

# Involving Family Members of People with Dementia in the Music Therapy Process at a Residential Care Facility

By

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## ABSTRACT

The therapeutic use of music with older adults with dementia is widely documented, and family involvement is encouraged in both music therapy practice and dementia care services. This qualitative study explores and describes the experience of a student music therapist involving the family members of people with dementia in the music therapy process in a residential care facility. Grounded theory methodology informed analysis of the data sources. Secondary data was analysed and a theoretical perspective regarding family involvement in the music therapy process in this setting was developed. The findings are presented in main categories consisting of: building relationships, sharing information, unplanned family involvement in music therapy sessions, flexibility, spontaneity, joy and humour, and negotiation of the music therapist role in the community of the facility. The emergent theoretical perspective suggests that involving family members in the music therapy process in residential care facility is valuable in fostering and strengthening a sense of community between residents, family members and care staff.

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***This exegesis is dedicated to my late grandparents Alison Jane and Michael James Ready.  
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## INTRODUCTION

The purpose of this exegesis is to examine and discuss my experience of involving family members of people with dementia in the music therapy process at a residential care facility, and to present my own theoretical perspective regarding this practice. This study took place over a one year music therapy student placement.

The global population is aging. According to statistical data held by the New Zealand Ministry of Health, the proportion of people in the population aged 65 years and over will increase 26% by the year 2051. It is estimated that 29.4 million people worldwide have some form of dementia. Dementia predominantly affects people aged over 65, and becomes more common with advancing age (New Zealand Ministry of Health, 2002). It is also estimated that approximately 60-70% of people living in residential settings in New Zealand have some form of dementia. Therefore it is important that music therapy research continues to explore how music therapy can be used and developed to best meet the needs of this population, and their families.

This study will begin by defining the main terms under discussion in this paper, provide a review of relevant literature, discuss my personal position in relation to the research and go on to present the research methods. An overview of my clinical practice demonstrates how the music therapy process took shape at the facility, and a clinical vignette presents a descriptive and reflective account of a particular aspect of the work. The theoretical perspective developed from this study is presented and the findings presented in six core categories supported by excerpts from data and relevant literature.

## Dementia

Dementia is a progressive degenerative disease of the brain and every person experiences the effects of dementia differently. The American Psychiatric Association (2000) defines dementia as

*“ A syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer’s disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain” (American Psychiatric Association, 2000)*

The most common form of dementia is Alzheimer’s disease, followed by dementia of the Lewy Body type, and then vascular dementia (New Zealand Ministry of Health, 2002). For the purpose of this paper, the term ‘dementia’ will be used to encompass all of the subtypes of dementia.

## The Residents and the Residential Care Facility

This research took place in a secure residential care facility that caters for people experiencing varying types of dementia and provides specialist dementia care to meet the unique needs of this population. The physical environment was spacious, with one large lounge, and several smaller sitting areas that provided a more private and contained

environment for music therapy sessions. There were 16 people residing at the facility, ranging in age from 65 years and onward. The term 'resident' will be used to describe the people living and receiving care at the facility.

Residents at the facility were all experiencing moderate to severe cognitive losses, with memory impairment and a range of sensory and physical impairments. The facility was secure, meaning residents were not able to come and go of their own volition because of the potential risk they posed to themselves due to their vulnerability should they leave the premises without support. The philosophy of the facility was one of person centred care, which encourages and nurtures residents' individuality, dignity and self- worth. The onsite multi-disciplinary team included Doctors, registered nurses, a diversional therapist and caregivers.

I worked closely with the diversional therapist to plan music therapy groups or individual sessions as part of the daily programme for residents. The programme was planned a week in advance and included activities ranging from massage, pet therapy, craft groups, cooking, van outings, gardening and music therapy. However, the diversional therapist worked from a premise of meeting the residents' needs on a day by day basis, so the programme allowed for spontaneity and resident choice. Music therapy was offered as a means of maintaining creativity, of reminiscing, facilitating social activity, communication, movement and helping to deal with the multiple losses that a person with dementia and their family members face.



## Family

Each person is part of a greater social system, and the functioning within these systems allows people the possibility and capacity to belong, to care and to share (Durie, 1998). I wanted to use a definition of family that captured the idea that people's understandings and beliefs of what constitutes 'family' are different, each of them being unique and valid. I have chosen to work with from a definition published by the New Zealand Ministry of Health (2000). The term "tangata whai ora" means: 'person seeking health'.

*"A family is a set of relationships that is defined as family by the tangata whai ora. Family is not limited to relationships based on blood ties, and may include: relatives of the tangata whai ora (including a spouse or partner), a mixture of relatives, friends and others in a support network or only non-relatives of the tangata wha ora " (New Zealand Ministry of Health, 2000, p. vii).*

## LITERATURE REVIEW

This literature review is commensurate with the size of this study. Further literature has been introduced as the theory was developed.

### Music Therapy and Dementia

The therapeutic use of music with older adults with dementia is widely documented (Aldridge, 2000; Bright, 1988; Brooks, O'Rourke, & Wellington Society of Music Therapy.; A. Clair, Mathews, & Kosloski, 2005; Dileo & Loewy, 2005; Holland, 2009; Kydd, 2001; Lester & Petocz, 2006; Mette, Wigram, & Ottesen, 2009; Odell Miller, 2002; Pavlicevic, 1999; Powell, 2009; Raglio et al., 2008; Raglio & Gianelli, 2009; Rio, 2009; Sixsmith & Gibson, 2007; Spiro, 2010; Svansdottir & Snaedal, 2006; Wall & Duff, 2010). According to the various studies, music therapy offers strategies for using music as a vehicle to provide diversion for inactivity, discomfort, and daily routine; decrease symptoms of depression, anxiety insomnia, and agitation; provide physical and emotional stimulation; help in the management of pain; facilitate social integration; communication; and the expression of feelings, including anger and grief (Clair & Memmott, 2008).

'Dementia in New Zealand: Improving quality in residential care' (2002) is a report that highlights the need for dementia care to adopt a more person centred approach. The report acknowledges music and arts therapies as interventions that recognise the social and emotional needs of people with dementia, and suggests that interventions that address these needs are critical in providing quality care for people with dementia. Improving quality of life for people living with dementia is widely accepted as an important focus in

dementia care services. In the most recent Cochrane Review of music therapy and dementia Vink, Bruinsma, & Scholten (2004) concluded that while evidence suggests that music therapy may be beneficial in managing dementia symptoms, a lack of randomised controlled studies and insufficient methodologically sound research in the area prevented any conclusions being drawn.

In a qualitative study, Simpson & Mitchell (2005) endeavoured to find out what was life like for people with dementia living in locked residential facilities. Key themes that emerged from the data analysis included choosing an attitude for living on, feeling worthy, living with loss, and struggles with thinking and communicating. Of the eight key themes two of the themes were apparent in all of the participant interviews. These were 1) Feeling content and 2) The importance of relationships. This study highlighted the importance of people being creative in finding new ways of connecting with and relating to with people with dementia both in care and research activities, when conventional means of communication are no longer possible. The increasing difficulty in communicating with someone who has dementia and the loss of the personality they once knew are some of the difficulties family members face. As the person with dementia faces many losses through experience of the illness, so too does the family and other loved ones’.

## Families and Dementia

Family relationships are an integral part of quality of life (Simpson & Mitchell, 2005) and contribute to the total well-being of each person. Haesler, Bauer, & Nay (2007), propose that a holistic approach and involving family members in the aged care sector has been recognised as one of the best guarantees of a resident’s wellbeing. They carried out a systematic review of strategies that support staff-family relationships in residential care

settings. From the review, six key factors were identified as essential for developing and maintaining positive staff-family relationships. These were; “upholding the patient’s uniqueness; assessing and addressing unique family needs; using effective communication skills; implementing a collaborative care process; understanding and addressing interpersonal power issues; and providing organizational support” (Haesler et al., 2007, p. 394).

The family systems theory (Bowen, 1983 cited in Piercy, 2010) considers the importance of focussing on interrelations and emotional processes that occur among people who are part of a family group (Broderick, 1993). The core assumptions that underpin family systems theory are: “interconnectedness, understanding by viewing the whole, reciprocal behaviour, and focus on knowing or thinking”(Piercy, 2010, p. 52). This highlights the value in seeking to understand the greater social system within which an individual functions, as such viewing ‘the whole’. Family members of those experiencing dementia often experience a sense of helplessness and immense loss as dementia progresses (Aldridge, 2005). The grief process and related depression or anxiety experienced by family members or carers of people with dementia is well documented (Bright, 2006; Brotons & Marti, 2003; A. Clair, 2002; A. Clair & Ebberts, 1997; A. Clair, Tebb, & Bernstein, 1993; Dileo & Loewy, 2005; Frank, 2007; Hanser, Butterfield-Whitcomb, Kawata, & Collins, 2011; Mahoney, Regan, Katona, & Livingston, 2005; Piercy, 2010; Rabins, Mace, & Lucas, 1982; S. Sanders, & Adams, K.B, 2005; S. Sanders, Ott, Kelber, & Noonan, 2008). Due to the long term progressive nature of dementia, anticipatory grief is pervasive throughout the dementia care process for family members and still occurs when a person is admitted to residential care facility (Frank, 2007 cited in Piercy, 2010). Piercy (2010) recommends that family members are provided

with information regarding the disease, supported by therapists to develop strategies to manage their loss, and to continue having meaningful interactions with their loved one. The New Zealand Ministry of Health (2002) calls for service providers to acknowledge the important role of family members and carers in dementia care, and to work with families on an on-going basis. The report goes on to suggest the family members and carers have direct input into the writing of care plans for their loved one, allowing them direct involvement in the care process (New Zealand Ministry of Health, 2002).

### Music Therapy and Families

Music therapy practice has traditionally included family when this is possible, as the issues surrounding some family systems can be complex. Where words may fail to express the depth of a family member's emotions, music can provide a way for family members to share, connect and process these issues (McIntyre, 2009). The use of music therapy with families in paediatric health and educational settings is well documented throughout music therapy literature and considers the use of music to strengthen parent-child relationships in many cases (Abad, 2004; Molyneux, 2005; Oldfield, 2000; Oldfield & Flower, 2008; Pasiali, 2010; Shoemark, 2004; Wetherick, 2009).

Hanson-Abromeit (2008) states that family centred care is “based on the assumption that family is a child’s primary source of strength and support” (Hanson-Abromeit, 2008, p. 26) and suggests that this approach be translated to music therapy practice with patients and families of all ages and across all health care settings. Therefore, the idea that the family is a primary source of strength and support can be translated to work with older adults with dementia. As Bright (2006) suggests, music therapists are required to work from a basis of cultural competence, which involves developing a deep sensitivity to, and understanding of

the “social structure, customs, and spiritual context of the macro- and micro-cultures from which (patients) come” (p.70).

Recent studies regarding music therapy in dementia care settings examine the use of music and music therapy to assist in the clinical care of dementia patients, and to support communication between staff caregivers and residents with dementia (Brown, Götell, & Ekman, 2001; Hammar, Emami, Engström, & Götell, 2011). These researchers found that music therapeutic caregiving could be used as a possible method to promote positive relationships in a caring situation with caregivers and residents with dementia. Davidson & Fedele (2011) found that singing activities improved communication and the quality of social interactions between caregivers and people with dementia. This study took place between care staff including occupational therapists and caregivers, and did not directly involve family members. However, it could be suggested that a music therapist could facilitate similar singing activities between a person with dementia and their family members with a view of achieving similarly positive results.

There are studies that look specifically at using music therapy to aid relationships between family caregivers and people with dementia. Claire & Ebberts (1997) explored the effects of music therapy on interactions between family caregivers and care receivers (people with dementia). They concluded that music therapy was important to the quality of life for both parties, when music was used to engage patients in purposeful joint participation. A more recent pilot study which examined the effects of music therapy on people with a diagnosis of dementia and their family caregivers found music therapy was effective in facilitating expression and communication between people with dementia and their family members

(Brotons & Marti, 2003). Another study by Clair (2002), found that music could be used effectively by family caregivers of people with late stage dementia to restore relationship reciprocity. The study found that mutual engagement increased with the use of musical applications, and caregivers eventually felt comfortable using musical applications independently (Clair, 2002).

Enhancing the relationship of persons with dementia and their carer is a common theme in the literature. Grocke (2011) investigated a process in whereby a music therapist visited couples in their home, and demonstrated to the carer how music interventions could be used with their spouse with dementia. The results indicated that all participants experienced a sense of enjoyment from the music programme with their spouse, and some experienced increased confidence in caring, relaxing effects and a strengthening of their relationship (Grocke, 2011). In a similar study, Hanser et al (2011) designed a home based family caregiver administered music programme. Both caregivers and care receivers reported increased relaxation, comfort and happiness. While some of the above studies took place in residential care facilities, the majority were community or home based interventions. It is important to continue developing interventions that support people with dementia to remain safely in their own homes and communities for as long as possible. However, there is still a large number of people who are admitted and living in residential care facilities that also require support to live well in the presence of dementia.

Dynamics between family members may change when a person is admitted to a residential care setting, and the use of music therapy interventions to help both the person with dementia and their family members to cope with this change might be necessary. As Bright

(2006) highlights, a music therapist needs to understand the emotional and spiritual needs of their clients and their families in order to provide them with the help they need to cope with life changes and move toward the future. The above studies are important contributions providing valuable insight into the potential use of music between family members and persons with dementia. The current study will add to and extend the literature base by exploring music therapy processes that supported the involvement of family members at a residential care facility.



## PERSONAL POSITION

I arrived at this research with a background in mental health nursing and a passion for working with people with dementia that dates back over 10 years to my first placement as a student nurse in a dementia care facility. At this time, I remember feeling out of my depth, and not sure how I could possibly connect or communicate with a person who seemed locked into their own world. It was during this placement, I learnt the value of simply “being with” a person, taking time to build relationships, and being creative in my approach to communication and care. It was also during this placement, that I first felt concerned by what I considered to be the depersonalisation of residents with dementia, and began to read the work of Tom Kitwood (1997), who developed the theory of “Personhood” in dementia care.

Personhood calls on helping professionals who work with people with dementia to consider the uniqueness of each person. It implies recognition, respect and trust. Kitwood (1997) describes personhood as the unique life experience of each person, of identity, feelings and emotion, a person’s total subjectivity. Therefore, care is viewed as primarily concerned with maintaining, and enhancing personhood, of understanding a person’s strengths, interests and values. Rather than focusing on the limitations dementia imposes on people, interventions are needed that stimulate present abilities, and improve their quality of life. The focus on improving a person’s quality of life is a core concept that underpins my work as a student music therapist working in this setting.

Throughout my nursing career and now as a student music therapist I work from a person centred and holistic approach. As a clinician, my understanding and concept of health is closely aligned with the Whare Tapa Wha model (Durie, 1998). This model compares health to the four walls of the house, with all four walls being required to provide stability and balance. The four walls represent taha wairua (the spiritual side), taha hinengaro (thoughts and feelings), taha tinana (the physical side) and taha whanau (the family) (Durie, 1998).

During my experience as a mental health nurse, I have also become well versed in the Recovery Model (O'Hagen, 2001). Although this model was written for the mental health sector, the core principles can be easily translated to dementia care settings. One of the overarching principles is that recovery is happening when people are living well in the presence or absence of their illness. I believe that music therapy has the potential to improve quality of life and support people to live well in the presence of dementia. The recovery model supports and encourages the personal resourcefulness of people using health services and expects workers to demonstrate high levels of self-awareness. One of the core recovery competencies calls on mental health workers to have knowledge of family perspectives and be able to support family participation in services (O'Hagen, 2001). This is an expectation that is echoed in the field of dementia care according to the New Zealand Ministry of Health (New Zealand Ministry of Health, 2002). I have been involved with family members in a professional capacity throughout my nursing career. I have seen the impact mental illness can have on family relationships, and how supporting family involvement in care and planning can have positive health outcomes for people.

My personal experience with dementia occurred when two of my grandparents were diagnosed with the disease and eventually required long term residential and hospital level

care. During this time, I did not view myself as a nurse; I was a granddaughter, and part of a family that was grieving the loss of someone they loved through dementia. Retrospect is a wonderful thing, and I wish I had of known at the time about the use of music as a means of being with, and communicating with someone with dementia. I remember sitting with my grandmother and feeling helpless, frustrated and deeply sad. This was a woman who I would look to for wisdom, a woman who could answer virtually any question on any topic and if she couldn't, she would make it her business find out. She was a remarkable conversationalist with a sharp sense of humour. Now, between us at times sat an awkward silence that felt so foreign, anxious chattering of her teeth, confusion and every now and then a flurry of mixed up words that I couldn't make sense of. I know living with dementia was a distressing and difficult journey for both of my grandparents, and also for our family. It is frustrating to think about the final years of my grandparents lives when I consider what I know now; that is that I believe music therapy could have made a positive difference in both my grandparents and our family's experience of living with dementia. My professional background as a nurse and personal experience as a family member of someone with dementia were significant factors in my choice to undertake this research topic. I am aware that personal and historical experiences shape my interpretation of the involvement of family members in the music therapy process at a residential care setting. My past experience influenced my practice in so much as I have a particular interest in and value family involvement as a practitioner, so it is an intrinsic part of my music therapy practice.

## RESEARCH METHODOLOGY AND METHODS

The focus of this research was to explore a music therapy students's perceptions of the involvement of family members of people with dementia living at a residential care facility. I took a qualitative approach, critically reflecting on my clinical data to provide my own interpretation of its value and to develop a theoretical perspective regarding my research question. Involving family in the music therapy process was within the scope of practice for a music therapist in this setting. Denzin and Lincoln (2005) propose that "qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them" (cited in Creswell, 2007, p. 36).

The information I recorded was not collected originally for research purposes, but as a usual part of my clinical practice. Secondary analysis of data was employed as the primary methodology of this study, as it uses pre-existing qualitative data that was originally collected for other purposes, to investigate new questions or specific problems (Heaton, 2004). In order to analyse my secondary data, I was informed by the qualitative approach of grounded theory.

Grounded theory was first developed by Glaser and Strauss (1967, in Wheeler, 1995). They proposed that "developing theory was essential for gaining greater insight into social phenomena, and that this theory should be developed through the researcher's intimate acquaintance with observationally derived data" (Aigen, 1996). Theories developed using a grounded theory approach are not presented as objective truths, they are interpretive in

nature (Creswell, 2007). Ultimately, my aim was to develop my own theoretical perspective based on my experience (Birks & Mills, 2011) to inform myself, other music therapy students and practitioners of the issues involved in including residents' families in music therapy processes. Because of the qualitative nature of this study, I am implicated in it and am intimately acquainted with the data. Therefore I chose to write in first person prose as I provide my interpretation of data and theory.

## Data Collection

As noted above, data was collected as part of usual clinical practice. My clinical practice did not change, but I recorded in detail my experiences of family involvement in my music therapy practice because I was particularly interested in this issue as a clinician. Data sources included clinical notes, reflective journaling, email and personal communication with family members.

## Data Analysis

Grounded theory methodology informed analysis of data sources. . The analysis process of this study had several steps. I engaged in concurrent gathering of clinical data, reflecting on it, analysing it, and further exploring my research question, in six week cycles. After each six week cycle, I brought the data together, by transcribing it or copying it into word or excel documents, I carefully read through all data sources and began open coding; the process of beginning to name emerging phenomena, patterns or themes and starting to compare these (Birks & Mills, 2011; Lyons & Coyle, 2007). Categories that emerged from the data during intermediate coding were defined through a process of critically analysing the initial codes and connecting them into categories (Rice & Ezzy, 1999, in O'Grady & McFerran, 2007). I chose relevant theoretical samples to test with the next cycle of data and

developed the categories further during each subsequent cycle until no new categories were identified (Lyons & Coyle, 2007). In accordance with grounded theory analysis procedures (Lyons & Coyle, 2007) the resulting main categories were identified following analysis of the initial codes and I linked these with my own existing theoretical constructs after each cycle. Throughout the process of data analysis I regularly recorded my thoughts and insights in relation to my research in the form of memos (Lyons & Coyle, 2007). In drawing together close analysis of my own data and existing literature; I developed my own theoretical perspective, systematically derived through the use of grounded theory methodology and based on my experience of the involvement of family members of people with dementia in the music therapy process.

## Ethical Standards and Considerations

I abided by the Code of Ethics for the Practice of Music Therapy in New Zealand (New Zealand Society for Music Therapy, 2006), and the Code of Ethics for Research with Human Participants (Massey University, 2010) throughout my clinical project and in undertaking this research. Informed consent was obtained from my placement facility for the clinical data to be subjected to secondary analysis for research purposes.

Informed consent was also obtained from family members and people acting as enduring power of attorney (EPA) or guardian for individual residents (see appendix II). Consent was gained for their clinical data to be used for research purposes, and to write a vignette to illustrate a particular point in this project (see appendix III). It is significant to note the inclusion of the residents in the consent process. As Dewing (2002) argues, an inclusionary consent process is a way forward in person-centred research with this population (Dewing,

2002). I spoke to each of the residents about the nature of my study, and was able to include family and residents in a discussions and questions about the research when I encountered them together on the unit. Out of the 12 residents and their families, eight gave consent and signed consent forms. I was unable to make contact with the four remaining family members throughout the placement. Therefore, no consent was obtained for these residents, and their involvement in music therapy has not been included in this study.

## CLINICAL PRACTICE

The purpose of the research was to explore the involvement of family members of people with dementia in the music therapy process in a residential care facility. Therefore, before presenting my findings it is important to outline how the music therapy process began to take shape, and how I approached my clinical practice with the residents. I spent 10 months at the residential care facility for people with dementia as my final music therapy student placement. Initially I spent time getting to know and building relationships with the residents by being with them and facilitating a series of open music therapy group sessions, which were 30 minutes to 1 hour long. As part of my own assessment process, I familiarised myself with residents' personal profiles, diagnosis and any physical health issues they were experiencing by reading files, and talking with multi disciplinary team members and residents.

The initial music therapy sessions took place in a large central lounge, and all residents were offered an invitation to attend. The location of the lounge meant that residents would wander through and join the group of their own volition. As part of my ongoing assessment, I would pay particular attention to when people chose to come and go, and try to notice what musical elements or other factors may have contributed to this.

Over the course of the placement I facilitated a wide variety of musical experiences. I view music therapy an intervention that recognises and attempts to understand the social and emotional needs of people with dementia. Pavlicevic (1999) described music therapy for people with dementia as making contact with a person's "healthy side, with the cohesive



side, rather with the affected side" (p.337). Thereby, I worked from the same premise, that the core of a person remains unaffected and can be reached in a positive way through music therapy; that music therapy can facilitate 'here and now' experiences, and provide people with an opportunity to feel valued for what they bring to these experiences (Pavlicevic, 1999).

Music Therapy sessions included:

- Familiar Song Singing
- Music and Movement (particularly rock n roll and swing dancing)
- Rhythm groups using a variety of structured sessions and improvisation
- 1:1 sessions
- Exploring different instruments with residents
- Relaxation music therapy sessions in the evening
- Supporting residents to attend music concerts and events

My initial contact with family members was in the form of a letter. I outlined my role as a student music therapist and invited them to be involved in music therapy with their family member and/or share knowledge of their musical history (see appendix I). I used information provided by family members to help guide my music therapy planning for individuals, with a view to creating individualised and meaningful musical experiences. Family members were invited to participate in music therapy groups or 1:1 sessions. From the outset it was important to me that family involvement was not restricted to their participation in active music making. It also included their involvement in sharing their knowledge of their loved one which I believed encouraged participation and positive

contribution in their family member's lives. I kept in regular email contact with family members to provide updates on the music therapy at the unit.

Initially music therapy groups included mostly familiar song singing, to assist me in beginning to understand individual residents' strengths or difficulties and musical likes or dislikes. When I was writing up sessions and reflecting, from the information I had gathered I would consider different ways I could facilitate music therapy sessions to best meet the needs of the residents during sessions. I continued to do this throughout the placement, but as the placement progressed, I became more fluid in my approach to facilitating individual or group sessions. Although I had regular individual and group sessions that occurred each week, I also assessed clinical need on a day to day and sometimes moment by moment basis, as I became more responsive to the needs of the residents. For example, if during the course of a day I noticed a resident appeared anxious or distressed, I would offer music therapy to assist them in managing their distress in the moment. As I developed closer therapeutic relationships with residents this "in the moment approach" became a more regular feature of my practice.

I began to develop a greater understanding of the community within which I was working. I considered the community of the facility and of the larger social systems the residents were a part of at the facility. Pavlecivic (2004) argues that "context needs to define how music therapy happens and how we think about it" (Pavlicevic & Ansdell, 2004, p. 45). Pavlecivic (2004) describes context as the collective physical, mental and social realities of all people who may be involved in the music therapy process, and discusses the importance of music therapists understanding themselves as part of the context within which they work. Because my music therapy practice was not confined to a designated 'music therapy room',

the music therapy sessions took place in communal areas, some more private than others. This meant that the music therapy sessions were visible and audible to others thereby affecting the milieu of the unit. Being present at the unit three days a week, meant that at times I was involved in other activities at the unit that were not musical. I struggled with this at first, but realised that by building relationships with people both in music and in other activities, I was able to observe how the shifts that happen in music therapy might transfer to other parts of their daily lives. I also felt that familiarity was important to the residents at the unit, getting used to having me as a part of their community and feeling comfortable to attend music therapy took time, and I believe this was aided by my involvement and presence in other activities at the unit.

During the course of the placement I was involved with some residents and their family members through the process of death and dying and I provided music therapy as a means of comfort and support during this time. When a resident I had been working closely with in music therapy was dying, I spoke with the team and family about providing music therapy to support him during his dying process. I was able to draw on my experience from our work together, and use music I knew he connected with to guide my practice. It was also important that my practice reflect the beliefs and values the family held in regard to the dying process, so I kept in close contact with his daughter. It was during this time, I noticed how the other residents were also affected by Jack dying, and realised that music therapy was providing support and comfort for not only for Jack, but also for his family, staff and other residents. The music therapy journey with Jack provided me with many insights early on about work with people who have dementia, their family members and the care staff.

## FINDINGS

I have developed my own theoretical perspective regarding the involvement of family members of people with dementia in the music therapy process at a residential care facility (see p. 26). I will present six core categories derived from the data, which integrate my descriptions and critical reflections of my practice. The findings include references from related literature, and excerpts from data to provide supporting evidence. To maintain confidentiality, residents' names have been replaced with '(R)' and family members' names have been replaced with '(F.M)'. I will begin my findings section with a vignette describing work with 'Jack' (pseudonym) to demonstrate how working with him developed my sense of connectedness with the community of the facility and my work with family.

## VIGNETTE

### JACK

*'Jack was an 82 year old gentleman originally from Scotland, who had been living with advanced dementia and a diagnosis of Cancer for several years when I met him at the care facility. I returned from a two week break to hear that Jack's physical health had deteriorated rapidly and he was now receiving all cares in his bed. Jack was no longer able to speak, very rarely opened his eyes and at times appeared to be in physical discomfort. His presentation came as a shock to me. Only two weeks before, Jack had been actively involved in music therapy sessions, wowing people with his rhythmic sensitivity on an array of percussion instruments. His drumming and spoon playing had become a central feature of music therapy sessions at the unit, and his participation in music groups had never faltered. My perception of Jack was that he was a warm, gentle and friendly man; he would often encourage other residents to join music therapy*

sessions, and demonstrate to them how to use certain percussion instruments. In email contact with Jack's daughter, she described him as a great lover of music and dancing, with favourite artists including Shirley Bassey, Ann Murray and anything Scottish. However it remained a mystery as to how or when Jack learnt to play the drums so proficiently, although he mentioned playing in a school band briefly during a session, and his music was reminiscent of marching band music, military or pipe band. My music therapy journey with Jack had been an exciting and rewarding one, and I realised I was embarking on a different journey with him as I negotiated how to support and be with him as he died. I began by bringing his favourite blue drum and beaters into his room, and leaving them within his line of sight. I spent time with Jack, sitting beside his bed, it felt natural and comfortable to be with him, having shared so much music together. I spoke to Jack, played him familiar songs that we had shared together, played my guitar beside him, or sometimes sat in silence with him. On one occasion I played 'Scotland the Brave', when I began to sing, Jack opened his eyes momentarily, we looked at each other and I felt a connection, an acknowledgement of the music. During the time I spent in Jack's room, a number of residents would wander in, and I was struck by their astute awareness and respect for Jack as they entered his room. The residents appeared to be emotionally connected with what was happening for him. Some would stand quietly and still for a few moments before leaving, one resident touched Jack's hand and said "there there", in a soothing way. It was then I thought about the experience of the other residents and their response to a fellow resident dying, as they were clearly affected by what was happening to Jack. I spoke with the staff about holding a small music session with residents outside Jack's room so he could hear the music of other residents. Staff agreed that this could be comforting for Jack, and supported me to do this. I invited residents that had been involved in music with Jack, and explained to them the reason we were meeting. Some group members were able to acknowledge this, and agreed

*they thought it would be a 'nice idea', one resident suggested we sing "gentle music that he liked". Others demonstrated their willingness to be a part of the group, by "being there", and participating in the quiet and respectful spirit of the group. We sat in a small circle together just outside Jack's room, and proceeded to sing, hum and be together in music for 20 minutes. The energy of the group was quiet and gentle, it felt like there was an unspoken respect and understanding between group members, somehow the music felt different and I acknowledged I was bringing my own sadness about Jack to the group. The same group was able to meet again once more before Jack passed away, and care staff occasionally joined us and sang. I continued to spend time with Jack, and during his turns and cares I would continue to sing, when care staff joined in there was often three voices singing to him in the room. The staff commented one day that singing during Jack's cares felt 'relaxing' for everyone. During these final days with Jack, I kept in contact with his daughter, to let her know I was spending time with Jack in music. Following a session with Jack that I felt would be our last, I received an email from his daughter to let me know Jack had passed away. She mentioned playing a CD of Scottish songs when she was visiting, and said this had calmed Jack, and her at the same time. I attended Jack's funeral with other staff. His love of music was mentioned a number of times during the service, and he was piped out of the chapel by a bag piper in full Scottish regalia. In his order of service the family had included the following verse, which the diversional therapist had pinned on Jack's wall.*

*Music touches feelings*

*That words can not*

*It is melody*

*Of the heart,*

*The voice*

*of the Spirit.*

*It inspires some*

*To think of the past,*

*Some to create*

*And some to cry.*

*Music makes me Love.*

## THEORETICAL PERSPECTIVE

Involving family members in the music therapy process in residential care facility is valuable in fostering and strengthening relationships between residents, family members and care staff. It requires the music therapist to position themselves and the family members as part of the community of the care facility; to encompass flexibility, openness and ongoing communication in their practice to meet, understand and balance the diverse needs of family members and residents in this setting.

### **1. Building Relationships**

**Taking time to negotiate the sharing of information between all parties leads to trusting relationships and ongoing communication.**

Building relationships with the residents, their family members and the staff at the unit was the foundation of the music therapy process. The relationships were the platform from which family involvement in the music therapy process evolved. Quite simply, there would be no family involvement in the music therapy process if there was no trusting relationship developed between myself and the people I wished to involve. Building these relationships took time and negotiation, with relationships continuously growing and changing during the course of the placement. As Stern aptly describes:

*“Relationships are the cumulative constructed history of interactions, a history that bears on the present in the form of expectations actualised during an ongoing interaction, and on the future in form of expectations (conscious or not) about upcoming interactions”. (Stern, 1989, pp. 54-55).*



Although email contact was a good way of creating a means for ongoing communication with family members', as an initial form of contact it didn't provide the stream of information and response I had expected. Developing relationships with the residents evolved through face to face contact with them, spending time, and inviting them to be involved in music therapy. I realised I had asked family members to share personal information about themselves and residents via email without having met me in person, and perhaps family were not ready to trust me with their stories and experiences without first meeting me. There was immense value in meeting family members in person, this meant approaching family when they were visiting to introduce myself. A common response was *"Oh yes, I received your email, tell me more about that"*. Allowing time for family members to make their own assessment of me was important, and this was aided by initiating a face to face contact with them at the facility and giving them space to observe music therapy sessions without an expectation of participation. I found that following this contact, they began to share information more freely, and began to demonstrate more interest in the music therapy process and what it meant for their loved one.

For example, Jack's daughter would email me regularly seeking feedback, or to share a piece of music she thought Jack would connect with. She commented that it was a comfort for the family to know that someone Jack had *"bonded"* with was spending time and sharing music with him during his last days. Building trust, becoming a familiar face, and being able to demonstrate my skill and therapeutic intentions with the residents was important in building relationships with family members.

***1.1. Seeking to capture the residents' experience and reflections about family members being involved in the music therapy process.***

It was important to me that I discussed with the residents my ideas and suggestions for their family members being involved in the music therapy process. There were varying degrees of comprehension and discussion from residents.

*"I think (husband) would fall off his chair if he saw me drumming! What a laugh".*

*"My (FM) likes music, yes".*

*"I wish my sister was here, she had a voice like an angel".*

As far as I could observe, I was not aware of any negative responses about family involvement from residents, but this is something I was careful to observe or notice. If I used any information I had received from family members during a music session like a song or a particular story, I would talk to residents about having spoken to their family, I would use their family members' names and try to expand on the story or memory of the song and its significance. Supporting residents to maintain a sense of self, sustaining relationships and individuality became important aspects of music therapy sessions. During sessions where family members participated with residents, I noticed a supportive quality about interactions. It was as if residents appeared to relax more when there was a familiar person making music beside them as part of a group, and supporting them to participate. Reminiscing, storytelling and talking about family members during music therapy sessions became a common feature of the sessions. It was important to me that I encouraged discussions and memories that perhaps helped residents to remember and connect to being a part of a family or larger social network outside of the facility.

However, there was also a strong sense of family and community within the facility, which was highlighted in my experience with Jack, and how other residents responded to his dying. Some of the residents' behaviour indicated awareness and a wish to show their respect for Jack as he died. Involving the residents in the music therapy with Jack as he died acknowledged the interrelations that occur among people living in dementia care facilities, a sense of community and family amongst residents. Being aware of the emotional connectedness amongst the residents outside of music therapy sessions enabled me to respond and facilitate music therapy sessions that were sympathetic to the experiences and needs of the community.

## ***2. Sharing Information***

**Inviting family members to share their knowledge of residents' unique music tastes and musical backgrounds, helps to provide musical experiences that are meaningful for the individual resident and creates ongoing dialogue between music therapist, resident and family members.**

The sharing of information became the most common way family members became involved in the music therapy process, and information provided rich history, and personal insights into the lives of people I was working with. This meant I was able to provide more personalised music therapy experiences. It seems that sharing information was a comfortable place for family members to begin and continue being involved in the music therapy process. As part of my music therapy practice, I would provide regular individualised email updates about music therapy. In turn, family members began to respond to my emails with more regularity. They seemed to be gaining a better understanding that music therapy could provide their loved one with a means of meaningful

activity, pleasure and access to musical skills they didn't know they possessed. I noticed that rich information sharing occurred during impromptu encounters with family members. Therefore, being available to talk to family members became an important aspect of my practice. It seemed that the more residents and family members engaged in thinking about, talking about or participating in music, the more they were able to recall and share stories, history, memories and experiences.

*"We once left a budgie with him for a long weekend while we went away and the budgie started whistling just like (R). You would have sworn he was in the house with you when the budgie started up and it only took a couple of days". (FM)*

*"I think music is such great therapy for not only dementia patients but all elderly as it is something that we all have in common and never forget certain songs or tunes". (FM)*

*"I didn't realise dad was such a star on the royal wedding day. It is a shame his memory doesn't let him recall, but as long as he enjoys the moment it is so worthwhile". (FM)*

*"Mum loves the music sessions and often talks about you and the dancing, it's the one time she seems really happy". (FM)*

It was interesting to note, that at times people didn't respond by email, and I would often wonder if there was value in continuing to email. However, family members often commented in person that it was 'lovely' to receive the emails, and hear about their loved one participating in music. Informing family members how the information they had shared contributed music therapy sessions with residents was valued by some family members and they would actively seek updates via email once this line of communication was open to them.

At times I encountered the expression of negative emotions, such as sadness, anger or frustration from residents in music therapy. There were also times when residents

deteriorated and their active participation in music was affected. It was also important to share information with family members that might be viewed less positively, and to let family members know if my music therapy relationship with their family member was coming to an end for some reason. However, family members seemed to appreciate that there was some form of ongoing interaction or assessment of their loved one. As well as sharing information, updates and ideas, family members began to share physical resources, including musical instruments, sheet music and access to particular websites or articles regarding music therapy. This indicated to me that family members were starting to explore and show an active interest and support of the music therapy process.

Sharing and exchanging information, stories, updates and resources, seemed to be how most family members were comfortable engaging in the music therapy process in an ongoing way. By letting family members know how the information they had shared with me was able to be used in meaningful musical interactions with residents, I was able to demonstrate how they had positively contributed to the residents' life and the benefits of sharing familiar music. Sharing with care staff some of information that families shared about residents was a way of collaborating with staff and increasing the collective knowledge about residents at the facility.

### ***2.1. Family members talking about their experience of dementia***

As relationships with family members developed I found they began sharing personal accounts of their experience with having a loved one with dementia with me. Universality in the experiences of family members was evident in the stories they were sharing.

*"I find it so hard to be with him now".*

*"Needless to say the past year has been a nightmare.....loosing dad really hastened mums deterioration, things happened so fast that it still seems like a blur".*

*"She is absolutely nothing like she was, she is a totally different person to me, I miss her".*

(F.M) went on to speak about missing talking to her mum, and explained her mum was someone you could talk to about absolutely everything and anything before she developed dementia.

(F.M) talked about trying to manage (R) at home for 10yrs, and how this became too difficult. She remembered being called away from work frequently to go to (R) house and unlock the doors, because (R) was forever losing her keys. She began to worry about (R) safety all of the time, and realised it was time to think about full time care.

Having an understanding and an awareness of the issues family members face and being able to provide them with support was key. Trust in the relationship is required before people will share intimate stories, experiences and ultimately their vulnerabilities. A family member once commented on the familiarity between her husband and care staff, and expressed frustration that she no longer seemed to share this same level of familiarity with him. The possibility that residents develop close relationships with people they encounter every day and regularly engage with individually was highlighted by this interaction, and I realised that this may be distressing for some family members, when they feel like the closeness with their loved one is gradually slipping away.

*"...at least he has a relationship with you, he remembers you. He doesn't even know who I am anymore"* (FM) was tearful at this point, and left.

I had to consider how I could respond and support family members when I began to notice they began to externalise their grief more freely. While I continued to encourage the idea of being involved in music therapy session as a way of being with their loved one, it felt like family members were seeking support on a more personal level. I was aware of a

collective degree of grief and the need for additional support for family members and started to feel like perhaps I was not equipped to manage this. By talking with other team members on the unit, I found they had also been noticing family members seeking more support, and time to talk about the difficulties associated with dementia. Therefore, I was able to consider how the unit which operated with a philosophy of involving family members was meeting their needs, and how I could contribute to this from a music therapy perspective.

I began to consider the existence of separate therapeutic roles and relationship; my relationship with residents and with family members, and between family members and residents in music therapy. The skill was being able to understand and work with the interrelatedness of these relationships, but in also being able to recognise when family might benefit from additional support. Knowing what other support services are available to family members at the unit or in the wider community and sharing these with families was an important part of my role.

### ***3. Unplanned family involvement in music therapy sessions***

**Supporting spontaneous family involvement in music therapy sessions creates therapeutic possibilities for residents and family members.**

When I first wondered what involving family members in the music therapy process would mean in practice, I believed that planned music therapy sessions with family members would prove to be the most therapeutic facet of their involvement. I would plan and facilitate a music therapy session with a family member and their loved one. I had invited family members to speak with me, if they felt this was something they would be interested in. However, I only facilitated one session that I planned with a family member, and she

reported it was to enable her to get a better sense of how music therapy could benefit her mother. Following the session, she reported she did not feel the need to plan any further sessions, but would like her mother to continue receiving music therapy. Other family members also described experiencing practical issues that would prevent them from 'planning' a session, such as transport difficulties and finding time outside of work hours. Despite the lack of planned music therapy sessions, there was active participation in music therapy sessions and family reported they enjoyed knowing it was "ok" to join in when a music therapy group was in session.

At times I was challenged when unplanned contact occurred, I wondered whether family members were more relaxed about joining music groups spontaneously, because they felt there were no expectations, or the focus was not directly on them and their family member. Perhaps this could be linked to people's anxiety or fear of making music and I wondered if I had described music therapy to family members in a way that had dispelled these fears adequately. The music sessions that family members did join, were often the larger groups in the lounge which were easily accessible for people. I also held groups in areas that were more private when I felt it was appropriate to facilitate a more contained session for certain groups. In all of the cases of unplanned family involvement in the groups, I noticed interactions between family and residents that appeared light hearted, fun, playful, and supportive.

(R) appeared happy and surprised to see her daughter join the group. Mother and daughter sat together, with (FM) prompting her mother with song lyrics, offering her instruments to play, playing instruments herself.

(FM) would use the instruments in a humorous manner and they both laughed. At the end of the group, (R) said to (FM) *"We used to have an organ at home"*, and they spoke about this for several minutes" .....



(FM) arrived just as the group was getting to rock n roll numbers, (R) looked surprised and smiled. (FM) took her mother by the hands and they danced. (FM) would dance in deliberately 'over the top' moves, eliciting laughter from (R) and other residents.....

(FM) interacted with her mum, asking what different things were, picking up instruments and playing them in a deliberately funny way, to which (R) responded with uproarious laughter and said to me "*Look what I had to put up with (smiling)*" and pretended to hit (FM) on the bottom. (R) also called to (FM) at one stage "*(Name)! Look at this*", I have not heard (R) use the (FM) name during any visit, and (FM) was surprised too.

My original therapeutic goals for music therapy sessions that involved family members included: creating a possibility for shared meaningful experience in music, helping family members to communicate with their loved one with dementia through the use of music, helping family members to discover different ways of interacting, integrating emotional experiences and also helping residents to find a new way of sharing and communicating. When I reflected on my observations of interactions between family members during spontaneous involvement in music therapy sessions, I realised that many of these goals were being achieved by supporting the spontaneous involvement of family members in music therapy sessions. They were also being achieved in other facets of the music therapy process, such as information sharing.

#### ***4. Spontaneity, Joy and Humour***

**Encouraging and incorporating spontaneity, joy and humour in the music therapy process can provide a "periodic release from the obligation to be rationale and logical all of the time"(Freud, 1967 cited in Haire & Oldfield, 2009, p. 29)**

It was evident that humour, playfulness and joy were apparent in my work and part of my therapeutic relationship with residents. I believe these qualities played an important role in

the therapeutic relationships developed at the facility, both with residents and family members. At times, communicating with the residents felt difficult, like a lot of verbal communication was “lost in translation”. Family members would often comment that they were unsure about what to talk about with their loved one, that interactions felt “*hard*” and “*awkward*”, often compounding their feelings of loss and grief. During music therapy sessions that family members were present, I often noted a light hearted and humorous quality about interactions between them and their loved one. Humour has been described as a “periodic release from the obligation to be rationale and logical all of the time” (Freud, 1967 cited in Haire & Oldfield, 2009, p. 29). This description struck me as particularly applicable when thinking about my work with people with dementia and their families.

Common qualities of humour according to Haire and Oldfield (2009) are incongruity, unexpectedness, freedom and creativity; and these qualities link to spontaneous musical improvisation. Although I am not suggesting that all interactions with people with dementia are humorous, or need to be; I consider qualities such as incongruity, unexpectedness, freedom and creativity as key to “meeting” people with dementia where they are, during musical and non musical interactions.

The majority of interactions I observed between family members and residents that I perceived shared a meaningful connection; all included some or all of these qualities to varying degrees. Perhaps spontaneous music making provided family members with an opportunity to be with residents in a way that didn’t feel hard or awkward. Music therapy is often referred to in literature as an intervention that facilitates communication and expression, providing a person with dementia the opportunity to make contact with the world and people around them (Jonas-Simpson & Mitchell, 2005; Raglio & Gianelli, 2009;

Ridder, Wigram, & Ottesen, 2009; Sacks, 2007). From my observations of interactions between family members in music therapy, I would argue that music therapy also provides the family of people with dementia the same opportunities for communication and expression. Perhaps music therapy is an intervention that gives family members permission to have a fun or relaxing interaction with residents, indeed the periodic release from having to be rationale or logical, and an experience of interactions that don't feel hard. The following examples are observations or comments made during spontaneous musical interactions between residents and family.

(R) would often look at (FM) and smile, on a few occasions it looked as if they were having a good joke about something.

Following the session (FM) commented to me that it was nice to have some fun with her Mum, like they were on the same wave length for a bit.

(FM) played instruments in a deliberately over the top and humorous way, eliciting uproarious laughter from (R) and other residents. I joined in, with a hambone, and for a moment we were united in our silliness. Following this impromptu music making, I held a music therapy group. The energy in the room seemed light hearted and joyous, I noticed people smiling, and (R) was still using instruments like a true comedienne.

I noticed (R) looking at (FM) a lot and smiling and she said at one point *"see I have talents I never knew about, I might just join a band yet"* (FM) said, *"it's nice to see you still have your sense of humour mum"*.

There was a lot of laughing, joking and 'tom foolery' (as one resident called it) in the group today. It was almost like the residents were having a battle of the quickest wit (!), one resident commented that her spirits were *"well and truly lifted"*, another commented *"Oh it's good to laugh"*.

Following the 1920s event, (R) wife commented that she wouldn't have wanted to be anywhere else. It was lovely to share a dance, a laugh and some music with (R), it was easy.

## **5. Flexibility**

**Accommodating the diverse ways in which family members and residents are involved in the music therapy process requires flexibility.**

It became increasingly evident that to involve family members in the music therapy process, and to balance the needs of family and residents would require flexibility on my part. Being flexible in my approach was crucial in developing a culture of openness, acceptance and acknowledgment of all forms of family involvement, whereby family members felt comfortable to engage in the music therapy process.

Flexibility also included practical issues such as work hours. Working with people that have dementia doesn't fit within the constructs of a 9am-5pm timetable. In fact, the 'Sundowning' is a phenomenon that can affect people with dementia, and is a term used to describe symptoms of increased arousal and agitation in the late afternoon and evening (Lester & Petocz, 2006). Therefore, providing music therapy for residents in the evening once a week became part of my practice at the facility, to maximise the benefit of the music therapy intervention. I also thought that being at the facility during this time would increase the chance of contact with family. Interestingly, while there was positive feedback from family members about having music therapy during these hours, the amount of family contact at the facility during these hours was actually less than during the day. However, this time provided me with a very different experience with residents, and called on different skills and music therapy approach to work with residents during times of heightened anxiety and arousal. I found that this was a time that residents spoke about their family the most. During sessions, residents would often appear anxious, and tell me that they had to leave to "*Get home and put tea on*", or tell me they were worried about the

children, their husband or their wife. Often residents would ask me *“Is (FM) ok?”*, *“have you seen them?”* Because of my frequent contact with family members, I felt more able to provide reliable reassurances, by using knowledge of family members’ names, work hours, or living situation to reassure residents during these times.

Because of the difficulties some people with dementia may have articulating their concerns; it is sometimes hard to understand the root of their distress. Having a deeper understanding and knowledge of their personal history, and their family system helped me better understand and provide informed reassurance to the residents. It also felt significant that family were able to consider music therapy as an accessible and valuable intervention that could provide comfort for residents in moments of distress.

*“Mum seems upset because we are leaving, could you please do some music with her now?”*

It was important to me that I could respond to these in the moment requests for music therapy, and it required flexibility to do so. Practicing music therapy with awareness of the how the community of residents was collectively affected by different experiences and responding to this in music therapy, also demanded flexibility of my practice. The music therapy sessions with residents that took place outside Jack’s bedroom as he was dying are an example of this.

## ***6. Negotiating my role in the community of the facility.***

**Being part of the community at the unit means extending the music therapy role to encompass other therapeutic opportunities with people based on the musical relationship.**

As a student music therapist, there was a certain luxury in being able to spend 3 full time days per week at the facility. Personal communication with a registered music therapist working in this field indicated that music therapists are often employed by rest homes or dementia units for set session times each week, limiting the amount of time spent with residents. Being the student music therapist 'in residence' at the facility, meant I gradually developed a strong sense of 'belonging' to the community. This sense of being part of the community linked to my emerging identity as a music therapist becoming closely affiliated to community music therapy. The core of my relationships was firmly grounded in music and these relationships extended outside the regular planned music therapy sessions at times. I became involved in supporting residents to attend other events at the facility, musical and non-musical, and at times to be involved in the planning of these and thinking how the residents could be supported to participate in other events. The relationship and trust I had developed with residents in music therapy made it possible for me to support their participation in other community events. Often family members were invited to larger events held in the wider facility, and it provided an opportunity for interactions between family members. Therefore, in my view it was very much part of the music therapy process.

My music therapy relationships with residents and their family members took me outside of the facility environment occasionally. On one such occasion I accompanied a resident with the support of the diversional therapist to a local instrument shop. The resident was an

accomplished musician, and played and owned a myriad of instruments. Her daughter met us at the shop, and we all spent time exploring the shop, looking at and talking about different instruments, this was followed by a cup of tea and cake at an adjoining cafe. Following the outing, the residents' daughter commented, *"It was so nice to be with Mum outside of the unit, and to share things she loves. There is still life outside the unit"*. This example demonstrated that creatively collaborating with staff and involving family members in the music therapy process could facilitate shared experiences outside of traditional music therapy sessions that are meaningful for residents and family members.

Another example of the extension of the music therapy role was facilitating visits between a resident I worked closely with in music therapy and her husband who resided in a different part of the facility. One of the music therapy goals with this resident was to help her to maintain a sense of connection with her husband because they lived in separate wings of the unit, and also help her to manage her immense anxiety and grief about being separated from him. I would often provide music therapy for her following visits with her husband, when she was distressed and I would sometimes accompany her to the hospital to visit her husband. It could be argued that facilitating visits is not within the scope of music therapy practice. However, again, it was the relationship we had developed in music therapy that enabled me to recognise that at times facilitating a visit would be the most therapeutic intervention, and also supported my own and the unit's philosophy of family involvement.

## DISCUSSION

Approximately 60-70 percent of people living in residential care facilities for older people in New Zealand have some form of dementia (New Zealand Ministry of Health, 2002). It is important that music therapy practitioners and researchers consider ways that music therapy can support residents and their family members to live well in the presence of dementia and in residential care facilities. Robison, Curry, Grueman, Porter, Henderson & Pillemer (2007) suggest that collaborative relationships between families of residents and staff members are essential for improving quality of life for the resident, and vital for residents with dementia (Robison et al., 2007). This study does not focus specifically on the topic of music therapy in palliative care. Nevertheless, the field of palliative care has a strong emphasis on enhancing quality of life. It aims to offer a support system for patients and their families to 1) help patients live as actively as possible until death, and 2) help families cope during the patient's illness and in their bereavement (World Health Organisation, 2012). Thus there are strong links between music therapy in dementia care and music therapy in palliative care, especially in hospital settings, suggesting that the findings of this study will be relevant to both fields. The theoretical perspective developed in the present study demonstrates how involving family members in the music therapy process can strengthen relationships between the residents, care staff and family members; by increasing communication between all parties and supporting a sense of community amongst the people living, visiting and working at the facility.

Haesler, Bauer, & Nay's (2007), proposition that a holistic approach and involving family members contributes to residents' wellbeing and the six key factors they identified i.e. "upholding the patient's uniqueness; assessing and addressing unique family needs; using



effective communication skills; implementing a collaborative care process; understanding and addressing interpersonal power issues; and providing organizational support” (p. 394), were also highlighted in the present study. The way in which each family member experienced grief was different for example, and my flexible approach enabled them to communicate what they needed in their own way. Music provided a focus for our communication, and broader issues were able to be addressed within this framework. The philosophy of the facility and their enabling and willingness to be involved in collaborative activity, such as singing with me in various contexts, was important. Power relationships, if they existed, evaporated as we sang and played together.

The importance of upholding a person’s uniqueness is a basic tenet of dementia care (Kitwood, 1997). Achieving this requires a commitment from people working with those affected by dementia to learning about ‘the person’ they are working with. It can be difficult to obtain a life history from a person living with dementia, or to get a sense of who they really are in the context of a residential care facility. Facilities can be clinical environments and sometimes the only clues regarding individual identity come from photographs on people’s walls, a few personal effects, what can be gleaned from medical files, and asking staff. When dementia prevents a person from being able to provide an oral history for themselves, or name a favourite song, it is important to seek the information from people who know. Family members often possess family history and knowledge and are usually happy to share it with helping professionals.

The findings of the present study demonstrated that the most consistent form of family involvement in the music therapy process was in the sharing of information. Sharing information provided rich history, and personal insights into the life of a resident and their

family. Negotiating the sharing of information was a complex process at times. Family members shared information in diverse ways, and it took time to learn how different families were comfortable communicating with me. For example, email was only an effective mode of ongoing communication for a small number of family members, I also had to rely on phone contact, chance encounters with family members at the facility, and some planned contact with them. Being active and resourceful in the way I encouraged and engaged with families to share information was essential. Sharing stories, history and personal experiences enabled family members to participate meaningfully in the music therapy process at the unit, and contribute positively to their loved ones lives. Actively seeking information from family members to better inform music therapy practice with residents demonstrated that music therapy was an intervention that recognised the importance of each resident's unique personality and life experience. When it comes to knowing 'the person', the residents and their families are the experts, and need to be regarded as such.

In learning about the life experiences of residents, it is impossible not to learn more about their families, and to come to know and connect with certain individuals from their family. A culture of openness and sharing was developed within the music therapy process. Every family approached being involved in the music therapy process differently. This meant taking an eclectic approach to involving families, and letting go of my preconception that the most therapeutic facet of family involvement would be their active participation in music making. I also found myself providing support for family members when they expressed grief and difficulty coping with their loved ones diagnosis of dementia. As Bright

(2006) states, music therapists often establish a milieu in which clients and their families are “empowered to confront their difficulties” (p. 70).

The collective experiences of grief and loss amongst families, and how or if music therapy could offer family members the appropriate level of support, became a significant consideration. Communicating and collaborating with other staff about this was important. In keeping with the philosophy of the facility sharing information from music therapy enabled the organisation to acknowledge family experience and to support them to address their issues or concerns. Some creative strategies were put in place, including a “Family Day”, whereby all family members were invited to the unit to share morning tea with the residents and staff. The aim was to provide an occasion for family to connect with each other and perhaps share experiences and support. It could be argued that if family members are afforded opportunities to talk about their grief and loss with others, that this will have a positive effect on their relationship with their loved one. Drawing on Piercy’s (2010) understanding of family systems theory, I would argue that practitioners need to have an awareness of how the emotional experiences of each member of the family affect the system as a whole. This is also an important consideration when thinking about the community of residents at the facility, and their interrelatedness.

Music therapy as a discipline shares some of the core common values associated with Family systems theory (Bowen, 1983 cited in Piercy, 2010), Personhood (Kitwood, 1997), The Recovery Model (O'Hagen, 2001) and the Whare Tapa Wha model (Durie, 1998). These include the delivery of holistic care, upholding people’s uniqueness, and ensuring family involvement. Improving the quality of life for people with dementia is also an initiative that spans health care literature (Chatterton, Baker, & Morgan, 2010; Jonas-Simpson & Mitchell,

2005; New Zealand Ministry of Health, 2002) and music therapy research (Aldridge, 2000; Bright, 1988; Clair & Memmott, 2008; Kydd, 2001; Pavlicevic, 1999; Powell, 2009). For example, in the present study it seemed that residents' quality of life improved as their relationships with family members strengthened through the initiation of playful social interaction. Through music making they developed an increased awareness of self and other, and thus their sense of belonging may have been increased.

Within the framework of community music therapy, health is considered a relational concept, and understanding the person in relation to their context is key (Stige & Aaro, 2012). Human connectedness, enhanced mutual relationships, collaboration, participation, partnership and exploring health promoting connections are some of the underpinning values that inform community music therapy (Stige & Aaro, 2012). There were references made to *"feeling part of a community"* or of a *"sense of community"* amongst people at the facility, including staff, residents, family and my own experience of feeling a part of the community was discussed. McMillan & Chavis (1986) cited in Stige & Aaro (2012) developed four main elements that contributed to their theory on 'sense of community'. These were,

*"membership (the feeling of belonging or of sharing a sense of personal relatedness), influence (a sense of mattering or making a difference to the group), integration and fulfilment of needs ( the feeling that members needs will be met), and shared emotional connection (the commitment and belief that members have and will have a shared history, common places, time together and similar experiences)"* (p. 90)

The participation in the music therapy process at the facility strengthened the sense of community amongst residents, families and staff. Residents spent more time together in

music, listening and responding, sharing musical experiences and parts of themselves with each other. Family members and staff were welcomed to participate and be a part of music therapy, and share in this sense of community. Sacks (2007) also highlighted the concept of sense of community in relation to music and people with dementia. He describes the power of music to elicit a sense of togetherness and states that in music; *“a sense of community takes hold, and these patients who seemed incorrigibly isolated by their disease and dementia are able, at least for a while to recognize and bond with others”* (p 345)

Viewing the unit as a community and learning how music could work in partnership with individuals and the community as a whole was key in establishing the role of music therapy. It is important to note that I was afforded the luxury of an extended time period with the residents and family members during the period of this study. This sustained interaction with the community allowed increased contact and availability in which to spend time nurturing relationships and to establish a music therapy programme that fitted within the philosophy of the facility. It is important that residential care facilities consider affording music therapy this time, including music therapists as an essential member of multi-disciplinary teams to participate fully in the comprehensive care delivery on a full time basis. Further exploration of community music therapy practice within residential dementia care facilities could provide valuable information for developing music therapy processes and practices that improve the quality of life for people with dementia and in turn their families. ‘Belongingness and relatedness’ have been suggested by Stige & Aaro (2012) as basic psychological or social needs that are so fundamental that if not met, can have harmful consequences for a person’s health and well-being. Music therapy provides creative strategies to address and advocate for people with dementia to continue experiencing

belongingness and relatedness in residential care facilities, and for their families to share in their community.

## Strengths and Limitations

This study complements other research that spans the music therapy, health care and dementia related literature exploring the involvement of family members of people with dementia in music therapy and other interventions. It could bear particular significance to beginning music therapy practitioners looking to understand and include family involvement as part of their music therapy practice.

Given that there were no participants in this study, I was only able to provide my interpretation of events. The data gathered was not specifically gathered as research data, because this study employed secondary analysis of data. Therefore, had the data been gathered specifically for the purpose of research, I may have sought to investigate other aspects of the practice or sought to capture other peoples' views through different data collection methods such as participant interviews. However, the data was collected as part of my usual clinical practice and included rich descriptions, personal reflections and clinical observations within which family involvement was included. The findings of this study are not representative of all residents with dementia and their families. They are based on the experiences of one student music therapist, at one residential care facility. Therefore, a different student music therapist asking the same research questions could have a different interpretation of events and findings. However, the findings and consequent theory developed from this study could be applied in other residential care settings and future

studies could seek to capture the subjective experience of the family members and residents involved in the music therapy process to better inform the practice.

## Conclusion

This exegesis explored involvement of family members of people with dementia in the music therapy process at a residential care facility, and developed a theory about this area of practice. Inviting family members to share their expertise about their loved one was a powerful tool that provided insights into the unique life history of each resident, informing music therapy sessions, and strengthening relationships with residents. Involving family members in the music therapy process facilitated moments of shared meaningful experience in music, and helped residents and their families to find new ways of sharing and communicating.

Flexibility, openness and ongoing communication were identified as core values of my practice, which enabled family members to participate in the music therapy process in diverse and meaningful ways and at their own pace. The negotiation of relationships, both with residents and their families took time and over time a sense of community in the music was developed amongst residents, families and staff. The culture of the music therapy process at the facility was one that encouraged and supported spontaneous, playful and humorous interactions in music between residents and family members. The experience of dementia can be an extremely difficult one for residents and their family members. Therefore, there was immense value in acknowledging and sharing moments of joy and light heartedness for residents and families involved in music therapy. A music therapy process

that values meeting and balancing the diverse needs of people with dementia and their family members can strengthen relationships, and foster a sense of community amongst people who are a part of life in residential care facilities.



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## **APPENDIX I: *Letter to Families***

28/3/2011

My name is Patrice Dennis. I have a background in mental health nursing and I am now a Masters of Music Therapy Student at the New Zealand School of music.

Music therapy is defined as the planned use of music to assist the healing and personal growth of people with identified emotional, intellectual, physical or social needs(see Music Therapy website: [www.musictherapy.org.nz](http://www.musictherapy.org.nz)). It involves using music to develop and maintain relationships with clients and can, among other things, help to develop communication, provide support in times of loss grief and pain, reduce stress and tension, assist memory, imagination and processing thought, and extend physical movement. Music therapy is provided to individuals, or groups of people.

This year I am lucky enough to be able to do my music therapy placement until November, at..... I have a particular interest in working with people experiencing Dementia, and have spent the last few weeks at ..... getting to know the residents, making music, singing songs in groups, and working with them to discover how music might be included in their lives.

It is very important to me that I provide musical experiences that are meaningful for the individual residents of..... It can be very helpful when family members are involved in music therapy sessions because they can share their knowledge of each resident's unique music tastes and musical backgrounds, and provide familiarity and comfort to residents. Family members usually enjoy being with residents during music sessions too, because their loved one can be more alert and communicative in a musical environment. This is why I am inviting you to be in touch with me if you would like to attend music therapy sessions with your family member and/or to share with me any of your knowledge about their musical history. I would be interested in knowing their favourite songs or musical preferences; whether they ever played an instrument; whether they enjoyed dancing or musicals; and about any pieces of music that might be particularly meaningful such as wedding songs, or lullabies that were sung to you, and so on. You can respond to this email, with any of the above information or stories.

My timetable is still relatively flexible at ..... and I would like to be able to plan sessions for times when family members can join me. I am there on Tuesdays, Wednesdays and Fridays from 9am to 3pm, and invite you to let me know if you can come in any time on those days. I would be very happy to discuss this further, answer any questions you might have, or make a time for you to attend a session. My email address for future correspondence is [patriceha@hotmail.com](mailto:patriceha@hotmail.com). If you are not able to email, please leave a message for me at the hospital and I will call you as soon as I can.

It is a special privilege to be working alongside the residents at ..... unit and I look forward to meeting you also. Thank you for your time in reading and responding to this email.

Patrice Dennis

## APPENDIX II: *Information Sheet for Consent*

Information and Consent Forms for Families about Music Therapy Research 2011: Patrice Dennis



### MUSIC THERAPY PROGRAMME (MMusTHER)

**Research Title:** Involving family members of people with dementia in the music therapy process at a residential care facility.

#### Information Sheet

Dear \_\_\_\_\_,

As you know, I am the second year Master of Music Therapy student completing my clinical placement at ..... Home and Hospital. As part of my training I am required to research an aspect of my practice, by looking back at the records I have kept about my work with residents of ..... and family members. I am also required to present a case study, verbally, at my final examination.

Family involvement is encouraged and valued as part of Dementia care in New Zealand, and I have chosen to explore the involvement of family members in the music therapy process at ..... The purpose of the research is to improve my learning and to inform other music therapy students, practitioners, and carers, of particular issues involved in the work.

I have been writing notes following music therapy sessions, keeping a reflective journal to record personal reflections about my music therapy practice, and communicating by email with family members. My research will involve looking back (secondary review) over these data with a specific interest in how family involvement has evolved during my time at ..... In my written findings, I will be including a case vignette from my practice to illustrate a particular point about my learning.

I am writing to ask your consent to review and analyse my work with ....., and with you, as their family member/guardian/EPOA. I am also writing to ask if I can talk about this work at my final examination. If you agree, I would not use your real names in any publication or presentation about this research. The ..... residents' music therapy will continue in the usual way, and there is no expectation of extra attendance or any extra communication outside of usual clinical practice. The secondary review of the data will take place at ..... or at my place of study (home office) on a password protected computer. Consent forms will be kept for ten years and stored at the New Zealand School of Music, Music therapy

Department, in a locked filing cabinet or cupboard and marked “confidential”. Only the research supervisors would have access to the data and would be responsible for its safe-keeping.

I will provide a summary of the results of my research to ....., and provide copies of the summary and vignette to your family, and to other team members that may be represented in the writing. I will present the practical case material to my examiners in a private session at the end of my university degree.

Please sign both copies the attached consent form and return one to ..... Home and Hospital c/o Patrice Dennis. You can agree to all, some, or none of the requests. If you decide not to allow data related to you or your family member to be used in my research, this is fine, and does not impact the ongoing music therapy session for your family member. Please do not hesitate to contact myself or the following people if you have any questions, or wish to discuss this further.

Dr Daphne Rickson, Research Supervisor at the New Zealand School of Music:

Ph: 04)8015799 x 6979 or email: [d.rickson@massey.ac.nz](mailto:d.rickson@massey.ac.nz)

Thank you for your time in reading and responding to this letter.

Yours Sincerely,

Patrice Dennis

Student Music Therapist

Email: [patriceha@hotmail.com](mailto:patriceha@hotmail.com)

Ph: 04)3829822

## APPENDIX III: *Consent Form*

Information and Consent Forms for Families about Music Therapy Research 2011: Patrice Dennis



### MUSIC THERAPY PROGRAMME (MMusTher)

**Research Title:** Involving family members of people with dementia in the music therapy process at a residential care facility.

### CONSENT FORM

I have read and understand the information sheet about the above study, and have asked all the questions I need to ask. I understand that I can ask further questions at any time.

YES ☐ NO ☐

I give consent for data relating to .....and myself to be reviewed for research purposes.

YES ☐ NO ☐

I give consent for Patrice Dennis to include a written case vignette about her work with .....

YES ☐ NO ☐

I give consent for Patrice Denis to talk about her music therapy work with ..... at her final examination.

YES ☐ NO ☐

I understand and give consent for case work relating to ..... may be used for publication at a later stage.

Signed.....

Print Name.....Date.....