries and communicating them with shouts. This occasion indicated how music can trigger experiences that are deep in memory and life events.

Regarding communication within social engagement, Albina also noted that for PwD many come from a generation that "…used to sing with their friends, they used to go to parties where they went singing together." Her experiences are that using music within a group setting can trigger inter-participant communication as they "are more willing to engage from that music perspective and build those social connections through that." Jane also noted music as being a shared experience for PwD came from their past histories of experiencing music in earlier life as "a relational thing." She further added that as "…a social thing for them whether they sang in a choir at church, whether they sang together at school, whether they were at a dance and, and so

it's quite a gift that almost immediately music brings about that social engagement," which "allows for conversations around those social experiences, which then often leads into more music." Johana also noted that group sessions result in her facilitating communication differently as compared to one-on-one. According to her, "the one-to-one experience allows for a little bit more, you know, you can really take your time. Give people a lot of time to respond right? And, and you can really take your time to probe and explore and, and find what, what works best for that individual person." In contrast, the group setting is more for creating:

> …opportunities for that social interaction and communication that can sometimes be affected when folks are, you know, lost in dementia. In, in just sort of their own, in their own, in their own mind…sitting in a room together and not really interacting.

A group musical setting can create a shared experience where PwD begin to interact. As Johana noted they are: "…in community. They are together." This feeling of community is reflected in, "… more often than not, you know, you see incredible engagement in the group setting." She looked for changed responses to indicate to her "to select a different piece of music. Perhaps I need to select an instrument. Ah, you know perhaps I need to change my tempo, or my volume, right?" Her objective during such sessions is to create an experience through the music with responses, looking for emotional expressions through body language as a guide for her musical interventions:

> …when I see smiling or even you know someone becoming tearful, having an emotional response. Um, you know when I see somebody, when I see affect into you know, indicates um, you know, almost contemplation or people begin to sing along, or um, you know a slight turn of the head, you know, little things that indicate: oh I'm listening, I hear you, I'm with you, this is affecting me in some way. Um, and you know sometimes

musical interactions, especially with instruments; um, with this population just elicit laughter.

Shared experiences within communication were experienced by PwD in a wide variety of ways. From a music therapy perspective, the therapist also seeks to attune themselves to share the experience with the PwD. For example, Lena noted that "I as the music therapist can really attune to their musical preferences, their emotions and try to guide the session that way." Within the context of a group setting, Robyn noted that for her she was able to use music to not only connect herself as the "performer," but also noticed that the participants in her group would begin connecting with each other "in their shared experience of the music." This was particularly noticeable through such visual cues as people singing together. The result of this is to strengthen and enhance communication between the PwD and the caregiver.

Finally, music as a shared experience can be the basis of a far more intimate communicative experience. An example would be Northern Woman's comment about Albert being there: "…he was there, he showed." Northern Woman saw these shared musical experiences on the level of connecting to her husband's "essence." She said: "…in that moment, I'm connecting to the essence of my husband. And it's, and it's, it's such a good feeling. That you know, that's when I leave the visits in tears. But I know like he was there, he showed. Um, it was wonderful."

**The Voice**

The second conceptual subcategory of *Relating with Others* that emerged from the findings is *The Voice*. The human voice is the medium of conveying music as used for song. For PwD who only engage with a word salad or do not speak, the use of the voice in song can still provide them with a way to communicate. As Tami stated:

> Often our clients with dementia, who don't speak will sing. And even if it, if there is some version of word salad it might be that they know the rhythm and the melody. But the only words that come are "bar da," right? And we know, then that, that is perhaps familiar and it might be that they just can't find the words for it. But it is something that is somewhere inside them.

Music provides PwD a way around using the voice for speech in communicating. The use of music as song on the other hand, opens up options for them to vocally connect and communicate. For example, Jane noted: "[they] can't have that regular verbal communication conversation, but musically can sing along to all sorts of songs and so now there's that vocal connection and communication happening through, through the song lyrics and sharing that together."

The voice, especially a familiar voice, adds to the emotional connectivity between the caregiver and the PwD, which can then enable communication. For Jay the voice is "…incredibly important." According to Johana, "the voice is very important…the voice is huge." The use of the voice in achieving communication is viewed by Jay as "…sort of like, it's like, it's a body language with your voice, right?" Johana noted the importance of the voice within her music therapy practice for achieving communication where "…the voice is important because the way we use our voices with this population is often to encourage. Encourage the folks we're having musical interactions with to use their voice."

The intimacy of the voice to elicit emotional connecting leading to communication was also identified in the findings. For example, according to Jane, the singing voice is "actually a really intimate form of communication," which has enabled her to connect more closely with her clients:

> It really allows people to connect soul to soul and human to human because it is a vulnerable part of someone to share their voice with another human being. Whereas if I'm clapping that's not near as vulnerable as me opening up and singing something to someone…

Robyn, who is also trained in opera, considered the human voice as a conveyer of "primal" emotions, as operatic technique employs the use of the diaphragm in singing, analogous to the use of the voice by an infant. This informed her view that "we just really respond to the human voice instinctively," including PwD who continue to respond to the human voice. According to her, when PwD engage in the manipulation of the "tone of the voice" they may be expressing "communicative elements." She gave the example of the tone of the voice communicating in her client: "And then I could see that at some point in her the story, or what she was telling me had changed. And now, you know, her expression was showing you a more, you know, serious emotion or tone of voice was communicating that as well." Another example of responding and interacting with the human voice to elicit communication from PwD was playfulness. Johana noted that, "one of the things that elicits the strongest response with this population JPV, is playfulness. Because at every age and stage, people learn and communicate and express themselves by being playful." Tami referred to her use of her voice in a playful manner to encourage PwD to communicate:

> I might do things with my voice where I sort of inject, like perhaps more exaggerated pitches to the song, or use my eyes, my facial expressions to communicate a little bit of playfulness with them.

Johana added that many PwD remember the voices of popular singers from their generation. “They remember Bing Crosby’s voice. They remember you know, Judy Garland's voice, they remember Elvis’ voice.” Such remembrance makes the musical experience a meaningful experience, facilitating communication by expressing via verbal or nonverbal indicators (such as smiling and tapping) engagement with the music and the caregiver. In contrast to the recorded voice, using the live voice brings an additional dimension of human contact, that recordings do not have, that can involve communicative spontaneity and improvisation with PwD. For instance, Johana noted that “…there can be a little bit of spontaneity, I can play around with tempo and rhythm, and I can, I can drop out and stop singing to see if they’ll fill in the blank. Which often folks will do.” She sees her voice as a tool to encourage PwD to use their voices in what she refers to as a “conversational communicative experience” involving mirroring, matching, and extemporizing. An example that Johana related is from the Elvis Presley song, “Love Me Tender.”:

> So, if for example if I was going, “*love me tender, love me sweet, never”* [singing] and I would stop singing and often the person I’m with would say, “*let me go”* [singing]. And I would say, “*you have made my life complete”* [singing] and I would look at them and smile and they’d say, *“and I love you so”* [singing].

The effect of this is a communicative back and forth. As Johana added, “…you speak, I speak. It’s, it’s that back and forth experience…” Communication evolves through the musical exchanges via the voice: *“*I can have this interactive moment. I’m connected, we’re connected right now. We are communicating, we’re sharing something right now.”

In sum, my findings show that the human voice is both a medium of communication by PwD, especially through music, and a flexible tool that caregivers can use to elicit various

verbal and nonverbal communicative responses from PwD.

## Body Language

*Body Language* is the third conceptual subcategory of *Relating to Others* that emerged from the findings. This subcategory subsumed an array of codes that involved the use of any part of the human body to indicate communication. Findings include the important role that the body, including the use of the face and eyes by PwD in responding to music and relating communicatively (including expressing emotion as an indication of making a connection) with their caregiver.

### *Visual Indicators*

*Visual Indicators* that emerged from the findings were body language indicators such as bodily gestures, positions, facial expressions, and the use of the eyes. How PwD responded to music, such as smiling, the use of their mouth, their eyes, hands, even dancing, was identified as an aspect of communication. Observation by caregivers was key to identifying communication. Tami looked for physical indicators that might be indications of communication:

> So that I look for movements. I would say maybe in the face that are more communicative. Whether that be in the mouth or the eyes. And then if there isn't much in the mouth of the eyes I might look for hand movements.

When she engaged her clients with music to determine communication she would:

> …study their face and their eyes…their mouth… see if there is even like that little tensing around the eyes for certain kinds of communication. Or if their hands come closer to me when I came closer to them… because I have to consider also what their visual field is like…we kind of look to the feet. Because if there's no response in any other part of the body, odds are their feet are going.

The feet were also brought up by other participants as an important indicator. According to Jay, PwD may not show any signs of response or engagement to the music except through their feet: “Somebody might not be singing along, and they might not even look like they’re paying attention, but if you look at their feet almost always you’ll see it, right?”

Looking for visual indications of cognitive and affective states were also determined by observation that would then inform the musical approach to the client. According to Jane:

> I come in and they’re in an agitated state and their body is communicating to me that they are frustrated, or I am anxious, or I am, you know, needing to move. And I see that being communicated in their body language. So, I might come in and I feel like if I came in and immediately met them in a different space in terms of how I would match that music, they might not feel that connection.

Through using music, she sought to match any possible movement, such as tapping or rhythmical responses to achieve nonverbal communication because according to her:

> …the music has maybe captivated and drawn them in. Because it’s often a motivating source and often something that they can relate to on many levels. It often speaks emotion on many levels and can draw and meet people where they’re at and draw them into something different.

Lena also related how she studied body language and the response to music to determine interaction:

> Yeah, I look for, for those physical responses as well. Perhaps you know if, if somebody’s not showing it on their face, they’re tapping their feet, are moving their, their finger to the beat of the music. Or kind of swaying back and forth.

The eyes were also identified as indicators of response and communication by PwD. Jane described this as, “you know, there’s lots of moments of connection there, but then when the music starts there’s often, particularly people with dementia, there’s often, you know, that awareness that kind of shines in their eyes, a bit more deeply.” Northern Woman spoke of eye contact for communicating, which then led to bodily swaying to the music during her singing to her husband a hymn that he was familiar with. Demonstrating with her arms by swinging them back and forth she stated:

> And he’ll be following me and I just sing it over and over and he’s coming along with me and we’re looking at each other’s eyes. He’s checking my lips, and you know, I’m sort of smiling. But we also often, I, I move, I keep moving. I can’t help myself.

According to Jen, the use of the eyes can convey engagement and focus on the caregiver by the PwD:

> You can tell that they’re engaged. I can see that they’re looking at me, they’re focused. And then I can use the music to be like, “Hey, I'm here. I know that you like this. I’m going to socially engage with you for a while”. We should make eye contact. “I know you can’t move your body. I know you can’t speak to me, but I can see in your eyes that you’re engaged”.

Facial gestures, including the use of the eyes, were also identified as indicators that could indicate a desire for mutual engagement or the expression of emotion towards the caregiver. Robyn gave the example that making eye contact with a client can indicate you are listening to them, communicating with them:

> And of course, I didn’t understand a word, but I just, I sat with her, I engaged, you know, with her. Eye contact, right signs of listening. Um, and I interpreted her, her the

> emotional content of what she was saying. And I sort of interpreted it to the best of my ability, what I thought she could possibly be talking about and responding with positive attention and trying to you know respond appropriately to the emotion.

Communication through facial gestures called for "different responses, during different types of musical interactions" (Johana). In her experience, facial expression, the expression of emotion is a vital factor between herself and the PwD to build communication:

> …I think those are absolutely critical to how we communicate and in particular with this population. You know, maintaining a calm and genuine and somewhat neutral effect as a provider. As, as, as a therapist, it is important because it leaves space.

Leaving "space," allows her to be "…attentive with this population when I'm delivering any kind of musical intervention or facilitating any kind of musical interaction." Her approach is to use her face to communicate to her clients that she is listening, which usually elicits a communicative response back, such as visual gestures:

> A lot of small smiles and nods. Mm mm hm [demonstrates] that kind of, you know, really communicated reinforcement…just keeping my face very relaxed, very calm. And as I deliver the musical piece and we interact musically, I respond to their affect accordingly. So, if they smile, I smile back at them….so if someone is frowning or, if someone looks angry or agitated; if I can see that in their affect or their body language, then I know that I need to make a change. I need to shift what I'm doing perhaps I need to select a different piece of music.

Finally, the value of facial expression for communication for PwD was noticed due to the COVID-19 restrictions that required masking thereby inhibiting the reading of the face. For PwD facial coverings were seen as inhibiting their ability to read facial expressions with the result

making communication more difficult. According to Jen she only had "…a third of my face left, this is part of my facial expression. So, I'm, I'm losing some of that. So yeah, I can be extra expressive with my eyes and eyebrows but I'm losing my smile which is hard." Her method of working around this restriction was having a small headset with a little mic inside her mask which amplified her voice: **"…**just so they can hear me better." But she noted that to compensate, she had to use much more gesture and body language of her own. "But it's just so; it's a lot more body language." Northern Woman in her first month of resuming visits with her husband was masked. However, she said that she began to remove it for short periods, because as she said, "…all we had was our eyes." Ella commented that masks were "limiting," giving the example that "…she smiles even when I'm masked, but not as much." Jane noticed that "it's been hard reading, you know, some of the facial cues for sure," limiting her ability to read the facial expressions of her clients.

***Rhythmic Reactions***

*Rhythmic Reactions* emerged from the findings as expressions manifested through part of the body (e.g., tapping, nodding, moving a foot, arm, or hand) responding to the beat of music by PwD and indicating communication. Jay referred to the beat as "…one of the most important parts of the song." According to him, "as people we sort of cue into those beats and tap along." Robyn spoke of the value of a "really good rhythm," that can induce a person to move to it. She gave the example of a man who threw away his cane to dance to a piece of music:

> …when I first met him he was, you know, very frail and he had a cane, and he was sitting in his chair. He's very, you know, kind of curled into himself into this chair. I put on, I can't remember, I think an Elvis song or some; one of these like 50s dance tunes. And it was like a transport, he kind of, he stood up. Basically, you know; threw away his

cane and he was dancing like he was 20 years old, again. It was amazing.

Rhythmical responses can become synchronized and cause entraining, which can indicate a sense of connection between the PwD and the caregiver, indicating communication. Albina noted that her approach to synchronization and entrainment is to work with a group for about 15 minutes to get her clients: "…firing on the same beat as everyone else. And that builds a sense of connection, I find." She expressed her experiences following rhythmical music sessions improving communication this way:

> …sometimes getting out at the end of sessions can be really adventurous because they're excited to tell me all these stories about the songs they heard…so they are a lot more interactive and engaged after versus before when it comes to communication.

Lena, in her practice, also entrained her clients in group sessions through the rhythmic use of the guitar to achieve a steady group beat to synchronize bodily responses to the music leading to communication that was also expressed as social communication amongst her clients. She demonstrated for me by playing staccato chords on the guitar in a rhythmically steady 4/4 meter. Her experiences of the effect of rhythm upon her clients include:

> …sometimes they are looking at each other and laughing at each other…sometimes they are focused on me when I'm doing, you know, big gestures like [plays the same steady rhythmical staccato chords in 4/4 on the guitar] like that. And they try to follow along. And so that way of communicating I guess musically with my head, with my body.

Another finding related to rhythmical reactions was dancing. A number of participants mentioned dancing as part of communicating together. Northern Woman spoke of "hand dancing" where:

> …my husband and I, we would be singing with our hands together doing movements. And sometimes I would just watch and then he would change to what movements we were doing. And then I would take the lead and then he would take the lead. Almost like sort of some kind of dancing. But that to me was also like touching. Like we were, we were connecting through the music but we're also connecting physically, visually.

Dancing seems to be deeply engrained in long-term memory. When long term memory is triggered through music (and dance), it can enable the PwD to reach back to meaningful events and express them communicatively. Moira mentioned how her husband reminisced and brought up dancing with her after listening to music with her:

> And he said to me I guess two weeks ago, "Do you ever think we are going be able to dance again?'" 'Cause we loved dancing. Now he's just learning to re-walk actually so I don't think there will be. But I, I can see him, you know, if we're playing certain music he might try.

Dinner likewise spoke of how he and Mona dance when he visits her: "Now when I come into her room it's almost like she will take, you know, she, she'll want to put my arm on her back and have my arm on her shoulder…we'll get to the singing and dancing." He also spoke of how Mona at times would also initiate the dancing while out on a walk:

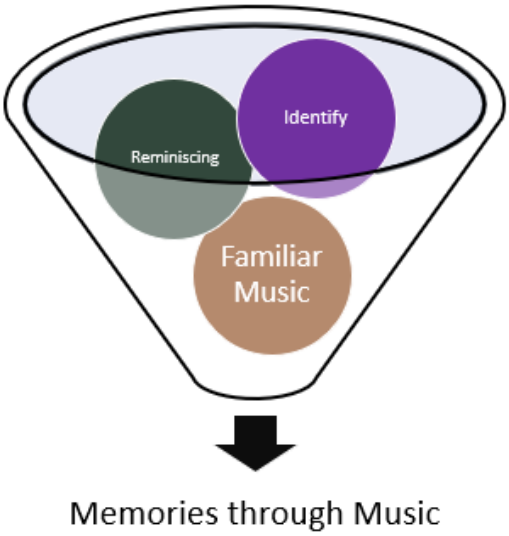
> Usually, it's me. Um, sometimes she'll want to. Like sometimes I'll just take her hands like that and just kind of move her like that. And then right away she puts her, her arm on my back and then will take my hand. And then will just kind of slow dance. Like that's as much as we do…I'll just slowly take, twirl her. She'll go underneath and then I'll bring her back. And that. So that's pretty much it.

## Category B: Memories through Music

### Definition

*Memories through Music* is the main category that is a conceptual synthesis of three subcategories reflecting some element of music that facilitated the triggering of memories in PwD leading to communication. The three subcategories are *reminiscing, familiar music, and identity*. They emerged from either focused codes, or focused codes that were merged. Figure 5 illustrates the subcategories that informed the main category. The use of a funnel is to reflect the coming together of the subcategories to emerge as the main category of *Memories through Music.*

Figure 5. *Memories through Music*




### The Main Subcategories

Three main subcategories (see Table 3) emerged from the analysis: 1) *Reminiscing*, in which music was seen as a trigger for memories that facilitated communication, 2) *Familiar Music*, or the use of familiar music to trigger memories leading to communication, and 3) *Identity*, or the awareness of the self by the PwD which enabled or enhanced communication.

**Table 4. Memories**

| Category B | Sub-Categories |
|---|---|
| Memories through Music | Reminiscing<br>Familiar Music<br>Identity<br>• Cultural Identity |

**Reminiscing**

*Reminiscing* is the first subcategory of *Memories through Music* and can be defined based on the findings as communicative acts by PwD that were triggered by memory recall brought about by the stimulus of music. Jay noted, "I feel that the effects of music on eliciting memories, it's fairly well documented…and how important music is into eliciting, eliciting memories." Johana approached musical memory based on neuroscience to then extrapolate the implications when used within music therapy for PwD:

> …musical memory is stored in some of the most protected neural circuitry like those, those most protected areas of our brain in the same place that controls our nervous system, our musical memories live, you know, and I think that that really speaks to what sets music apart it's, it's the way that it affects people. And the way that you know, music as a tool and as a therapeutic medium is just so easily translatable across populations right? Whether they're clinical populations, right? Like across pathologies, but across like communities and contexts as well.

Music was seen to trigger verbal reminiscing about past experiences. For example, using music for memory can take PwD "somewhere else" (Lena) allowing them access to meaningful events from long-term memory. Lena gave the example of how she used a song to induce recollection resulting in communicative verbalizing about the past:

> I play a song and somebody might say, ”Oh yeah, I have to go to the farm today,” or “I’m meeting my sister.” Um, things like that, that means, you know, they’re telling me that they’re thinking about, um, their home on the farm or, or their family members.

Using music to facilitate communication may include trying to bring back a past memory for PwD. Lena noted that she would see her role to facilitate communication in:

> …trying to bring that experience to them and they relay back to me whether you know, in their movements they’re dancing. In that previous experience, or they are, you know, singing along, in that previous experience and they communicate that back to me.

She gave a concrete example of reminiscing, recalling working with a client where she sang “She'll be Coming Round the Mountain,” and this caused her to remember her past life living in the mountains and riding a horse. The session included “…trying to grasp her tone of voice and trying to put together words um, and connect some of her, her, her thoughts. And then I kind of relay them back and she’s like, oh yeah right, that’s, that’s what happened.”

Other examples of reminiscence by PwD could evolve from their spontaneous mnemonic reactions to music. Johana noted how she would engage clients either through their visual indicators reacting to familiar music within the context of a familiar recording: “…they often, you’ll see them close their eyes, and it’s like they’re lost in memory because every piece of that pre-recorded song is predictable. They can predict what the guitar solo is going sound like.” Pre-recorded music was noted to provide PwD a familiarity open to reminiscing, which in turn opens the possibility to establish and develop communication:

> …that familiarity and structure and so that; I use that very purposefully in therapy often. I would pair it with an image. We would look at an image and listen to a familiar song and, and we would reminisce. I would ask open questions: “What does this song mean to you,

> what do you think about?". Or, you know, I'll ask questions, you know: "tell me about, you know, I notice you singing along. Did you sing a lot growing up? Was music a part of your family life?" (Johana)

Reminiscing can go back decades. Jay gave the example of a man who would recall his teenage years in California every time The Beach Boys were played:

> …every time I turn on The Beach Boys, he has something to say about his teenage years of going to California…it's just remarkable. I remember one time, the first time that I played it, he said all that, and he went off on this sort of 15-minute harangue and he even went, you know, he could name the people that he went with. And, and some of the interactions with the ladies that he had.

Johana gave the example of a man being triggered to reminisce about his job in the Middle East after hearing an Elvis Presley song: "He said 'Oh, that on the radio when I was in Saudi Arabia,' ha, ha [laughs]. "What were you doing in Saudi Arabia?!" He said, 'I worked there.'" Jane related how using music may stimulate reminiscence based on "where they're at in their stages." Some may just nod, while for others it might "then lead into beautiful discussions" with recollection such as "…I used to plant a garden, and in our garden, we plant tulips, and then go into singing about tulips. And so yeah using that music to come and kind of meet them where they're at and then take it further from there."

Music was also found to trigger memories that had strong emotional content for the PwD. Robyn noted: "Often it has like an emotional significance for them. Um, you know memories that are associated with that particular piece." She then gave an example, "I think I had one client who their, you know, their parents always love to play that song. So, reminding them of their parents." Albina gave the example of a bedridden client who might speak one or two-word

answers “on a good day.” Having consulted the family, Albina began using her client’s favourite artist from her youth, Elvis Presley, and related how her client reminisced:

> Albina: And she couldn’t remember that Elvis was her favourite artist, but as soon as we started playing *Love Me Tender*, she could connect with that song. And she would remember singing that to her daughter and her two sons. And if they were in the room, she was often; they were able to ask the right questions of like, “Oh well, you used to sing this to me and then we would do this.”
>
> JPV: Mm hm.
>
> Albina: And she would be like, “yeah,” and then we would also do this, this, and this. And being able to kind of pull up that song that she had sung her kids as a lullaby was able to give her more memories of her kids.

Another finding was that reminiscing could become a dialogical two-way street. This shared reminiscence was noted by caregivers who were family and as a result, had a long intimate connection with the PwD. In such cases the effect of music triggering reminiscence in a loved one resulted in a mutual triggering of the shared memory in the caregiver facilitating a more emotive, meaningful communication. For example, Moira stated: “Well for me, it brings back memories. Um, it gives me food for thought. For me, it’s a form of medicine, actually.” She added, “Well, there’s been times and in my relationship with my husband that music encouraged him to communicate with me. He would say, ‘Oh, I remember that.’ We went maybe to see a musical and that was the show.” The effect of her husband reminiscing makes her happy, though she is ambivalent if it does the same to him:

> I really can’t tell if it helps him. But it makes me happy that he remembers. So, to me that means that he enjoyed music, which I knew he did, and that, you know, it’s helpful. It’s

helpful. Like he doesn't come out the way he says things sometimes. But I personally can see that he enjoys it.

Dinner noted the effect of music on Mona and then on himself as a result of its effect on her when it triggers memory:

JPV: So, the music is also a way of sharing, returning to memories?

Dinner: Oh, oh my goodness. Absolutely, absolutely!

Dinner added "…that's the beauty of, of music. It is at a moments notice, you don't know. And that's why I love this routine with her".

Regarding himself he stated:

And it can trigger memory, it can trigger. I mean there's been times where I've been out on that walk with her and, you know, um I'll have my sunglasses on and, and I mean just welling up the tears because it brings back such good memories.

**Familiar Music**

*Familiar Music* is the second subcategory of *Memories through Music* that emerged in the findings, and can be defined as music that is familiar to the PwD and that this familiarity is expressed through indicators of communication, both verbal and nonverbal. According to Albina people are by nature musical, and that sense of musicality grows throughout life:

…we're musical from before we're born. So, we're already built to encode music and we're built to learn music and everything like that. So, when it comes to music things that songs that connect to important parts of our lives are going to stay with us. They are going to get encoded really deeply in our brains.

This encoding of music in the person in early life determined her approach to PwD by using music that became familiar to them early in their lives. As Albina recounted:

> …it's been shown, they've done studies, I think it's between 12 and 25 are kind of our big years. Because there so many changes during that parts of, those parts of our lives. And those songs… get deeply stuck in our brains…So a lot of the music I do with my seniors is stuff that was popular between those ages of 12 and 25.

For PwD there is a long history of the efficacious use of familiar music, which was reflected in this study. An example would be Jen's comment:

> And that's really important with music in this population, is that you're playing preferred music. There's been so many studies done on not just with music therapy, even just with music listening on the effect of preferred versus non-preferred music.

The reason being is that "preferred music is so, so important because it, it starts to connect some of those pieces for them that they can't remember on their own anymore" (Jen). Consistent with the above justifications for using familiar music, my findings in this study also found that the common experiences of the caregivers were that familiar music due to its triggering memory, also facilitated communication in PwD. Music from early life was consistently referred to as triggering memories. Ava stated: "I believe that if you put on music, say you were listening to in the 50s and that triggers some kind of a memory of, you know, going to dances or whatever. So, I really feel that these any kind of melodies, tones could very well trigger some memories to them." Regarding familiar songs triggering communication, Albina's experience with PwD was "…they remember the words, they remember the melodies, and they're able to pick them up really quickly when we're listening to them." Moira also mentioned how her husband would be able to recognize pieces of music and begin verbalizing by even

calling out the title during music group sessions:

> They play, like "Fiddler on the Roof", and she'll say, "which song is this? What's this one called"? Now Larry, I would say 75% of the time, could recognize the piece. And he'd say, "Oh, you know," and he'd give her an answer. And he really enjoyed that.

Familiar music can be identified by looking for some indication of recognition from the PwD. Tami stated recognition should be within seconds for songs that have been relevant to a person over decades:

> And so when I choose that music I'm looking for some sort of instant recognition. So within 10 to 15 seconds, I want to see the bobbing of the head. A smile, a patting of the knee. So maybe some eye contact if that person is capable. And then if I'm not getting that within 15 to 20 seconds, then I switch to something else.

Familiar music was also seen as a type of "conversation" between the PwD and the caregiver. Jen likened engaging a client with familiar music "in the same way that I might sit down with a friend and have a conversation: 'How are you doing, what have you been up to this week?'" She gave the example of using a drum and giving each participant in a group session a mallet to use within the context of singing a familiar song. Communication was achieved by taking turns amongst the clients with the objective of engagement:

> And there's no need for me to say um, "It's my turn, it's your turn." Um, I can just gesture with it, I can pass around the drum, and everyone knows that when there's a drum in front of them, they've got to hit it. Um, so that would be like an example of turn-taking. We're socially engaging with each other by playing this instrument and I'm singing a song; they might be singing along with me.

Response to familiar music on the part of the PwD can include visual and vocal indicators that can be indicative of emotional communication such as relaxation, comfort, as a response to an awareness of something positive that has been mnemonically triggered. From a music therapy perspective, Tami regarded affective indicators as also building a relationship from the communication. According to her, indications of a positive encounter with familiar music might be a "sigh," or the relaxing of the body and facial muscles. As she noted:

> …those I would regard as feelings of comfort. Familiar music could precipitate this: It could be familiarity, it could be a feeling of security. Um, most of us have, the bulk of our memories to do with music are positive.

Emotion was seen as speaking on "many levels" to PwD. According to Jane, using familiar music enabled her to "draw and meet people where they're at and draw them into something different." She gives the example that some "…might stop-start non-verbally and no lyrics and maybe just the music" in their responses. Through such a process familiar music might then facilitate a "move into the lyrics and singing a song that is often familiar to people."

Relationship building with PwD through familiar music was also noted by caregivers who were family. Dinner's experiences with Mona were expressed as "the highlight of my day." In fact, the efficacy of familiar music to facilitate his relationship causes him to worry as he reflected on the progress of Mona's dementia, and that a day may come when she will not respond to familiar music.

> JPV: Do you think the familiarity of music helps um, um facilitate that relationship of bonding, of, of unity?
>
> Dinner: Absolutely it does! Even to the point where I worry what will happen when she no longer can respond to the music. Where will that leave our; what will our relationship

look like or the dynamic of that relationship? Because right now it for me, it is honestly, it's probably the highlight of my day. Um, being able to go and to sing…well it brings me joy. When I see her and Mona has; it, it's hard to uh, maybe comprehend this but seeing her happy with the music, with me, wanting to dance.

Familiar music and bonding also arose in another interview. Jay stated: "so when you play this familiar music it helps develop that initial bond and connection…so it helps make that connection between me, the caregiver, and the client. I further questioned him on this:

JPV: So, is bonding then part of communication?

Jay: Absolutely.

JPV: Okay, so what is, what is bonding…what are indicators of bonding with the use of music?

Jay: …I think that when, when we play familiar music if you're asking how, like how it sort of bonds, I feel like if you play familiar music: I know the song, you know the song, we're both singing along. Then perhaps there's an innate connection …we have similar interests we have…like experiences.

Within the focus group discussion, Tami's interpretation on the importance of identifying familiar music was focused on working with the family of the PwD:

…whatever information I can gather from family or stuff. Whoever I can get the ear of that is so important. And, and makes that therapeutic relationship that much more powerful, if I can know something about that person. And who they were and what importance music played in their lives. And what musical experience they had.

Lena replying to Tami stated that knowing her clients was important as:

> …what can I do with the music with how I interact with them. What can I do to encourage them to you know, open up to me. To, to say more about themselves. To sing, to dance, to do what they enjoy doing to connect with the others around them. What, what sorts of decisions do I have to make in the moment to, you know, get more of that engagement.

To conclude, participants viewed and experienced familiar music to be a vital channel for engaging communicatively both verbally and nonverbally as indicated by the triggering of memories, the expression and exchange of emotion, and building relationships.

**Identity**

*Identity* is the third subcategory of *Memories through Music*. It is defined as music creating a sense of awareness, of belonging, as well as appreciating the uniqueness and culture of each person, which the findings of this study showed helped facilitate communication for PwD. Findings in the data indicated not only PwD touching aspects of their identity but being able to become more aware of self and recall meaningful aspects of their past that make up their identity. One cannot belong if one does not connect, and Robyn noted that one value of music was the ability for it to be used for connection and leading to identity. She said:

> …it is a really valuable tool for connection. And I would hope that they would, they would understand at least the value of connection. Because maybe, you know, that even that's not necessarily what, you know, everybody's focus. But I think like just as humans, we just, we want to be seen.

She then stressed that this being "seen" is more difficult for those affected by dementia, but that through music the building of connection and identity can facilitate communication:

> We want others to see us, especially when we're going through something really difficult. And especially when we're going through something that is robbing us of our identity and communication. Um, anything that's going to foster connection and identity and communication is beneficial and music is like extremely, specifically, powerful for that.

Musical sessions were seen by Robyn as opportunities for building identity to lead to connection. She noted she saw sessions for "creating a sense of connection between all of them. Between me and them," with one of her objectives to "…bringing a sense of their identity to them, back to themselves. Which music really does for many of them. Really gives them a real sense of identity."

Helping to facilitate identity to lead to communication requires learning about the person. As Jen noted, "…so I have learned about their musical tastes, I've learned about their musical history. And when I worked with them one-to-one, I try and convey some of that." Similarly, Tami spoke of her experience as a music therapist and coming to learn about each person's uniqueness:

> what I quickly realized is that a' it's not even remotely about me, and 'b' these are not static individuals, regardless of the stage at which they're at in their illness. This is a person. This is a whole person who had a whole life before I met them. And music is most; had been an enormous part of that.

Music for facilitating a sense of identity and communication was also discussed in the focus group. Dinner related his impression of seeing a group of residents responding to a musical performance at Mona's LTC facility:

> …I just think of that setting and just all of the residents being themselves and letting loose and if someone to stand up and start clapping. And you know, it really is a form to, to express their inner identity, themselves.

Responding to Dinner's statement, Lena added that this communication by PwD can be manifested in quite demonstrative ways, indicating the eliciting of intense feelings from those involved in the musical experience:

> …I'm seeing a group for the first time and I happened to sing one of their favourite songs. And then after the songs done, they just kind of stand up and shout, "I love you." I mean, like we met for the first time, but I know that you know it's not literally what they mean but they're feeling those emotions feeling. Feeling the love, right?

Some PwD were former musicians, and as such music is an important part of their identity. Johana related that when she engages with clients who were musicians she seeks to help them recover some aspect of their former musical lives:

> I think too about some of my clients that have been musicians and, or who are musicians, and who have perhaps lost some of their faculties due to dementia…who are rediscovering their musical identity and who are forging a new relationship with that musician part of themselves…

In such situations, she uses an instrument to reawaken identity her objective, rather than seeking any musical fluency in her client is "…let's find a way for you to have a relationship with this instrument."

She also spoke of the uniqueness of each person within the context of engaging them and to focus on their identity: "…through the process, we discover what wellness is for them. And we nurture it. And we attend to it. And we strategize toward it. And we experience it in therapy.

You know, feelings of wellness and, and wellbeing." Applying this to using music she stated:

> And sometimes that looks like using the voice. And sometimes that looks like just remembering, having space to remember. Sometimes it looks like writing songs, or improvising, or you know, sometimes it looks like just figuring out purposeful playlists, you know. Making playlists for different things to help make them more tolerable.

For Albina, identity and a sense of self was enhanced by social connections, as many of her clients in their early adulthood "…used to sing with their friends, they used to go to parties where they went singing together." It is because of their identification with these past experiences of music within a social setting that they, according to her are a "…little more willing to engage from that music perspective and build those social connections through that."

Identity within a musical context was also very important for spouses to facilitate communication. Northern Woman recollected how music from Albert's childhood was able to reattach him to his identity. "I found this Swiss-Austrian, I think it was an Austrian CD. And he really enjoyed it. He was talking about, they had the Alpine horns going and so, it was, it was, and it took him back to his Swiss childhood." During his walks with Mona, Dinner would note that music was able to keep Mona as "the person that she always was," by her "…just singing, she's just singing…and she's content. And I just say that's why I'm so grateful for music. That it allows her to continue to be the person that she always was, albeit in another, you know, less cognitive state." Dinner also made references on multiple occasions to Mona's smile as an indication of communication brought on by music. Music, according to him, "…allows me to see Mona smile." It is through his musical engagement with her that he comes again to touch the person he identifies with and see her identity as his wife irrespective of her cognitive decline:

> But to see when the music comes on and her start to sing, and just the other day it was, you know, even though she can't communicate, just that smile tells me that the power of music! Oh, that there's something inside of her that just comes to life…it means the world to me …that she is still my dear Mona who would be the life of the party. And, just responds to it…but it just, it gives me joy to know that her being on a locked unit and, you know, being the youngest by far that she can still derive joy in her daily life with me, her husband.

***Cultural Identity***

In the findings of this study *Cultural Identity* also played a factor in music facilitating communication for PwD. For those in late-stage dementia and for whom English is not a first language, Tami mentioned with only long-term memory from their home country she might be unable to make connections with them. As she noted, "There's no recognition even if there is music." Cultural awareness was something that Jane saw as the way of the future to ensure including people's identities when seeking to facilitate communication with music. She noted that "Canada has become way more diverse than it ever was," adding that "cultural awareness and experience" will play a large role going forward, noting that identity "…in the past to music was a very social activity, whereas now it's a very individualized activity."

Culturally appropriate communication using music also emerged in the findings. Jen noted that for some cultures:

> …eye contact is just a big thing…you have to be careful with that culturally, because there are some cultures who don't look people in the eye…But in general, I think that eye contact is the key piece to communication…So for me, eye contact is a good thing for the most part. If they are looking at me that's a certain level of engagement.

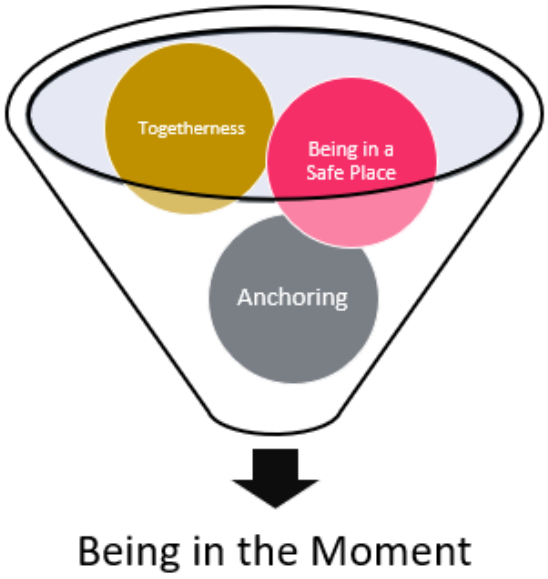
Lena also noted how cultural identification with the client can be beneficial, giving the example of singing a Chinese folk song. “And that’s when that rapport is developed, they tell me, you know, my mom used to sing this song, or I used to sing this song a lot….and that’s where my conversation starts.”

## Category C: Being in the Moment

### Definition

*Being in the Moment* is the main category that emerged in the findings and is a conceptual synthesis of three subcategories. It reflects some element of an awareness of the unique presence in the moment between people and achieving a mutually beneficial and relational connection as triggered by music. The three subcategories are *anchoring*, *togetherness*, and *being in a safe place.* They emerged from either focused codes, or focused codes that were merged. Figure 6 illustrates the subcategories that informed the main category. The use of a funnel is to reflect the coming together of the subcategories to emerge as the main category of *Being in the Moment.*

Figure 6. *Being in the Moment.*



**The Main Subcategories**

Three main subcategories (Table 4) emerged from the analysis: 1) *Anchoring,* or the PwD's awareness of self and being in the moment that is triggered by music, 2) *Togetherness,* or the relational and connecting in the moment with the other, and 3) *Being in a Safe Place,* or indicators of (e.g.,) safety, comfort, validation of the PwD that facilitates communication.

**Table 5. Being in the Moment**

| **Category C** | **Sub-Categories** |
|---|---|
| Being in the Moment | Anchoring<br>• Building Intimacy<br>Togetherness<br>Being in a Safe Place |

**Anchoring**

*Anchoring* emerged as a subcategory of *Being in the Moment*. Based on the findings, it is an awareness of self, the other, and connecting and being in the moment triggered by a musical experience. Anchoring emerged from the effect of music on PwD, creating for example a sense of "in the moment," "awareness," "emotion," "anchor to the connection," and "intimacy," which then could facilitate communication in PwD. From Dinner's perspective, music allowed Mona to be "in the moment," adding "people as you know with dementia just live really in the moment. And she's enjoying that and I think I really cannot ask for more. If she is content in the moment and music is what has allowed that." Johana noted that in her experience, "…music opens a door. The music anchors them to the moment the music anchors them to themselves. In, in a way you know where they are connected for in that moment with their memory." The "moment" for Johana also included "…just being present without expectation or judgment." It is allowing the person to be who they are without creating stress, judgement, or expectations. She developed this concept further:

> Music doesn't ask you to change how you feel or how you show up or how you interact. There's no right or wrong way to experience music. There's no way that you should or shouldn't experience music. And, so often musical experiences just sort of allow folks to really be in the moment. It's not about what you remember, what you used to be able to do.

Similarly, this sense of acceptance was noted by: "…I'm saying, 'Hey, I'm here and I just need you to know that I'm here and I'm with you.' And that's all. It's not asking for a response, not asking for engagement. It's just letting people be in that moment with you."

Lena gave the example of anchoring by PwD also becoming aware of others:

> …for example, if they're sitting in, in this particular room, they're sitting on this couch, they are sitting on, next to whomever. And on the other side is another person. And they are experiencing this song with, with me, and with the other people in the room.

For Ava anchoring also emerged from accepting the person through a sense of togetherness and emotion, leading to communication. The coming together through music with her clients, which could involve holding their hands, looking into their eyes and leading to what she sees as, "You kind of share that moment…togetherness and emotion is a good, good way of putting it." This sense of acceptance was also expressed by Ava as validating her clients: "I would say, 'Oh, do you like the song?' Or something along those lines of showing them that I am listening and I see that they're communicating and enjoying the song." The idea of validation had emerged from my questioning her on the importance of letting the PwD see that someone is listening to them:

> JPV: So how important is that to show them that you are listening and communicating with them?

Ava: I think it is very important. Because you're validating. You're saying, "Hey I, I see you. I see." You know? You're communicating. So, you're, you're validating, "Hey, I see you."

Anchoring can be created through more demonstrative activities such as dancing, which according to Tami can create a sense of connection and being in the moment. Tami recalled how:

…some of my clients that I worked with over the years have been of course incredible dancers because that's what this generation had. And, so I have had clients who have wanted to dance with me. Which of course is such a beautiful way of connecting and being in a moment together.

Rhythm was also identified as being able to achieve connection and then anchoring. According to Albina: "So if I don't give them a steady rhythm, they don't have anything to latch onto to join me." Rhythmical entrainment with her clients can be indicative of an acceptance of her invitation to join her, to anchor with her through "meeting her":

JPV: So, by receiving a steady rhythm latching on through let's say, tapping, moving…

Albina:…yeah…

JPV:…that, that indicates to you what?

Albina: That they are meeting me where I am starting and that I might be able to take them somewhere with that.

JPV: OK, so when they are meeting you, do you, is that an act of communication on their part?

Albina: I think so. It's an acceptance of an invitation.

***Building Intimacy***

*Building Intimacy* emerged in the findings as facilitating communication through the caregiver conveying a sense of being there for the PwD during the musical encounter. As Johana remarked connecting "…can sometimes be about intimacy it can be about meeting a need; it can be about being hurt or understood it can be just rooted in a desire to understand others or be with them." Jen, for example, mentioned how she plays with her voice's tone and volume: "It is asking people to look at me, it's asking people to engage with me, to be there with me." Jen also sought not just utilitarian responses, but to use music for enabling PwD to communicate immediate awareness and feelings:

> So, say I am asking them "How are you feeling today?" And they say, "Well, I don't know." I could give them something and say, "Well, instead of telling me, instead of telling, instead of telling me how you're feeling, can you play what you feel on this?" So, maybe I will give them a drum, maybe they'll tap it really quietly. Maybe they'll bang it really loudly.

As a spouse, caregiver intimacy was also important to Dinner who described his musical encounters with Mona as the "best part of my day":

> …it allows us to have that intimacy and I, I have to say this. I leave my job and I go and see her. And it's the best, by far the best part of my day. Because it, you know, any other crap that's gone on, it just, she makes it all melts away…I don't even have the words to describe where I would be without music with Mona.

Findings also included the deliberate use or not use of musical instruments for the purposes of achieving connection and intimacy. Jane spoke of how she used her guitar softly to connect with a client. She stated:

> And I started playing my guitar softly…and I'm playing softly. He picked up the mallet and started to play softly as well. And so, I continue to play softly and he's looking at me and his eyes are kind of twinkling now like, hey yeah, we're doing something here.

This initial response is then followed by changes in tempo and dynamics using mirroring and matching for "very intentional communication and interaction and musical dialogue." A sense of connection is then achieved with the PwD who had previously been withdrawn and now is emotionally, and then communicatively engaged:

> …before he was curled over and now he's sitting up and he's ready and he's going and he's laughing and he's just fully engaged in this human experience and, and this dialogue, which we then hope to take that musical dialogue and to create into a communicative and, and verbal dialogue.

In contrast, Tami spoke laying her guitar aside, as "sometimes I find it to be a barrier…when I want to engage someone in a more intimate way. So, I will perhaps put my guitar down and bring myself closer to them hold their hand. Make sure that I'm in a place where they're seeking out my eyes." For her, this closeness creates "that idea of touch combined with eye contact and proximity, you have to come into that moment with me." Having drawn the person into the moment with her, she then engaged with song: "…adding that next layer of singing, um whether it be a familiar melody or not, that is such an act of intimacy. That, that person is kind of brought into that moment with me. The intimacy of music, according to her brings her clients to "…to the place where we're both present."

**Togetherness**

*Togetherness* is the second subcategory of *Being in the Moment*. It emerged in the findings as a sense of the PwD being together and connecting with the caregiver in the context of being in the moment. For example, Ava related how she would engage clients with dancing when she uses music, even those in a wheelchair, "I grab a hand and we go back and forth…" For her, the exchanging of smiles, the holding of hands is "a sense of togetherness at that time." She would be "engaging together" and "it's an emotional level because we're both; it seems like we're both happy." The sense of togetherness and "sharing" the moment in group music sessions was also noted by Robyn. According to her, as dementia progresses her clients speak less but increase their bodily movement. Through music, she noticed that her clients were expressing togetherness through a shared musical experience:

> So, some who really cannot speak anymore they'll do all kinds of movements, and I think it is an expression. I think it is part of the communication as well. Um, the, they're movement is connecting them to the musical experience that we're all sharing.

Johana viewed togetherness as emerging from her clients' reactions, which itself is the beginning of communication. For her, their reactions "totally guides the experience" of her musical interventions to achieve that response of "I'm with you" from her clients:

> …when I see positive affect when I see smiling or even you know someone becoming tearful, having an emotional response. Um, you know when I see somebody when I see affect into, you know, it indicates, you know, almost contemplation or people begin to sing along, or you know a slight turn of the head, you know, little things that indicate, "Oh, I'm listening, I hear you, I'm with you, this is affecting me in some way." Um, and you know sometimes musical interactions, especially with instruments; um, with

this population just elicit laughter.

Togetherness leading to communication was expressed as a sense of connection brought on through music. Dinner having spoken of learning to read Mona's nonverbal cues, "my ability to respond to her nonverbally has risen because I'm able to have to pay more attention to her cues be they facial or other expressions," added that communication is far more than words, and that through music he may be able to connect with Mona:

> Dinner: But I realized on those walks. Not a lot needs to be said. [slowly with emphasis]. Right? It's like where those awkward moments you feel you've got to fill in the spaces and I realized how beautiful it is just to be walking, holding hands, hearing the birds and, you know just saying, "Oh, you know what kind of bird is that?" And I mean I'm not expecting an answer from her. You know? And then, and then, when I started with the music, not so long ago, and then you know that we don't; obviously we're not talking there. But then when we have that dance or we're singing, we're very much connected. Very much connected. [with emphasis].
>
> JPV: So the music is integral to that, making the connection?
>
> Dinner: Absolutely. Yeah. So.

One aspect of togetherness is immediate, spontaneous interaction by PwD. It can even be pre-musical based on recognition of previous musical experience with the caregiver, suggesting mnemonic recall of a past musical event. Jen noted, "If I don't come with my guitar they won't recognize me. But if I walk in with my guitar they're like, 'Oh, I know who this person is.'" Spontaneous togetherness can also be brought about by live music. Jen stated that in her experience live music was more amenable to interaction between herself and her client as "recorded music, it's like one-directional. You press play, it does its thing. There are no changes,

It's always the same." In contrast, she found that when she engaged in live music, she was able to respond to the immediate needs of her clients, as "with live music, it's like this bidirectional process." The example she gave was how she changed singing "Hound Dog" by Elvis Presley, from the original upbeat tempo to which her client was not responding to a slowed-down version. As she noted:

> So maybe I pull back a little bit. Maybe I slow down my playing, *"You ain't nothin' but a hound dog*" [sings slower]. And maybe from there move into a different song because that one's not where they're at today. So, with live music, I have the option of changing things in a split second.

A live music encounter with the PwD enables the caregiver to facilitate their needs *in vivo* leading to communication: As Jen said:

> This is working. Now it's not. How am I going to respond? So, they are communicating to me how they're feeling, what their experience, what they are experiencing and I'm responding to that. And in responding to that I'm communicating to them that I'm here with you. I hear you. And I hear what you're saying.

This interactive "hearing" the PwD was also identified as leading to togetherness. Jane stated that she sought to identify the "self" of the other to achieve connection or togetherness, "a way that I work is definitely using therapeutic use of self is a huge way that I work. And, and when I'm working with someone, um, I'm trying to figure out what's important to them." According to Lena, music "openness" to the PwD opened up possibilities for connectedness: "When working with people with dementia, I think music provides that safe space for that kind of self-expression and therefore even more connection. And more openness from both sides to create and maintain the relationship." Northern Woman related an occasion when after singing to

her husband there is togetherness through the shared music:

> Yeah, as we're holding hands. And then our, then, then if it's something more rousing, we'll do things like this, and he's just getting right into it. We both love music, so I guess; you know but I'm, we've strong eye contact. And then I'll say, "Wasn't that fun?" And he'll say, "Yeah, that was fun" [laughs].

**Being in a Safe Place**

*Being in a Safe Place* is a subcategory of *Being in the Moment* and emerged from caregivers speaking of PwD communicating and being more open to communicating when they experienced a sense of being in a safe place. This concept was expressed by participants in a variety of ways, such as: "a bubble," "container," "autonomy," "space," "comfort," and "therapeutic relationship." Jen described the sense of safety as the PwD being "enveloped" in music, facilitating a feeling of tranquillity and awareness of being with someone (the caregiver):

> So, as I'm singing and creating this environment to, to, for them. It's like the music is almost enveloping them and it's taking us to this place where it's quiet, where it's peaceful. Where there's somebody with them, where they feel cared for. So that like just being with them in that moment.

PwD were found to be more open to communication if the music they are exposed to may trigger emotions or memories that may create a feeling of safety. The idea of music creating a safe place for facilitating communication was also noted by Lena:

> I think that the music helps contain those emotions a little bit more, too. Contains that, their reminiscence or their experience within the song…And, and I kind of imagined kind of like a bubble, within, within the room. Encompassing all of the participants and me. And the song that fills the room becomes that bubble and contains the whole

experience.

I further questioned her on her use of the term, having been exposed to it being used in an earlier interview by Jen.

JPV: Is the “bubble” a term used by music therapists? Or is it…?

Lena: Container is the word.

JPV: Container.

Lena: Yeah.

JPV: So, “container "is? What do you mean by container? Can you define that then for me?

Lena: Um.

JPV: So, in music therapy “container” is?

Lena: A holding space where people can safely express themselves.

JPV: OK. Right. So, but you also called it a bubble?

Lena: Hmm, hmm, [laughs], yeah.

JPV: No, that’s interesting, very fascinating because…

Lena:…yeah…

JPV:…someone else called it a bubble as well.

Comfort and a sense of autonomy were also identified within the context of seeking feedback and engagement from PwD regarding the music being used to engage them:

> …if somebody puts on some music and they don’t like it, there’s no way for that to change. It’s just there. But if I’m able to adapt and adjust, it’s like they, their response is being heard, and they are able to influence. So, there’s a feeling of comfort and there is a feeling of autonomy, um, and then there’s also the social aspect of somebody sitting here with me and engaging with me (Lena).

Knowing the person and their musical needs and interests makes communication easier and more open to being maintained during the engagement. Music should be used to fit the person so as to develop a relationship. The use of humour, playfulness, changing the music between low and high energy were also some of the ways to facilitate communication:

> …you know, might want a quieter more soothing kind of a slower approach and so knowing how to come in, which is hard when you don't know the person yet at all, but when you have that relationship to know how to come into their bubble (Jane).

The result being that an approach which is not creating autonomy can lead to losing the safe place and as a result lose communication. As Jane put it: "You might pop it and they might not let you back in." Knowing the person to achieve optimal results for communication involves "…trying to figure out what's important to them…that we can then engage in a time that is meaningful to them, a time and a space that feels safe for them to start expressing and sharing with me." Jane noted her approach to autonomy was from a "music therapy background and experience," which regards the use of "interplay that's definitely an important part of communication for me." Lena referring to autonomy remarked: "I think what we try to highlight is their independence and autonomy whenever possible. And so, they can do whatever the music makes them do." If her clients begin to respond, she keeps "reinforcing," with visual cues such as "…doing what they're doing, I start nodding my head to say, 'Yes that's, that's great.' And they, they follow me as well. They start nodding their head as well. And are looking straight at me." Like Jane, her objective is also to " …try to acknowledge their responses.…to acknowledge that experience. And so, it makes them feel like they are listened to. That perhaps this could be a safe space to, to express even more." The understanding of the person, leading to the creation of a safe space opens up possibilities for greater expressive opportunities, or communication.

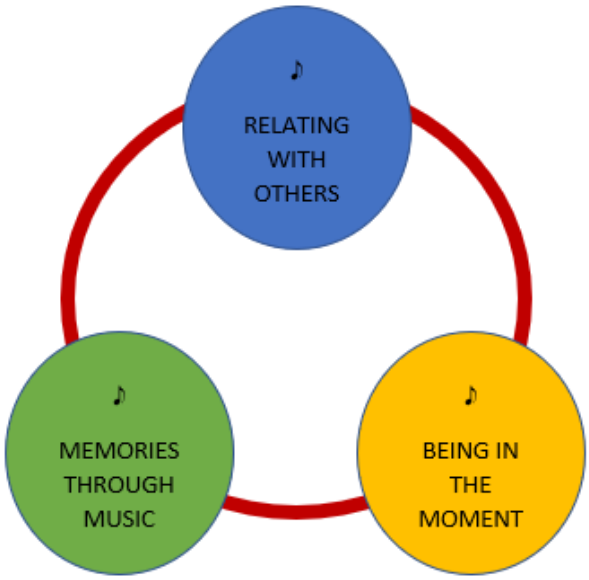
Albina also referenced a “safe space” to optimize communication through music, which according to her would be indicated in “people tapping their toes, or moving in rhythm to the music or making eye contact if they’re enjoying what we’re doing.” A safe space enabled her to strengthen her relationship so as “to know them better as we build up a bit of trust,” leading to:

> …a therapeutic relationship…a safe place where they come to. They can talk to me. It doesn’t have to be about the music, um, they can bring other things in and maybe we can tie it back to the music. Sometimes we might just use verbal counselling. But I find it’s often that people forget the therapy part of music therapy. And that we’re trained in that as well.

**The Interconnection of the Main Categories**

As noted at the beginning of this chapter the three main categories are dynamically interrelated from which emerged the core category of *Communication through Emotional Connectedness.* The main categories are not separate concepts but rather exist in a state of constant dynamic interplay (Figure 7) (as reflected in the red circle connecting the categories) as lived out in the communicative experiences and behaviours of PwD. The purpose of the following section is to present a number of representative examples from the findings that reflect this dynamic interrelationship between the main categories that enabled music to facilitate communication for PwD.

Figure 7. The Interconnection of the Main Categories




This interrelationship reflecting the dynamic interplay between categories consistently emerged from the interviews and focus group. For example, the interrelationship of categories might be how the perception of *familiar music* (Memories through Music Relating - Category B) precipitated *body language* (Relating with Others - Category A), to enhance a *sense of anchoring* (Being in the Moment - Category C) through focusing on the caregiver. An example of this interrelationship is reflected in Jen's comment on how a PwD anchored on her as the caregiver through recalling the familiar music and relating it through body language by using her eyes:

> So, there's one resident that I work with and completely nonverbal. And they are constantly making verbalizations. So, they're moaning or sighing, or things like that. And it's like incessant. They're always doing that. And as soon as they hear their preferred music; so if I go in, and I play them an Elvis song. They really like Elvis. The verbalizations are gone immediately. And their eyes are on me.

Other examples in the data were the effects of music facilitating communication through the interconnection of reminiscing with familiar music, leading to an awareness of a sense of

identity. For example, Johana's comment of a music session that facilitated communication in PwD involved *reminiscing* and *identity* (Category B) which then precipitated *sharing experiences* (Category A) and a sense of spontaneity or *togetherness* (Category C):

> …folks are indicating to me that they want to reminisce and chat and they are spontaneously sharing memories…I'll ask questions you know, "Tell me about, you know, I notice you singing along. Did you sing a lot growing up? Was music a part of your family life?"

Findings included emotions as *a conduit (*Category A) as a trigger for *memories* (Category B). For example, Robyn noted: "And then you know as part of that helping them deal with emotions. Maybe, you know, experience emotions, express emotions in, within the context of that connection. As well as triggering memories." Another example was *identity* (Category B) triggered by a mnemonic recall that could lead to *relating with others* (Category A). This is reflected in Albina's comment that: "I want them to own the music and bring their own styles and their own preferences into it. I want them to interact with each other…" *Familiar music* (Category B) not only stimulated *crying* (Category A) but could also create an emotional state of *being in a safe place* (Category C). Lena noted:

> …upon hearing a familiar song, they would start crying kind of out of nowhere. But because, because of that song or that environment that they are in, in the moment, something gets them right there right away…I've seen clients who are a little bit agitated or angry at something and I play it. I know from experience I play a song that they, I know that they enjoy…a switch flicks and it brings them to, you know, to a happier moment**.**

To conclude, the findings from the data showed that the main categories were not hierarchical or linear, but rather a dynamic interrelationship of relating with others, memories, and being in the moment that created the fusion of the grounded theory for this study, *Communication through Emotional Connectedness.*

**Video Observation**

Twelve of thirteen participants opted for the use of Zoom for interviews. Observation was limited to the faces and upper bodies of participants. Review of the interviews revealed people who by their facial expressions and alertness engaged reflectively in the interview process. Review of the focus group identified the participants as not only engaged with each other without the need for prompting, but also people who were at ease with each other as reflected in smiling, laughter, and even humour (such as Tami saying “I do know melodies”). Body language was consistent across interviews and the focus group with participants making causal hand and arms gestures whilst engaged in conversation.

Review of videos was a way to obtain a different perspective (as compared to transcript review) of the interviews and focus group as they had happened and provided me with another approach to exploring the data and developing my analysis through memos, jotting ideas, and adding/merging codes (or inspiring me to compare with other codes, incidents in other interviews or the focus group).

Six caregivers (four music therapists, one HCA, and one informal caregiver) were willing to engage within the interview process to demonstrate with song. These musical expressions have value as data because they provided me examples of how the caregivers communicated music to PwD. Such demonstrations gave me a better understanding rather than them just explaining what might be done musically with a PwD. Singing involved demonstrating what

song was being used, such as "You are My Sunshine", or the use of a melody with vowel or syllable sounds. Only very short phrases were sung, such as "*you ain't nothin' but a hound dog*…" Two participants sang three times, two sang twice, and two sang once for a total of 10. Northern Woman (who also sang in her interview) also sang a short phrase of "You are My Sunshine" during the Focus Group.

Two visual standouts were Northern Woman's hand and arm gestures when she spoke of "hand dancing," where her husband Albert would, according to her, match her and place his hands on hers and move them rhythmically. The second was Lena's use of her guitar to demonstrate her approach to using music (such as playing rhythmic chords) to achieve entrainment, whereby PwD would begin to match her tempo with hand clapping. To conclude, all of these examples provided me with a window into the musical approach (e.g., dynamics, gesture, tempo, rhythm) by the caregivers to engage in communication with PwD.

## Serendipitous Findings

A number of discoveries emerged from the data and its analysis, which, following Stebbins' (2001) definition of serendipity is that it is a form of discovery that can include "informal experimentation, accidental discovery, and spontaneous invention" (p. 3). Within the context of my exploratory study, serendipity flowed from the result of exploration via the interviews and focus group.

Participants felt there should be a greater appreciation of the value of music within healthcare settings. Dinner wanted more research "…into the hands of, you know, activity directors." He further suggested getting information to "family councils and residents councils as well." His hope was that they could become "advocates for music within the home." The issue of the environmental setting of institutions to being more sound- and music-positive was also

raised. Sound in the environment has been known as affecting health outcomes, especially levels of stress (Foster et al., 2016). Jen who recalled experiences with uncontrolled noises in LTC facilities felt that uncontrolled sounds could be detrimental to the health and wellbeing of PwD. She mentioned one incident where a call bell that was near a resident's room and rang on and off all day. As she called it "…an incessant ringing bell. Different tones but it just creates kind of a horrible atmosphere." She noted that resident proximity to extraneous noises may be harmful to their health. "So, if the person is bedridden or they can't leave their room, they are just stuck listening to that sound all day. So the environment I think has a huge impact on wellbeing." She further linked this to music sessions by adding:

> …I'm running the group in one of the lounges and the call bell goes off. There, it's gone. That circle that we created, that presence of everyone's here in a cohesive group. It's gone. Everyone's like, "somebody turn off the bell," or "somebody answer the phone," or whatever it might be that day. So, it inhibits the ability to communicate effectively.

An issue that arose during the focus group was, was there sufficient awareness of the value of music within institutional settings? For example, during the intake process for entrance into institutional living, such as a LTC facility, the importance of including music as an activity for PwD was raised by Dinner who felt more could be done to highlight the need for music:

> So, I guess for me, JPV, to answer your question, the importance has become paramount to the, to the point where I'm pissed off that at intakes when people go into; whether they be long-term care, there's really not a huge intake inventory for music.

Tami further commented on the issue of intakes for PwD adding: "I want music to be on the intakes of all of our clients that we see which would be so wonderful." She then suggested greater use of technology should be made to make music more accessible:

> I was going to say, I mean as long as we're dreaming here, all of those things I want music to be on the intakes of all of our clients that we see, which would be so wonderful. I love the idea of iPods, but I think it also has to do with that ease of accessibility…as we move forward in technology, perhaps this will become more possible.

The value of family involvement was also noted. For example, Jen stated that if her clients are unable to communicate verbally with her, "I'll just call one of their family members or one of their supporters and ask them and will be able to give me an answer of what kind of music they prefer."

Another finding was the personal effect that communication had on caregivers who were family caregivers and spouses, and therefore had lifelong, close attachments and shared memories with loved ones. The desire to maintain communication was spoken of in terms of "gift," "gratitude," "grateful," "soothing," and "healing." An illustrative of this was Dinner's comment:

> …guess that's why I say music, music can; this gift of music can bring her joy. And by extension it brings me joy. Because I see this, my wife, the mother of my children who's had this horrible disease come into her life, that she's still able to have that million dollar smile on her face and sing along and make me laugh and make me just forget about all the other crap that goes along with this disease…And it's, it's, you know, there's not many bright spots in my day, but that is, I mean it's guaranteed that it will happen when I'm with her. And that music comes on, and I'm, I'm grateful.

Also illustrative was Northern Woman's use of the word "soothing" to describe the effects of her successes in communicating with Albert and its implications for her as a caregiver when he still lived at home before moving into a LTC facility. For her, achieving communication

was described in psychological and practical terms creating for her:

> A frame of mind and also place where I can reach Albert. And if I'm…it's also; I find it soothing for my soul, that means I'm going to be better caregiver…you know, things like, ha, ha [laughs], I think I could tell Albert that I was doing some quilting and I put on some good rock and roll music, and he might just start laughing…. we would boogie and dance back past each other.

## Summary

In this chapter, I presented the demographics of the participants who contributed to the findings of the emergent grounded theory of *Communicating through Emotional Connectedness.* Three main categories supported this core category: Relating with Others, Memories through Music, and Being in the Moment. Examples were quoted from the data which illustrated the resultant grounded theory and the main categories. How the three main categories interrelated and informed the emergent theory were also presented. The chapter was concluded with a review of video observation and serendipitous findings that arose during the data gathering.

# CHAPTER SIX: DISCUSSION AND RECOMMENDATIONS

The purpose of this study was to explore how music facilitated communication for people with dementia (PwD). The researcher investigated this from the experiences and perspectives of formal and informal caregivers. Despite interest in music for dementia care, as well as the effects music has on communication, there remains a paucity of caregivers' perspectives who are often the primary interlocutors with PwD. Further, the use of grounded theory research into communication and music is largely absent in the extant literature. This study is unique in that it is the first grounded theory study to focus specifically on communication, music, and dementia. The research question was: *does, and if so, how does music facilitate communication for the PwD*? To answer this question, I conducted 16 interviews and one focus group with 13 caregivers (nine formal and four informal) of PwD. Given the subjectivity of communication and music, a constructivist grounded theory methodology was adopted to address the research question. The contribution to current research is an exploratory substantive theory grounded in the data that was generated during the study.

Four grounded theory categories emerged from this study, including the core category of *Communication through Emotional Connectedness.* There were three main categories: *Relating with Others*, *Memories through Music*, and *Being in the Moment*. The theory emerged from the identification and analysis of the relationships between the main categories, providing an explanation on how music facilitates communication in PwD through the process of emotional connectedness with others. Specifically, there exist three main categories of communicating for PwD and they exist in a nexus of dynamic interplay. The findings were presented in Chapter Five.

In this chapter, the meanings, importance, and relevance of the findings are discussed, including comparing and contrasting them with the extant literature. Following, three examples are presented as illustrations of how the main categories interplay to generate the theory. Next, limitations and strengths of the study are considered, followed by recommendations, and a conclusion.

## Discussion of the Findings

The theory from this current study is that communication for PwD comes through emotional connectedness, where communication can be seen as an active, dynamic interplay of the three main categories of *Relating with Others*, *Memories through Music*, and *Being in the Moment*. This theory brings clarity to understanding how music facilitates communication for PwD, where music acts as a channel for emotion and connectedness is needed to communicate. In each of the three categories there is a sense of connection in action impenetrated with a sense of emotion existing within the temporal experience of the PwD (e.g., during the experience of singing, hearing the music, interacting with the other person). Thus, emotional connectedness can be seen as integrated actions or processes of "relating," "remembering," and "being". Key to understanding the theory is that it is not a linear balance between the three categories. What emerged was that each category influenced and was influenced by the others, and by the presence and action of the interlocutor, such that emotional connectedness can therefore be seen as unique to each PwD. This theory also reflects that communication for PwD is a desire for, and when successful, the entering into a dialogue that supersedes regulation of behaviours, such as ADL. For instance, the sharing of experiences, the use of the body and voice to communicate identity, intimacy, and togetherness. This finding is reflected in the literature, where communication for PwD takes on significant meaning, involving relationships, memories, and

intense positive emotional experiences, giving rise to connectedness with others (Dassa & Amir, 2014; Götell et al., 2009; McDermott et al., 2014; Osman et al., 2016).

In this study communication through emotional connectedness emerged from the person, linked to the individual's past (e.g. reminiscence), present (e.g. anchoring), and aspirations for the future (e.g., security, autonomy). Communication as emotional connectedness reflects what Ridder (2005) suggested is the success of communication where the entire person is considered, "a person with emotions, cultural identity, psychosocial needs and a personal biography" (p. 72-73). This potential for communication of the person that emerged from the data reflected the unique contribution of both informal and formal caregivers and the value they placed upon the therapeutic relationship, as reflected in the interrelationship *of relating*, *remembering*, and *being*, the latter reflected in such descriptors as "container", "comfort", and "autonomy".

It is perhaps appropriate at this point in the discussion of the findings to reflect upon the role of music therapists. They have a vital role in enabling PwD to demonstrate a rich facility for communication, as reflected in this study. Music therapists may wish to consider a number of implications to foster awareness of the importance of using music for communication. For example, they might consider increasing their focus on communication within their sessions, as well as ensuring their professional colleagues are aware of the efficacy of music as a therapeutic intervention to improve the QofL of PwD. Within LTC contexts, music therapists might consider increasing their contacts with administrators, nurses, recreation and occupational therapists, as well as social workers to promote the use of music as a strategy to facilitate communication. To raise awareness of the value of music amongst families, music therapists might make a presentation at a residents' council meeting. Music therapists may consider undertaking

communication focused research with findings published in music focused journals. Findings from such studies could also be presented at conferences.

It should be noted that in this study, as trained musicians, music therapists at times introduced technical musical terms within the context of their personal experiences of using music to engage PwD. Examples include Lena's reference to her practice of shifting tonality between major and minor in familiar songs, Albina's use of tempo, and Tami's use of tone and *a capella* versus accompanied singing. In each case musical terminology was used to provide context on personal experiences of how music was used to facilitate communication.

**Communication in the Theory**

Emotion was found to be a universal factor in facilitating communication in and within all three main categories, such that relating, remembering, and being can be seen as integrally emotive, and therefore integral to the expression of communication. The findings in this study are confirmed by the identification of emotion in the literature as an integral part of human communication (Clare et al., 2020; Götell et al., 2009; Hiller 2015; Sacks, 2007; Söderman & Rosendahl, 2016; Tomaino, 2015)**.** It may be opportune to revisit the concept of communication as discussed in Chapter One which was presented as relational/emotive and content, involving sharing with another. Aldridge (2005a) suggested that the person cannot be separated from the shared message and that communication is reflected through such influences as memories, identity, and body language. His view of communication as a "mutual expression of human emotion and the sharing of ideas" (Aldridge, 1989, p. 743), is reflected in the theory of this study, as, for example, the *shared experiences* of *relating with others* a memory that, being meaningful is interwoven with emotion and expressed through connectedness.

**Emotion in the Theory**

Emotion emerged in this theory as an integral part of communication and connectedness. This reflects the centrality of music as perceived on an emotional level by PwD, and then acted communicatively upon it. When a PwD engages in remembering via familiar music, the reminiscence of the music linked to their autobiography facilitates an emotional response, which then engages in interplay with the other main categories, leading to communication of which integral to it is emotion.

The findings in this study on the effects of music on emotion are reflected in the literature where music is seen as primarily emotive and a trigger for emotive responses (Baird & Thompson, 2018; Cross, 2014; Juslin & Laukka, 2004; Hiller, 2015; Ridder & Gummesen, 2015; Sacks, 2007). Further, for PwD, emotion begins to play a greater role vis-à-vis content, due to the cognitive inhibitions that dementia places upon, for example, the ability to speak. Understanding their emotional world can bring about a mutually positive experience of communication between the PwD and caregiver (Garabedian & Kelly, 2018; Ridder & Gummesen, 2015). This may be reflected in the idea of the "container" within the main category of *Being in the Moment* as a way of using music to help the PwD "contain" emotion and channel it towards positive and appropriate affective responses and communication with indicators of being expressed through joy, contentment, calmness, through body language being more active, and open towards the interlocutor. These findings are supported in the literature (Clare et al., 2020; Engstrom et al., 2011a; Garabedian & Kelly 2018; Marmstål Hammar, Götell et al., 2011; Raglio et al., 2008). Also, when words were used, they indicated positive affect through intonation, dynamics, and singing. Similar findings also exist in the literature (Bannon & Montgomery-Smith, 2008; Dassa & Amir, 2014; Götell et al., 2000, 2009; Marmstål Hammar et

al., 2010a; Ridder & Gummesen, 2015).

**Connectedness in the Theory**

Connectedness in the theory was the process of the PwD making that connection with the other to achieve communication. It was multi-dimensional and incorporated all aspects of connection with the other as reflected in the main categories. Music was seen to be essential for making connectedness. Connectedness came in a multitude of ways, such as through sharing experiences, immediate feelings of togetherness (physical, emotional, and cognitive), open and engaging musical body language (e.g., rhythmical matching and mirroring, tapping, nodding), body language reflecting emotional connection (e.g., hugging, smiling, kissing). The vast panorama of possibilities for connectedness, as identified in the findings, were integral to and informed the interplay of relating, remembering, and being.

Connectedness with the other person (e.g. a caregiver) facilitated not only emotion in the PwD, but as communication as a dialogue, it was seen many times to positively impact caregivers, especially those in long-term relationships, due to a sharing of meaningful memories and life events with the PwD. This serendipitous finding of connectedness leading to an enriched symbiotic communication through recalling shared past experiences and strengthening the relationship reflects the value of communication for optimal dementia care. Such benefits for those in long-term relationships have also been noted in the literature (Baker et al., 2012; Dassa, 2020; Götell et al., 2000; Osman et al., 2016). Unadkat and colleagues (2017) noted benefits for family caregivers, especially between couples that enabled a return to shared activities and past experiences, leading to a sense of togetherness. Benner and Wrubel (1989) noted that the understanding of past experiences is part of caring and can create “meaningful connectedness” for the person being cared for, such that the “past and present enables the emergence of the

possibilities of the future" (p. 112).

In the literature, connectedness is seen as an exchange and linking between people that involves a content and relationship aspect (Aldridge, 2005a; Chew, 2014; Kuemmel et al., 2014; Ridder & Gummesen, 2015). Connectedness in this context might be seen as an increase in talkativeness (Götell et al., 2000), increased cooperation (Marmstål Hammar et al., 2010b), mutual interaction (Götell et al., 2003), bonding (Brown et al., 2001), or sharing meaningful experiences (Clare et al., 2020; Garabedian & Kelly, 2018; Dassa, 2018; Harmer & Orrell, 2008). In contrast, connectedness in the study is within the context of emotion and interwoven with it on a theoretical level that communication for PwD comes not from connectedness, but *emotional* connectedness.

One study that does identify emotional connectedness was by McDermott and colleagues' (2014) on how PwD engage in meaningful shared experiences. According to McDermott et al., musical engagement can trigger emotions, which can lead to a sense of connectedness between the PwD and the caregiver. They proposed that the use of music can create a sense of "musical connectedness" leading to "development of a relationship" through communicative indicators such as musical interactions, both verbal and nonverbal (p. 712). This, in turn, can lead to what they termed "emotional connectedness with other people" (p. 714), but as a reflection of meaningful musical experiences leading to connection. In contrast to my study McDermott and colleagues' (2014) used a deductive approach that followed Spector and Orrell's (2010) biopsychosocial theory, with their focus on experiences, meanings, and values whereas my study had a different focus and followed inductive reasoning with theory generated from the data without any preconceived theoretical approaches. Nonetheless, the value of their study was that both emotion and connectedness were identified as core components of the experiences of

PwD.

## Situating Communication through Emotional Connectedness

The following section focuses on the relationship between the emergent theory and the main categories, comparing and contrasting it with the literature. Included is how the theory was generated from and integrates with the main categories, as well as their interplay upon each other.

### Relating with Others within Emotional Connectedness

*Relating with Others* is that part of communication that involved the PwD engaging in some manner with their interlocutor as a dynamic response to and through music that led to emotional connectedness. Within this theory, this act of relating was both emotive and connective, as seen in the subcategories where emotional connectedness informed them. For example, *a conduit*, *sharing experiences*, *the voice*, and *body language*, all are manifestations of emotion in interplay with connectedness. The value of connectedness in this theory is that it is more than just communication in the moment or facilitating utilitarian responses for successful ADL during caregiving; it is relating with the other to build a relationship, to build "emotional connectivity" (Robyn).

To reflect the more relational aspect of this category the word "conduit" (subcategory *a conduit*) was selected to reflect the variety of ways in which music was seen to facilitate connectedness between the PwD and the caregiver. The word itself is interpretive in keeping with a constructivist approach. I considered alternatives such as "bridge" or "pathway," but felt that these two descriptors were less linked to the idea of communication, whilst conduit was more appropriate as etymologically, it derives from the Latin "*conducere*" (trans. bring together") connoting a linking up between entities, rather than something just to be traversed.

Hence “conduit” reflected the variety of ways in which music brings together the PwD and the caregiver. Though it may be accompanied by similar indicators (e.g., words and gestures) the *conduit* for each PwD remains unique and personal.

This personal uniqueness was seen through the various examples in the findings of music facilitating *relating.* Illustrative of this on the nonverbal level was the use of body language. Body language emerged as part of relating not only as a physiological response but by emotion, memory, awareness, the feeling of sharing, and a desire to express oneself through familiar music. These findings are consistent with the literature where the use of music has been found to facilitate relating with others that is imbued with emotion and relationship building (Allison et al., 2019; Clare et al, 2020; Dassa, 2018; McDermott et al., 2014; Ridder & Gummesen, 2015).

Emotional connectedness, in this study, is reflected in *the voice* being identified with such variables as tone, intonation, and dynamics. The use of the voice commences in infancy and predates spoken language as a conveyer of emotion. The voice as a conveyer of intensified emotion has been noted to facilitate communication (Götell et al., 2009; Pavlicevic, 2013; Ridder & Gummesen, 2015). Singing in this study also emerged as a communicative substitute for the spoken voice, where it provided an opportunity for PwD to use their voices to relate, circumventing the difficulty of using speech. The singing voice built “emotional connectivity” and was identified as a primal and intimate mode of vocal communication that could enhance and enable relating between the PwD and their caregiver, or in group music settings between the PwD, the caregiver, and other participants. Such findings are congruent with the literature where the voice is seen as an aural focus for expression given the intensity of dynamics and melodic inflection for indicating emotion (Bannan & Montgomery-Smith,2008; Brown et al., 2001; Dassa & Amir, 2014; Engstrom et al., 2011b; Marmstål-Hammar et al., 2010a).

*Relating with Others* as a category also informed and was informed by the other main categories. *Sharing experiences* through *Music through Memories* via *familiar music* enabled the triggering of long-term memory to awaken meaningful past life events that enhanced or triggered *identity*, a sense of self-awareness, *intimacy*, and *togetherness*. This is particularly evident in spousal communication where, given years of shared intimacy, becomes imbued with emotional connectedness. Similar findings exist in the literature on the communication enhancing effect of music due to its triggering reminiscence, identity, and bonding between PwD and significant others (Dassa et al., 2020; Garabedian & Kelly, 2018; Osman et al., 2016). Baird and Thompson (2018) noted in their study of a spousal couple that even in late-stage dementia "music engagement, in particular emotional responsiveness to music can persist…" (p. 459).

*Relating with Others* is also linked to and informed by remembering (such as familiar music triggering identity) and being (such as music triggering a sense of togetherness). Such interplay between these categories and subcategories are indicative of the dynamism of their interplay giving rise to the core category.

**Memories through Music within Emotional Connectedness**

*Memories through Music* is that part of communication that is brought about through familiar music triggering reminisces, and the recollection of these memories can reawaken the PwD to their identity. Memories through music are founded upon emotions, the recollection of past events, and the awakening of a sense of self. This triggering and expression of memories to and with others builds emotional connectedness. The findings of this study on music triggering memories and having emotive links amongst PwD are well established in the literature (Baird & Thompson, 2019; Baker et al., 2012; Dassa & Amir, 2014; Dassa, 2018; Garabedian & Kelly, 2018; Mandzuk et al, 2018; McDermott et al., 2014). Central to reminiscence was the idea that

the given piece of music has played a significant role in the person's life. In the findings reminiscence involved the entirety of the person because it is part of identity. Identity can be particularly emotive, as was evidenced in music triggering long-term memories as noted in the findings. The value of reminiscing has also been noted to facilitate strong emotional content and lead to a closer connection with the caregiver, especially those who are family (McDermott et al., 2014; Garabedian & Kelly, 2018; Osman et al., 2016).

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Familiar music plays a central role in triggering reminiscence for PwD being ingrained in their long-term memory. Familiar music in this study was reflected in emotional connectedness because memories are linked to emotion leading to both verbal and nonverbal indicators of connectedness, indicative of communication. Similar findings are reflected in the literature where emotion being linked to familiar music and facilitating communication has been well established (Bannon & Montgomery-Smith, 2008; Dassa & Amir, 2014; Foster et al., 2009; Levitin, 2007; Mandzuk et al., 2018).

Another reason that familiar music may elicit emotion is that it is accessible for the PwD. They may not only recall melody, rhythm, but also words. Familiarity with music was seen to improve both dyadic and group interaction, with emotional indicators such as smiling, facial relaxation, positive body language reflecting a desire to interact and connect. This accessibility also is reflected in the category of *Being in the Moment,* where coming to an understanding of the music as familiar can then facilitate in PwD feelings of safety, calmness, comfort, togetherness, and the containment of the emotion. Such findings are reflected in the literature where secure feelings can enable positive emotions and enhance communication (Brown et al., 2001; Götell et al., 2002, 2003; Marmstål Hammar Götell et al., 2011).

Memories for PwD may also involve reconnecting with *identity*, which plays an important role in communication as the dialogic exchange comes through the mediation of one's identity. Identity was triggered using familiar music and links to mnemonic recall, leading to emotional responses to memories. Identity was manifested through vocalizations (such as increased speech, the recollection of past events, singing) and body language (such as smiling, eye contact, increased proximity to the caregiver). In this study, music was seen to open up the PwD to express their inner selves, through touching back to memories, meaningful events, and reconnecting themselves with their autobiography. These findings are reflected in the literature where identity has been noted to become less obscured, music permitting the PwD to reach back to being who they were (Baird & Thomson, 2018; Dassa, 2018, Dassa et al, 2020; Genoe, 2009; McDermott et al., 2018). *Identity* becomes informed by memories in the sense of linking memories to *relating* (e.g., relating to another because of self-identification of an existing relationship, or a desire to share an experience), and as part of *being in the moment*, in the sense of immediate temporal awareness of identity (as reflected in the *togetherness* of emotional connectedness to the self and the other).

A serendipitous finding in my study, which has also been noted in the literature (Dassa & Amir, 2014) is the importance of culture within the context of facilitating access to identity. Cultural identity is in long-term memory; music that is selected and presented in a manner that reflects the PwD's culture not only will allow for identity to be accessed, but by engaging with something familiar, can also create a sense of anchoring, reflecting interplay with the category of *being in the moment.* Diversification of the Canadian population calls for a diversification of musical selections to match the identities and experiences of the PwD.
To ensure optimization of emotional connectedness, music needs to touch the PwD's identity,

memory, and sense of safety. To conclude, memories through music for PwD cannot be separated from their sense of being and their relating with others but exist with them in dynamic interplay.

**Being in the Moment with Emotional Connectedness**

*Being in the Moment* is that part of communication that reflects an interior state that is expressed through communication. For PwD, music was seen to facilitate various states of mind that enhanced emotional connectedness. This sense of interior being is expressed externally, both verbally and nonverbally. Music can provide PwD an *anchoring* moment in themselves leading to create the potential of creating connectedness with others. *Anchoring* in a sense of self-awareness in the current study was indicated by PwD recalling past events, sharing experiences, and expressing emotions. Musical indicators of anchoring could be melodic and rhythmical interactions, indicating connectedness through responding to the music, including mirroring and matching. It is within the "moment" of the temporal experience where the PwD is no longer indicating confusion, distancing, or unresponsiveness, but begins to show communicative indications of interaction reflecting emotional connectedness. Awareness of self and the other has been noted in the literature (Baker et al., 2012; Clair & Ebberts, 1997; Dassa, 2018; Götell et al., 2000, 2003, 2009; Schoenfelder & Gerdner, 2010). However, in contrast to the literature, the concept of awareness within a rich tapestry of the self and self with others was further developed in this current study, where it was identified to be closely related to other interior states that enhanced emotional connectedness, such as *togetherness* and *intimacy*. A sense of awareness enabling anchoring also comes from interplay with the PwD engaging in relating (e.g., expressing emotion and connection using the singing voice), and remembering (e.g., responding to familiar music and one's identity).

*Intimacy* as a subcategory of *anchoring* that reflected the bonds of a closer emotive relationship between the PwD and the caregiver. Intimacy is highly emotive and necessitates connection to the other. Intimacy, in this study, was particularly reflected in spousal communication, but not exclusively. As part of their training, music therapists seek a therapeutic relationship with their client, which emerged in the findings as using the musical encounter to build connectedness, sharing feelings, listening to, and responding to PwD's needs, and using musical cues to enhance interaction. Substantive literature exists on the value of intimacy as a product of musical encounters with PwD. For example, it has been noted that PwD can indicate intimacy in a variety of ways including holding hands (Allison et al., 2019), kissing, hugging (Götell et al., 2003), and touching (Clair & Ebberts, 1997). Such acts of intimacy reflect communication through emotional connectedness.

*Togetherness* was another aspect of *Being in the Moment*, that reflected the immediacy of the connection between the PwD and the caregiver. It is a sense of being with the other, as manifested in communicative indicators that indicate a deeper level beyond mere reaction, but of emotional response that can go deeper than words. Togetherness emerged not just as connecting to the other person, but connection being interwoven with the concept of *anchoring* and a feeling of safety, reflecting the immediacy of *Being in the Moment.* Togetherness becomes more than just an activity indicating connection, but emerged as a state of mind, of awareness of the connection with the caregiver. Togetherness as connection could build during the encounter or it could be spontaneous, both being a creative interaction indicating communication.

*Togetherness* is reflected in the literature more as engaging in activities jointly between PwD and their caregivers (Allison et al., 2019; Dassa, 2018; Götell et al., 2009; Osman et al, 2016). However, it has also been described as a form of "reciprocity," and as shared and

purposeful “being in the moment” (Baker et al., 2012, p. 14). Clare and colleagues (2020) identified music as facilitating togetherness with the emphasis on achieving a sense of immediate, purposeful connection, with an emphasis on the relational impact of togetherness. These latter two studies parallel the immediacy, emotiveness, and connectivity found in this current study.

The third major subcategory was the need of PwD to feel *being in a safe place* when communicating. The need for security is identified in the literature as a core need for PwD (Clare et al., 2020; Fischer-Terworth & Probst, 2011; Jonas-Simpson et al., 2006; Nolan et al., 2004). PwD are already compromised cognitively, and by not living within the community in a familiar surrounding, many are also compromised psychologically and socially (Clare et al., 2020; Garabedian & Kelly, 2018: Thuerer et al., 2015). The need for security was reflected in the findings under various descriptors, indicative of its subjectivity. Instructive is the word “container,” which helped me consider the importance of the state of mind of a PwD to achieve positive, successful communication. Safety, security, awareness of being able to freely express themselves, a feeling of autonomy were seen as vital to the creation of a safe space by the caregiver.

A sense of safety can be achieved by just listening to the person’s musical needs through their verbalization or taking the time to read their nonverbal indicators. Knowing about the person and acknowledging them is instrumental in building the sense of safety or the “container” for them to perceive they can engage in expressing themselves. As such, the sense of being in a safe place was seen to inform the desire and ability to relate and participate in a musical activity that can trigger reminiscence. In the literature, music is noted for its ability to influence mood as part of affect regulation that is influenced by mirroring, matching, vocal responses, and

facial/eye contact by the caregiver (Aldridge, 2005a; Götell et al., 2009; Marmstål Hammar et al., 2011). Once affect is "contained" then the possibility opens up for communication (Ridder & Gummesen, 2015). Emotional connectedness optimally exists within a safe, welcoming space, where the PwD has the freedom to express themselves as an autonomous person—a person who is heard and influencing the choice of music and interaction. Human communication with PwD in this study was found to be not forced, but free, a true dialogue.

Related to the sense of safety and being in the moment is the serendipitous finding of the potentially negative effect of extraneous sounds in LTC facilities. The effect of sound and noise has also been noted in the literature, where what has been termed as the overall collective environmental "soundscape" (e.g., loud repetitive noises, staff talking) has an effect on the health and well being of PwD and can induce agitation and feelings of unsafety (Devos et al., 2019; Janus et al., 2021). Everyday sonic environment can be both positive, such as natural sounds and music, or negative, such as loud repetitive sounds which can induce in PwD agitation and feelings of unsafety (Devos et al., 2019). The effects of soundscapes should be further researched, including the incorporation of background music.

## Three Illustrative Examples of the Theory

Having given an interpretation of how the main categories generate the emergent theory, in this section, I present three illustrative examples of the interplay of the main categories that resulted in communication through emotional connectedness. Such examples providing an interpretive lens into the theory in action, reflecting Charmaz's (2014) suggestion that situating a theory within its context, in empirical reality, strengthens the theory.

My first example is selected from Johana's statement:

…often, you know, if folks are indicating to me that they want to reminisce and chat and

> they're spontaneously sharing memories. Or you know, I'll ask questions you know, tell me about, um, you know, I notice you singing along. Did you sing a lot growing up? Was music a part of your family life?

In this example, music is seen to trigger remembering and identity (Category B), through mnemonic recall of familiar songs, resulting in sharing experiences through relating (Category A), via the conduit of music. Further, the shared experiences are tied to a sense of spontaneity and openness of being aware (Category C). Awareness informs the ongoing reminiscing and expression through relating with the other, indicating interplay resulting in emotion connectedness.

My second example is Jen's comment:

> So, there's one resident that I work with and completely nonverbal. And they are um constantly making verbalizations. So they're moaning or sighing, or things like that. And it's like incessant. They're always doing that. And as soon as they hear their preferred music, so if I go in, and I play them an Elvis song. They really like Elvis. Uh, the verbalizations are gone immediately. And their eyes are on me.

In this example, the resident transitions from being withdrawn and incoherent to engaging with body language, and responding to familiar music (Category B) and anchoring and being in the moment (Category C) leading to relating with Jen (Category A). Relating is sustained through a sense of being and remembering, indicating the constant main category, the interplay of familiar music and mnemonic recall, anchoring in the moment of the musical experience, identifying with it, and relating with body language. This example reflects a shift to positive emotion and indications of connectedness.

My final example comes from Lena. She stated:

> …upon hearing a familiar song, they would start crying kind of out of nowhere. But because, because of that song or that environment that they are in, in the moment, something gets them right there right away. Um, sometimes when I've seen clients who are a little bit agitated or angry at something and I play, play it. I know from experience I play a song that they, I know that they, enjoy. Um they're kind of, they move, they're kind of some; a switch flicks and it brings them to, you know, to a happier moment.

In this example, we have the use of familiar song (Category B) precipitating an emotional response (Category A), and a "switch" from emotive negativity to positivity, to a sense of happiness (Category C), indicating the effect of music on emotion, precipitating a change into a sense of awareness and anchoring in the moment, indicating the main category interplay leading to happy emotions and connectedness. In summation, all three main categories indicate that communication for PwD is a process of *relating*, *remembering*, and *being*. Each coming in any order, with different emphases, dynamics, and duration due to the subjective nature of emotional connectedness.

## Strengths and Limitations of the Study

This study is timely given that Canada is an aging society with a growing demographic that has or may develop some form of dementia. First, an understanding of how music may facilitate communication can lead to both improved QoL and quality of care for PwD. Secondly, the strength of the study included addressing the issue of communication for PwD by seeking input from both health care professionals, who have extensive experience in the use of music, and family caregivers, who often have an intimate knowledge of their loved one's needs, resulting in eliciting rich data from the varied and diverse experiences of the caregivers. Thirdly,

a constructivist grounded theory (CGT) was utilized for this study that was amenable to the subjective phenomena of music and communication, as well as the subjective experiences of the caregivers from whom, via interviews and a focus group, the data and subsequent analysis were generated. This enabled an open, flexible approach to an exploratory subject in a little researched area, so that a substantive theory could be generated leading to new insights and perspectives on how music facilitates communication for PwD. Fourthly, this CGT study is of utility from its application to real-life situations, and in daily familial interactions for informal caregivers. By involving a wide variety of caregivers, a credible grounded theory can be proposed precisely because of the varied voices that contributed to the data. As a result, this research may be of use health care professionals, students, families, and stakeholders in both institutional and community settings.

There are also important limitations to this study. The first is that the research is limited to data generated from thirteen caregivers (and their unique experiences with PwD) and that the study findings are not therefore proposed as a claim for universal generalizability; rather, the goal was to develop theoretical concepts from the data that may be useful for individuals and organizations that promote music for dementia care. Music therapists, nurses, and recreation and occupational therapists might use the findings of this study to promote the use of music amongst fellow health professionals.

Sixteen interviews and one focus group may seem limiting but following grounded theory methods for theoretical sampling, sampling was stopped when saturation occurred with no new theoretical insights discovered or new properties for the emergent main categories and core category. Further, although music therapists and allied health care aids were represented, multiple attempts to recruit from other health care professions, such as nurses, recreation

therapists, and occupational therapists were not successful. As such, their use of music in clinical settings were not represented. The reason for the lack of success in recruiting is unknown but may have been due to a sub-optimal healthcare professional-client ratio during the COVID-19 health care crisis or the fact that, for example, nurses are over-researched.

Finally, this study was based on my interpretation of the interviews and focus group, and that the construction of the theory as noted is but one interpretation. Further, my history, biases, and experiences with PwD (especially as a family caregiver) could be interpreted as a limitation. As noted, to deal with my biases, I began to engage and explore my assumptions and experiences prior to undertaking this research. Being aware of my personal history, I strove throughout my doctoral studies to question myself and constantly be open to new perspectives. One understanding that I came to realize emphatically throughout my studies and research was the subjectivity and uniqueness of each person's musical experience. This belief strongly underlies this study and I believe ensured that I stayed faithful to the constructivist position that ensures credibility, notably that there be logical links between data gathered and analysis, allowing the evidence to support the claims of the researcher (Charmaz, 2014).

## Recommendations that emerged from the Study

### Recommendations for Administrators of LTC Facilities

- Review admission procedures to ensure that the musical history of new residents is included on intake forms.
- Review environmental sound to minimize sounds and noise that could be detrimental to residents' experiences of safety and comfort. The administrator (or a designate) and a music therapist should conduct an assessment of staff activities and practices to optimize a positive soundscape atmosphere.

- Ensure families are made aware in resident council meetings of the value of music as a possible communication tool.
- Review the place of music related activities in complementary and recreation therapies programs to ensure optimal use of music.

**Recommendations for Staff Educators**

- Invite a music therapist to provide a workshop for staff to increase awareness and knowledge of the benefits of music and sound for PwD.

  Teach (inservice) staff about the use of music for communication with residents.

**Recommendations for Music Therapists**

- Educate informal caregivers about the benefits of music for communication.
- Work with families to encourage them to use music with their family member, such as playing favourite songs, singing to and with them.
- Suggest family members attend a music recreation activity, attend LTC concerts, sing-a-longs with their loved one.

**Recommendations for Nurses**

- Nurses in LTC environments should work collaboratively with recreation therapists to optimize communication for residents.
- Ensure that the list of preferred music taken from the intake form is in the resident's room and establish a protocol so that it is regularly reviewed and followed by care staff.
- Use the resident's favourite songs as background music during caring contexts.
- Home care nurses as appropriate, should counseling older clients and families on the benefits of music and music therapy.

- Home care nurses should consider using music as an intervention as part of their services.
- Nurse educators should review undergraduate curricula to ensure programs include information on the use of music for health and wellbeing.

  Actions for consideration might include: inviting music therapists to give seminars on the use of music, having nursing students observe music therapy sessions.

**Recommendations for Informal Caregivers**

- Develop a “favourite music list” based on your family members preferred music. This can be done by reviewing their record/CD collection, speaking with them and family members. Focus on music from their early years (childhood to young adult).
- When communicating with your family member consider including singing with and to them their favourite songs.
- When communicating with your family member consider including using the melodies of familiar songs in your speech.
- In a LTC environment, ensure a list of preferred music is in your family member’s room and review with staff on when and how to use the music.
- Consider providing your family member a CD player, iPad, radio for listening to preferred music.

**Recommendation to the Canadian Association of Music Therapists**

- Review educational requirements specific to music as a tool for communication within dementia care.

**Recommendations for Seniors-focused Organizations**

- Consider including music-based activities in programs and services.
- Provide information on music and music therapy to families of people who live in the community and have been diagnosed with dementia.

## Future Directions

In this section, I outline five suggestions (two with possible strategies) for future research aimed at exploring and developing the understanding gained in this exploratory study.

- Test the substantive theory from the perspectives of health care professionals whose practice involves regular, direct contact with PwD (nurses, music therapists, recreational therapists, occupational therapists), exploring any differences in experiences, as well as other variables that may influence the theory.

  Action Item: An executive summary of the study will be sent to the following professional associations suggesting it be included in their newsletters: Canadian Association on Gerontology, Canadian Association of Music Therapists, Canadian Gerontological Nursing Association, Canadian Therapeutic Recreation Association, and the Canadian Association of Occupational Therapists.
- Test how this substantive theory could be explored and promoted within a context of caring in nursing theory.

  Action Item: A short summary of the study will be sent to the Canadian Holistic Nurses Association to be potentially included in their association newsletter.
- Conduct future studies into how communication affects the informal caregiver's well-being and mental health and its impact on quality of care for PwD.

- Conduct concatenated research from a mixed methods perspective to explore the substantive theory from an interprofessional perspective (e.g., medicine, neuroscience, nursing, psychology, sociology) (Stebbins, 2001).
- Conduct concatenated research to explore the findings of this study regarding understanding the experiences of PwD from the perspective of anchoring, safety, and autonomy to add to the understanding of the "voices" of PwD.

## Conclusion

This study used a constructivist grounded theory approach to explore the question of caregivers' experiences of how music facilitates communication for PwD. Data was collected from formal and informal caregivers from across Canada. The inductive logic of grounded theory provided the key to explore, question, analyze, and synthesis the data through to the discovery of the created categories that built the emergent theory. Three main categories emerged: *Relating with Others, Memories through Music*, and *Being in the Moment*. These categories provided the conceptual framework that gave birth to the substantive theory of the core category: *Communication through Emotional Connectedness*. The theory's main underpinnings of PwD Communicating through *relating*, *remembering*, and *being* were substantially supported by the literature. As the first constructivist grounded theory dealing specifically with how music facilitates communication for PwD, this study offers clarity on the dynamic influences that interplay and provide impetus towards communication.

A number of recommendations were proposed for health care professionals, including changes to curricula to ensure that music is included. This is particularly prescient for those who may be involved in clinical practice with older people. The use of music in this study emerged as having the potential to improve QoL as well as being a component of best practices for quality

dementia care. It is hoped that this emergent theory will not only benefit our understanding of how PwD engage in communication via music, but also be the basis for concatenated research so that new and fresh insights may take us from exploration to ever greater understanding, drawing on “cumulative expertise” and “team research” (Stebbins, 2001, p. 16). To conclude, music in this study has been seen to empower PwD to communicate, resulting in them being able to engage in relationships, remember meaningful events, and become aware of self. As has been seen in this study, PwD respond to the beauty and mystery of music; the curtain is lifted and they can communicate again: through emotional connectedness.

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Appendix A

**Recruitment Flyer for Formal Caregivers**

# DOES MUSIC FACILITATE COMMUNICATION FOR PEOPLE WITH DEMENTIA?

## Do you use music as part of dementia care?

## I would like to hear from you about how music affects their ability to communicate, and how this might influence your approach to your care plan.

## This study will be completely online!

My name is Jon Parr Vijinski and I am a doctoral student in nursing, and my supervisor is Dr. Sandra P. Hirst, RN, Ph.D., GNC(C), of the Faculty of Nursing, University of Calgary.

I am doing research into the use of music for communication for those who are experiencing dementia from the perspective of family members.

## Please contact me to learn more!

**Jon Parr Vijinski, MSc, PhD (C)**

**416-766-6741 or at: jon.parrvijinski1@ucalgary.ca**

Appendix B

**Recruitment Flyer for Informal Caregivers**

# DOES MUSIC FACILITATE COMMUNICATION FOR PEOPLE WITH DEMENTIA?

## Does your family member love music?

## I would like to hear from you about how music affects your loved one's ability to communicate.

## Please join my online study!

My name is Jon Parr Vijinski and I am a doctoral student in nursing, and my supervisor is Dr. Sandra P. Hirst, RN, Ph.D., GNC(C), of the Faculty of Nursing, University of Calgary.

I am doing research into the use of music for communication for those who are experiencing dementia from the perspective of family members.

## Please contact me to learn more!

**Jon Parr Vijinski, MSc, PhD (C)**

**416-766-6741 or at: jon.parrvijinski1@ucalgary.ca**

Appendix C

**INFORMED CONSENT FORM – FORMAL CAREGIVER**

**TITLE:** Caregivers' Experiences of How Music Facilitates Communication for People with Dementia.

**INVESTIGATORS:** Principle Investigator: Dr. Sandra P. Hirst RN, PhD, GNC(C) (Supervisor)
Co-Investigator: Jon Parr-Vijinski. MSc (Doctoral candidate)
Faculty of Nursing, University of Calgary
2500 University Drive NW
Calgary, AB, T2N 1N4

This consent form is only part of the process of informed consent. It should give you a basic idea of what the study is about and what you will be doing. If you would like more information, or have any questions, please ask. Take the time to read this carefully. You will receive a copy of this form for your records.

## A. BACKGROUND

One of the major effects of dementia is a gradual loss of the ability to communicate. This not only impacts the person with dementia, but also formal and informal caregivers in their personal interactions and caregiver activities with people with dementia. Communication is a vital part of dementia care, and music has been identified as a facilitator of communication. Formal caregivers, such as nurses, music therapists, recreation therapists, occupational therapists, and health care workers have been involved in using music in their respective disciplines for dementia care for years. Informal caregivers, such as family members, use music as part of their shared personal and social life with the person with dementia.

## B. WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to explore how music may facilitate communication (verbal and non-verbal) for people with dementia, who live in a long-term care facility or the community (e.g. at home). The exploration will be from the perspectives and experiences of formal caregivers (such as nurses, music therapists, recreation therapists, occupational therapists, HCAs PSWs) and informal caregivers (such as family member or friend).

## C. WHAT WOULD I HAVE TO DO?

If you agree to participate in this study, you will be agreeing to participate in one of three options:

**Option 1.** Interview. The interview will consist of open-ended questions conducted by the Co-investigator about how you may experience music as facilitating communication for people with dementia. The interview will last between 45-60 minutes (if you wish, you can choose to have the interview in two sections on different days). You may be asked to participate in a short follow-up interview. The follow-up interview would only be required if the Co-Investigator needed to clarify some aspect of the main interview or ask an additional question. Interviews will be conducted using your choice of either: Zoom, Skype, or the telephone. You will select the date and time of the interview/s.

**Option 2**. Focus Group. The focus group (no longer than 60 minutes, maximum of eight participants) will be conducted using Zoom with a group of formal and informal caregivers. The purpose will be to discuss in a focus group setting, similarities, and differences of your experience of the effect of music on communication for people with dementia. The date and time of focus groups will be selected by the Co-Investigator, but you will have a choice of morning, afternoon, or evening sessions.

**Option 3.** Interview and Focus Group. You have the option of participating in both an interview and a focus group.

Please indicate with an "X" in the appropriate box below the Option you have selected to participate. If you select Option 2 or 3, you are also agreeing to keep confidential the identities of other participants in the focus group, and the contents of the focus group.

Option 1. An Interview: ☐

Option 2. Focus Group: ☐

Option Three. Interview and Focus Group: ☐

## D. WHAT ARE THE RISKS?

There are no known risks for you participating in this study.

## E. WILL I BENEFIT IF I TAKE PART?

If you agree to participate in this study, there may or may not be a direct benefit to you. The information obtained from this study may help to provide a better understanding of how people with dementia communicate, as well as generate new knowledge for your profession.

## F. DO I HAVE TO PARTICIPATE?

Participation in this study is completely voluntary. You may withdraw from the study at any time simply by informing the Co-Investigator. Once you have completed your participation in the study the data cannot be withdrawn.

## G. WILL I BE PAID FOR PARTICIPATING, OR DO WE HAVE TO PAY FOR ANYTHING?

You will not be paid, but you will receive an eGift Card valued at $15 from your choice of: Presidents' Choice, Tim Hortons, or Amazon, which will be delivered directly to your email. If you do not use email, the gift card of the same value will be mailed to your home address.

## H. WILL MY RECORDS BE KEPT PRIVATE?

All information, all data on my laptop will be available only to me, and my doctoral thesis supervisory committee. My laptop will be password protected and all files encrypted. An external hard drive for digital back-up will also be password protected and have all files encrypted. Online access for participation in interviews and focus groups will be password protected. The laptop and hard drive will be locked in a fireproof cabinet.

Your privacy will be protected by you being identified with a pseudonym of your choosing in all written documentation. Anything written about you will only use your pseudonym. Your real name and information will be kept only on your Demographic Questionnaire that will be locked in the fireproof cabinet. Your real name will only be used in any focus group.

Data that is collected for this research will be re-identified and stored in a database for possible future use by the Principal Investigator (Thesis Supervisor) and other researchers. Any future use of this research data is required to undergo a rigorous review by a Research Ethics Board.

## I. IF I SUFFER A RESEARCH-RELATED INJURY, WILL THEY BE COMPENSATED?

This research is a minimal risk study, involving only your participation in an online (or telephone) interview, and/or an online focus group. It does not have the potential for research-related injury.

## J. SIGNATURES

Your electronic signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a participant. In no way does this waive your legal rights nor release the investigators or involved

institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time. If you have further questions concerning matters related to this research, please contact.

Mr. _____ (416) ___-____

Or

Dr. _____ (403) ___-____

If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

**By checking this box ☐ and typing your name below, and emailing it back to me, you consent and understand that you are electronically signing this consent form. If you wish to physically sign this consent form, a copy will be mailed to you to check the appropriate Option Box (see above page 2), and for you to sign below.**

| | |
|---|---|
| Participant's Name | Date |
| Co-Investigator's Name | Date |

The University of Calgary Conjoint Health Research Ethics Board has approved this research study (REB 20-2192).

A copy of this consent form has been given to you to keep for your records and reference.

Appendix D

**INFORMED CONSENT FORM – INFORMAL CAREGIVER**

**TITLE:** Caregivers' Experiences of How Music Facilitates Communication for People with Dementia.

**INVESTIGATORS:** Principle Investigator: Dr. Sandra P. Hirst RN, PhD, GNC(C) (Supervisor)
Co-Investigator: Jon Parr-Vijinski. MSc (Doctoral candidate)
Faculty of Nursing, University of Calgary
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One of the major effects of dementia is a gradual loss of the ability to communicate. This not only impacts the person with dementia but also formal and informal caregivers in their personal interactions and caregiver activities with people with dementia. Communication is a vital part of dementia care, and music has been identified as a facilitator of communication. Formal caregivers, such as nurses, music therapists, recreation therapists, occupational therapists, and unregulated health care workers have been involved in using music in their respective disciplines for dementia care for years. Informal caregivers, such as family members, use music as part of their shared personal and social life with the person with dementia.

## B. WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this study is to explore how music may facilitate communication (verbal and non-verbal) for people with dementia, who live in a long-term care facility or the community (e.g. at home). The exploration will be from the perspectives and experiences of formal caregivers (nurses, music therapists, recreation therapists, occupational therapists, HCAs, PSWs) and informal caregivers (family member or friend).

## C. WHAT WOULD I HAVE TO DO?

If you agree to participate in this study, you will be agreeing to participate in one of three options:

**Option 1.** Interview. The interview will consist of open-ended questions conducted by the Co-investigator about how you may experience music as facilitating communication for people with dementia. The interview will last between 45-60 minutes (if you wish, you can choose to have the interview in two sections on different days). You may be asked to participate in a short follow-up interview. The follow-up interview would only be required if the Co-Investigator needed to clarify some aspect of the main interview or ask an additional question. Interviews will be conducted using your choice of either: Zoom, Skype, or the telephone. You will select the date and time of the interview/s.

**Option 2**. Focus Group. The focus group (no longer than 60 minutes, maximum of eight participants) will be conducted using Zoom with a group of formal and informal caregivers. The purpose will be to discuss in a focus group setting, similarities, and differences of your experience of the effect of music on communication for people with dementia. The date and time of focus groups will be selected by the Co-Investigator, but you will have a choice of morning, afternoon, or evening sessions.

**Option 3.** Interview and Focus Group. You have the option of participating in both an interview and a focus group.

Please indicate with an "X" in the appropriate box below the Option you have selected to participate. If you select Option 2 or 3, you are also agreeing to keep confidential the identities of other participants in the focus group, and the contents of the focus group.

Option 1. An Interview: ☐

Option 2. Focus Group: ☐

Option Three. Interview and Focus Group: ☐

## D. WHAT ARE THE RISKS?

There are no known risks for you participating in this study.

## E. WILL I BENEFIT IF I TAKE PART?

If you agree to participate in this study, there may or may not be a direct benefit to you. The information obtained from this study may help to provide a better understanding of how people

with dementia communicate, from the perspective of family members or friends as informal caregivers.

## F. DO I HAVE TO PARTICIPATE?

Participation in this study is completely voluntary. You may withdraw from the study at any time simply by informing the Co-Investigator. Once you have completed your participation in the study the data cannot be withdrawn.

## G. WILL I BE PAID FOR PARTICIPATING, OR DO WE HAVE TO PAY FOR ANYTHING?

You will not be paid, but you will receive an eGift Card valued at $15 from your choice of: Presidents' Choice, Tim Hortons, or Amazon, which will be delivered directly to your email. If you do not use email, the gift card of the same value will be mailed to your home address.

## H. WILL MY RECORDS BE KEPT PRIVATE?

All information, all data on my laptop will be available only to me, and my doctoral thesis supervisory committee. My laptop will be password protected and all files encrypted. An external hard drive for digital back-up will also be password protected and have all files encrypted. Online access for participation in interviews and focus groups will be password protected. The laptop and hard drive will be locked in a fireproof cabinet.

Your privacy will be protected by you being identified with a pseudonym of your choosing in all written documentation. Anything written about you will only use your pseudonym. Your real name and information will be kept only on your Demographic Questionnaire (including a Demographic Questionnaire for your loved one) that will be locked in the fireproof cabinet. Your real name will only be used in any focus group.

Data that is collected for this research will be re-identified and stored in a database for possible future use by the Principal Investigator (Thesis Supervisor) and other researchers. Any future use of this research data is required to undergo a rigorous review by a Research Ethics Board.

## I. IF I SUFFER A RESEARCH-RELATED INJURY, WILL THEY BE COMPENSATED?

This research is a minimal risk study, involving only your participation in an online (or telephone) interview, and/or an online focus group. It does not have the potential for research-related injury.

## J. SIGNATURES

Your electronic signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a participant. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time. If you have further questions concerning matters related to this research, please contact:

Mr._____ (416) ___-____

Or

Dr. _____ (403) ___-____

If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

**By checking this box ☐ and typing your name below, and emailing it back to me, you consent and understand that you are electronically signing this consent form. If you wish to physically sign this consent form, a copy will be mailed to you to check the appropriate Option Box (see above page 2), and for you to sign below.**

| | |
|---|---|
| Participant's Name | Date |
| Co-Investigator's Name | Date |

The University of Calgary Conjoint Health Research Ethics Board has approved this research study (REB 20-2192).

A signed copy of this consent form has been given to you to keep for your records and your reference.

Appendix E

**Demographic Questionnaire – Formal Caregiver**

**Pseudonym: _____**

1. Name: _____
2. Age _____
3. Gender: _____
4. Highest level of education in your professional designation:_____
5. What is your professional/clinical role when you work with people with dementia? _____
6. Do you, or have you ever had any active musical interests? Yes: ____ No: _____. If "yes", please indicate how (e.g., participated in a musical, was a member of a choir):_____
7. Does music have any specific cultural significance for you? Yes_____ No:_____ If "yes" please indicate how (e.g., country music, opera, ethnic-specific music) :_____
8. Number of years in your professional discipline:_____
9. Primary area of practice: _____
10. What is your primary environment of work? (e.g., community, LTC, acute care): _____
11. Number of years that you have worked with persons with dementia:_____

Appendix F

**Demographic Questionnaire – Informal Caregiver**

**Pseudonym: _____**

1. Name: _____
2. Age: _____
3. Gender: _____
4. What is your relationship to the person with dementia? _____
5. Do you or have you ever had any active musical interests? Yes: ____ No: _____. If "yes", please indicate how (e.g. participated in a musical, was a member of a choir):_____
6. Does music have any specific cultural significance for you? Yes____ No:_____
   If "yes" please indicate how (e.g., country music, opera, ethnic-specific music):
   _____
7. Education: ( ) 0-8 years of study, ( ) some high school, ( ) high school graduate, ( ) some postsecondary, ( ) postsecondary graduate.

Appendix G

**Demographic Background Questionnaire for the Person with Dementia**

**as provided by Family Member**

1. Age of the person with dementia: _____
2. Gender of the person with dementia: _____
3. When was your family member diagnosed with dementia_____ type_____
4. Current place of residence_____
5. Years in residence in the LTC facility: _____[if applicable]
6. Did he/she have an interest in music before diagnosis with dementia?
   Yes: ___ No: ____
7. Does he/she have a continuing interest in music? Yes: _____ No: _____
8. Type of music interested he/she is interested in? _____
9. Has his/her taste in music changed since he/she was diagnosed with dementia?
   Yes: ____No____
   If "yes", please indicate how (e.g. liked big band, now likes classical) _____
10. Did music have any specific cultural significance for your loved one? Yes____
    No:_____ If "yes" please indicate how (e.g. country music, opera, religious, ethnic-specific music) :_____
11. Did he/she ever have any active musical interests (e.g. participating in school musicals, being a member of a choir )? Yes: ____ No: _____. If "yes", please indicate how (e.g. participated in a musical, was a member of a choir):_____
12. Does he/she engage in any formal music therapy or interventions? If so, what type/s? (e.g. group singing)_____
13. Does he/she use music within any particular setting? (e.g. playing the radio):_____
14. Is there a key word or phrase you might describe your family member's experience with music since diagnosis with dementia? _____
15. Does he/she have any formal musical training? Yes: ____ No: ____
16. Education: ( ) 0-8 years of study, ( ) some high school, ( ) high school graduate, ( ) some postsecondary, ( ) postsecondary graduate.
17. Family history of your loved one: occupation: _____; marital status:_____ children: _____
18. Where was he/she born?
    Born in Canada: Yes: _____ No:_____ Born outside Canada (country):_____

Appendix H

## The Interview Protocol and Guide

The researcher will contact the participant on the pre-arranged date and time using Zoom or Skype (those choosing Zoom or Skype will be told they also have the option of just using audio) or the telephone. The researcher will confirm that permission is granted for the interview and to record it. The participant will be reminded that he/she has the right to refuse to answer a question, move to another question, and to end the interview at any time. To avoid any possibility of unwanted disruption during the interview, the researcher will ask the participant, to mute/close phones, or any other electronic device. Both the researcher and participant will, if possible, ensure that privacy is maintained throughout the interview. The researcher will also have a notebook to jot any ideas or questions that might arise.

The following *Interview Guide* will be used:

The format for the interview guide will be based on a structure recommended by Charmaz (2014, pp. 66-67), that is, on three stages: initial, intermediate, and ending questions. The following are potential questions.

Initial Open-ended Questions:

1. How would you describe communication?
2. What makes for good communication?
3. What could make music a form of communication?
4. Tell me about your experiences with people with dementia and music.
5. When, if at all, has music facilitated communication for a person with dementia? If so, can you describe what happened?

Intermediate Questions:

1. If you notice a person with dementia begins to communicate how do you communicate back?
2. Have you ever been with a person with dementia who did not seem communicative? If so, why do you think that was?
3. Can you talk a bit about responses or non-responses to music?
4. How does the person with dementia respond to music when it is heard, perhaps on the radio or a choir visiting the facility?
5. How might the environment (home, LTC), the lived setting influence the communication of people with dementia?

Ending Questions:

1. How might your views of music as communication be changed by your experiences?
2. What might be different ways to use music to facilitate communication?
3. What advice would you give families/nurses/music therapists/recreation therapists with regards to using music for people with dementia?
4. Is there anything you would like to ask me?

Appendix I

## Final Interview Guide

The format for the interview guide will be based on a structure recommended by Charmaz (2014, pp. 66-67), that is, on three stages: initial, intermediate, and ending questions. The following are potential questions.

Initial Open-ended Questions:

1. How would you describe communication?
2. What makes for good communication?
3. For you, what is communication?
4. What could make music a form of communication?
5. Tell me about your experiences with people with dementia and music.
6. When, if at all, has music facilitated communication for a person with dementia? If so, can you describe what happened?

Intermediate Questions:

6. If you notice a person with dementia begins to communicate how do you communicate back?
7. How does emotion play a role in communicating with music?
8. Have you ever been with a person with dementia who did not seem communicative? If so, why do you think that was?
9. Can you talk a bit about responses or non-responses to music?
10. How does the person with dementia respond to music when it is heard, perhaps on the radio or a choir visiting the facility? Does it differ from live music?
11. How might music influence your relationship with your client?
12. Can you talk about any effects of music on memory, and how that impacts communication?
13. How would you compare a melody line to a spoken sentence? And how, if at all do PwD respond differently?
14. How might the environment (home, LTC), the lived setting influence the communication of people with dementia?

Ending Questions:

2 How might your views of music as communication be changed by your experiences?
3 What might be different ways to use music to facilitate communication?
4 What advice would you give to LTC staff, management with regards to creating an optimal environment for communication?
5 What advice would you give families/music therapists/HCAs with regards to using music for people with dementia?
6 Is there anything you would like to ask me?

Appendix J

## Focus Group Interview Guide

The researcher will contact the participants on the pre-arranged date and time using Zoom. As participants join the focus group, the researcher will confirm their willingness to participate, and remind them the focus group will be recorded. The researcher will remind the participants that all answers and opinions are of equal value, that they have right of refusal to answer questions, engage or not engage in dialogue, and remind participants that once the session begins, even if a participant withdraws, data cannot be withdrawn.

The format of the focus group will be an open discussion, moderated by the researcher, following the Focus Group Interview Guide. The main aim of the focus group will be to engage directly with caregivers about their experiences on how music may facilitate communication for people with dementia.

### *Interview Guide*

- What does communication mean to you within the context of music?
- How do you know the person with dementia is communicating?
- What changes and indicators do you see in them following musical activities?
- How do you know if the music is meaningful to them?
- How has your thinking evolved on the use of music for communication for dementia?
- Do you see your profession (or family/friend input) evolving in the future with regards to music for dementia care?

Appendix K

## Focus Group Protocol

### Overview and Guidelines for Researcher and Participants

- Each focus group will be recorded using Zoom
- No right or wrong answer to any question
- All opinions equally valued
- Right to refuse to answer, engage or not engage in dialogue
- All participants will be emailed by the researcher to determine how they wish to be addressed during the focus group. (e.g., first name basis, or more formally).
- Electronic devices either turned off or on mute. If participant needs to step out, please do so quietly and rejoin as soon as possible
- The researcher's role will be as the Moderator, to guide the discussion

### Procedure for Focus Group Sessions

- Introduction and welcome by Moderator. The researcher will remind the participants that participation is voluntary and that the session will be recorded
- Each participant will introduce themselves
- Overview of the purpose of Focus Group, and reminder that once the session begins, even if a participant withdraws, data cannot be withdrawn.
- First Question. Follow-up questions will be based the evolution of the first question, and on how unanticipated statements and stories emerge

### Conclusion of the Focus Group

- Summarize the focus group conversation
- Review the purpose and ask if anything has been missed
- Thank participants and close session

### Moderator:

- The researcher
- Will use pre-determined open-ended questions following the *Focus Group Interview Guide*
- Will facilitate an open discussion environment
- Will strive to keep focus group conversational

**Participants:**

- A maximum of six in a group (excluding Moderator)
- Any combination of formal and/or informal caregivers

**Focus Group Environment:**

- Via Zoom
- Date and time of session will be decided by the Moderator
- Participants will have a choice from a morning, afternoon, and evening session

**Analysis:**

- Recording will be transcribed
- Will use a constructivist grounded theory analysis of the transcript listening to the subjective voices of the participants' experiences