Supporting people with dementia who are experiencing loss and grief; developing student
music therapy practice.

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Abstract

This study is an action research project to develop my music therapy practice with people living with dementia who are encountering loss and grief. The research was developed during my practicum at the Music Moves Me Trust; a charitable trust offering music therapy services to people and their families living with dementia in the Waikato, New Zealand. The researched question was, “How can I use music therapy to support people with dementia through loss and grief?” This research is particularly relevant given the call for non-pharmaceutical dementia care in New Zealand. Over three action research cycles, I planned, performed, evaluated and reflected upon focused research actions. Thematic analysis was used to find common themes across the research cycles. Five themes of: sensing over speaking; human connection; honouring spirituality; knowing individuals closely and therapist self-care are presented in the model of a human hand. The palm of the hand holds the core theme *valuing the person*, as inspired by Kitwood (1997)’s model of personhood. The research’s findings valuing spiritual care, and an emphasis on nonverbal connection aligns with Kirkland, Fortuna, Kelson, and Phinney (2014)’s study of a spiritual care and music therapy group.

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Glossary of Terms

Conjugal Bereavement: Loss of a spouse. This term includes consequential losses such as in social role, confidence, and loneliness (Cheng, Lo and Woo, 2013)

Life Review: Looking over one's life, reflecting upon experiences and finding meaning. This may encourage positive self-esteem; affirm life issues; and help to find motivation for life in the here and now (Kampfe, 2015)

Compassion Fatigue: When a carer becomes exhausted emotionally and/or spiritually from their work and becomes less able to maintain compassion towards those they care for (Aycock & Boyle, 2009).

Disenfranchised Grief: Grief experienced by an individual who does not have the opportunity to mourn. This may be for reasons such as: an individual not being supported in their grief; not being able to publicly mourn; their grief is not accepted; or guilt experienced around grieving (Berenbaum, Tziraki, & Cohen-Mansfield, 2017).

Anticipatory Loss: Specific to palliative context, anticipatory loss describes the mourning of future losses before they occur. In dementia, this may include loss of speech, cognition, personality, memories, and loss of life (Irish Hospice Foundation, 2018).

Complicated Grief: A diagnosed condition of prolonged and persistent grief which causes impairment in day to day functioning. Is colloquially described as "getting stuck in grief". Diagnosis can occur after six months or longer of intense grief, following a loss (Shear, 2015; The Irish Hospice Foundation, 2016).

Loss-Oriented (L.O) Grief Response: A response of confronting grief, and allowing ones self to experience the fullness of sadness and loss (M. Stroebe & Schut, 2016).

Resource-Oriented Grief Response: Where a mourner shifts their focus from their grief, and attends to external, restoration changes to continue life after the loss (such as making new routines, or constructing a new identity) (Smit, 2015; M. Stroebe & Schut, 2016).

Overload: When a grieving individual feels fatigued, worn out and/or anxious and that they are facing more stressors than they can feel they can manage (M. Stroebe & Schut, 2016).

Ontological Meaning: The search for meaning in the present and in day to day living (Kirkland et al., 2014).

Quality of Life: In a palliative context, quality of life is described by Hughes, Lloyd-Williams, and Sachs (2011) as a certain amount of psychological and spiritual contentment.

Introduction

The Experience of Dementia

Dementia is a neurocognitive disorder where an individual experiences chronic or progressive deterioration of cognitive function (World Health Organization (WHO), 2012). Graboys and Zheutlin (2008), in an autobiographical memoir of one man's experience of cognitive deterioration, described losing what was logical to him and had previously come as "second nature". His experience included becoming lost in his home, and pouring himself orange juice with the glass upside down (Graboys & Zheutlin, 2008). Cognitive loss has a systematic effect on an individual's entire being. Some people, like Graboys, have insight into their cognitive decline, and others do not – which can make the experience even more confusing and frightening (Berenbaum et al., 2017). Regardless of cognition, people with dementia have described that they still experience emotion, desire to retain their identity, and feel a need to contribute to and take part in the world (Sakamoto, Moore, & Johnson, 2017; Wallace, 2011).

Appropriateness of the work

The wellbeing of people living with dementia is a pertinent research topic as the number of people with dementia continues to rise. In *Alzheimers New Zealand* (2017, p. 3)'s most recent national report on dementia, they referred to its rapidly increasing prevalence, claiming that New Zealand 'cannot afford to do nothing'. The report estimates that the number of people in New Zealand living with dementia will almost triple by 2050. The report also mentions that to cope with the increasing presence of dementia, New Zealand needs to work towards understanding how to best care for people who have been diagnosed with dementia.

The 'New Zealand Framework for Dementia Care' (Ministry of Health, 2013) has said that evidence-based, non-pharmaceutical approaches should be the first-line of care for individuals with dementia. These approaches are favourable as they are often less intrusive and are less likely to have negative side effects than medication (Galik, 2016). This is particularly important for those whose bodies are frailer, due to age and illness (Brandt & Mansour, 2016).

Music therapy is a holistic, non-pharmaceutical, alternative dementia care for people living with dementia (Jones, 2016; Ray & Mittelman, 2015). By definition, music therapy in New Zealand is an evidence-based practice, implemented by a trained music therapist (Music Therapy New Zealand,

2012). Given this definition, the practice can be considered a high-quality pharmaceutical alternative. Music therapy is individualised to clients, suiting the variable nature of the causes and symptoms of dementia (McDermott, Crellin, Ridder, & Orrell, 2013). Individualised music therapy champions specific strengths and care for the specific needs of one person (Odell-Miller, 2017; Ridder, 2017). Music therapy research has shown to help people manage the behavioural and psychological symptoms of their dementia (BPSD) (McDermott et al., 2013; Raglio et al., 2013; Ridder, Stige, Qvale, & Gold, 2013). A music therapist can also care for the emotional and spiritual sides of a person, in a way that pharmaceuticals cannot.

Research Setting

The Music Moves Me Trust (MMMT) is a charitable trust, established in 2015 by a music therapist, a palliative care doctor, and a singing teacher, each with a personal interest in the wellbeing of people with dementia. It works to deliver professional and high quality music therapy to people living with dementia in care homes around the Waikato region (Jones, 2016). The therapy is offered at no cost to clients, making it accessible for all. The Trust currently employs two part-time music therapists, who work individually with clients and in interactive groups, supported by a myriad of volunteers. The Trust was the context of my research as I completed around 750 placement hours in six care homes. It was this work which inspired my research topic, and where I carried out my research actions.

The MMMT does not have an organisational therapeutic approach. Rather, treatment depends on the employed practitioner's preference. However, it is evident that the Trust's foundations are person-centred and humanistic, as its origin story confirms. The MMMT was created in memory of a founding member's late grandmother, in accordance with the member's personal conviction that people with dementia should receive more loving care than she had received. I acknowledge that MMMT's emphasis on treating people with dementia with care definitely influenced my personal therapeutic approach, and the services I provided.

Naming the facility in research

Facilities are often not named in research, due to the increased risk to participants' anonymity. All residents written about in the present research, and their Power of Attorneys (POA) have been informed the MMMT being named, and the risk involved (as shown in Appendix 5. **Permission Request Letter to Facility** and Appendix 6. **Permission Request Letter to Care homes**) I have made deliberate effort to anonymise any defining features of their characters.

Therapist Approach/Personal Interest

I have had close relationships with older people throughout my life, which have taught me that there is wisdom and value in age. As I grew up, I was close with my grandparents. I had a great grandmother who died of Alzheimer's dementia when I was young, and I do not remember much about her other than that her behaviour was unpredictable and that my grandfather and great grandfather clearly still loved her unconditionally. Last year, I was employed to visit a woman with Alzheimer's three times a week and plan enjoyable and accessible activities for us to share together. I came to love this woman.

Upon beginning to read about dementia, I was looking out for humanistic approaches to care which aligned with the love I had witnessed and experienced. I wanted to learn about caring in a way which tackles the challenges of dementia appropriately, without losing sight of the person. Kitwood's (1997) model of needs describes that a person with dementia carries at their core a need for unconditional love. His description of personhood is that all humans are persons and have value regardless of disability (Kirkland et al, 2014). As a result of this reading, I carried a 'personhood' approach to care before I had even started my placement.

Following my previous placements at a children's hospital and day facility for people with intellectual disabilities, I feel that that a person-centred approach (Rogers, 1961) is relevant to all populations, and that resource-oriented approach is an extension of person-centred care. That is, building on the client's strengths and interests to encourage successes, and increase their quality of life. While not explicitly 'relationship-based', I recognize that the therapeutic relationship is essential to successful therapy.

My focus on loss and grief came as I was struck by the amount and diversity of grief at my placement. I visited 6 different care homes around the Waikato and it was evident that residents were experiencing grief in all of them. I wanted to safely support the grief of those who shared their experiences with me. I watched busy carers sympathise with their clients before quickly moving on; or find a grieving person a positive distraction to occupy them for a short amount of time before they remembered their grief. As a music therapy student, I was privileged with the luxury of time and the powerful tool of music, and felt was in a prime position to support the grief I saw. The present study's topic was a way of equipping myself for this work, by developing strategies and approaches through focused action and reflection. I used this research to develop my practice across the year, aiming to truly provide the most relevant form of therapy for those I visited, who were mourning. My research aims to inform my own practice, but also, hopefully, to inform other student therapists in similar situations. This research aims to inform my own practice about approaches to grief and loss.

In this research, there is a greater focus on individual sessions, and people with more advanced dementia, as this is what I encountered the most in my placement.

Literature Review

The present study's literature review was compiled by systematically searching: *Dementia and grief OR loss and "music therapy"*. Related literature was also included.

Key terms for the present study include: *grief, loss, dementia, personhood, music, "music therapy" and "music therapy student"*.

Types of losses experienced in dementia.

Throughout the advancement of their dementia, a person will experience many changes and losses, which may be grieved. The progressive nature of dementia means grief support is relevant from the anticipation of loss at diagnosis, and throughout the disease as their abilities change (K. Allan & Killick, 2011). A person with dementia may need support for losses which are a direct result of dementia. They may also require support in grieving other, life-associated losses such as bereavement, or physical disability. All losses may be experienced differently when encountered with the cognitive decline of dementia (Rentz, Krikorian, & Keys, 2005; The Irish Hospice Foundation, 2016).

The risk of dementia rises with age and the increased loss of loved ones has been documented as one of the most challenging aspects of growing older (Selbaek & Borza, 2015). It is likely that an older person with dementia will encounter bereavement. Two of the greatest protective factors against depression in older people are their social networks and loved ones; similarly, bereavement may increase an individual's risk of hospitalisation and depression (Selbaek & Borza, 2015; M. Stroebe, Schut, & Stroebe, 2007). Conjugal bereavement¹ is considered a major life stressor and grief reactions may have resulting losses to an individual (Cheng, Lo & Woo, 2013). Bereavement may have consequential losses, such as of social role. For example, a transition from 'wife' to 'widow' may create distress around a person's identity and cause them to withdraw, becoming isolated in their grief (Cheng, Lo and Woo, 2013).

Dementia will inevitably change a person's socialisation and the way they interact with those around them. In early dementia, loss of mobility, driving, and independence may make it more difficult for an individual to engage in their social circles (Barber & Cooper, 2011; Graboyes & Zheutlin, 2008). As a person's dementia progresses, it may limit their verbal communication and create behavioural changes which can make social interaction more difficult (K. Allan & Killick, 2011). Changes in social role may be particularly pronounced in those with early onset dementia, as they experience early retirement, less independence, and additional time in hospital compared to their peers (Barber &

¹ See Glossary of Terms

Cooper, 2011). Moving from home into fulltime care can create grief around the loss of the support, familiarity and comfort from a person's loved ones who they previously lived with. Social changes are related to the way a person with dementia perceives their position in society and may be tied to their confidence and self-esteem (Selbaek & Bonza, 2015). Many authors have written about a cultural devaluation of elderly people with disability which contributes to a person with dementia's decline (K. Allan & Killick, 2011; Kitwood, 1997).

Mastery and skills which once were known and habituated can become lost, such as driving and cooking (Selbaek & Borza, 2015). There is evidence that procedural memory is maintained for longer than episodic in dementia, meaning learned schemas and 'muscle memory' can be maintained into a person's progression (Smith, 2017). Some people with dementia may maintain their musical skills, playing instruments for longer than many other skills (Clark & Warren, 2015). However, these memories may become disorganised with cognitive deficit, and it can be confronting and demotivating for a person with advanced skills to experience decline in their ability (Krout, 2009).

Anticipatory grief² is a term used in palliative settings as people grieve future losses, including the moment of their death. The Irish Hospice Foundation (2016) suggests that anticipatory grief in dementia can carry many elements, such as mourning the anticipated loss of communication, the potential loss of their person, and the ensuing effect on their family. Cheng, Lo, and Woo (2013) in their article on older persons nearing the end of their lives suggested that exploring spirituality and wholeness through art therapies can be an accessible way of expressing grief for those with cognitive deficit.

Ambiguous loss

In the later stages of dementia, it is discussed that a person with dementia may still emotionally experience a loss, or a lingering notion of loss, without certainty of the reason for their grief (Gataric, Kinsel, Currie, & Lawhorne, 2010). Doka (2010) described ambiguous loss as a "sense of wrong being". That is, the intuitional knowledge that something is wrong without being sure what it is. For example, in bereavement, a person with dementia may be informed of a loss and experience following emotional distress even though they can't recall why (Gataric et al., 2010). This sense of loss can be major source of distress or ongoing sadness (Rentz et al., 2005).

Griffiths (1995) observed that people with dementia may misattribute their feelings of loss after a recent grief to a salient past grief, for example, perseverating over the loss of their parents. Griffiths (1995), in a psychodynamic explanation for the misattributed grief, says that the person may use the grief as a pointer to communicate and describe how they are feeling. However, they may be confused, considering the past event the cause of their grief (Griffiths, 1995). It can be difficult for carers to support this kind of grief, as they cannot tell what is the cause of an individual's ambiguous, or misattributed grief (Gataric et al., 2010)

Evidence of grief in progressed dementia

People with dementia often cannot explain how they are feeling due to communicative, and sometimes insight loss. So it may be asked whether they can or do experience grief. Crying or sadness may be brought on by other dementia related symptoms. For example, there is evidence that people with dementia may cry and exhibit signs of sadness when experiencing physical pain (Jordan & Lloyd-Williams, 2011). Some authors suggest that people with dementia do feel grief, although it may be experienced differently.

Rentz et al. (2005) considered how grief and loss may be experienced while living with dementia, releasing an article which included a series of case vignettes of people living with dementia who were struggling to cope with loss. In the article's discussion, the authors related the lived experiences outlined in the vignette, to functional Magnetic Resonance Imaging (fMRI) research to demonstrate that there are many brain areas which process emotion, even when an individual is not consciously aware of it (Guendel, O'Connor, Littrell, Fort, & Lane, 2003). Rentz et al. (2005) say that we should not be surprised that the brains of people living with dementia are still capable of experiencing grief, however they may have an altered experience of grief. Their reactions to grief may be affected, as impairment to frontal and temporal lobes may mean they cannot modulate their emotions and responses. Their responses may seem overly exaggerated, or blunt.

Given that people with dementia may not have insight or understanding into losses they have experienced or know how to express their grief they are feeling, they may require help from others to mourn. Unacknowledged grief can easily become disenfranchised grief², making this kind of support especially important. Without the capacity to mourn, a person's grief is more likely become stuck in complicated grief² (Shear, 2015; The Irish Hospice Foundation, 2016).

² See Glossary of Terms

² See Glossary of Terms

Caring for people with dementia encountering grief.

Gataric et al. (2010) published reflections from healthcare professionals working in dementia care, suggesting they mostly believed that those they cared for experienced grief. The professionals agreed that people with dementia may have difficulty understanding and formulating an emotional response to loss, requiring help from others. They mentioned it was important for a person to have an empathetic supporter who will just 'be with them', and 'meet them where they are'. Music, particularly hymns and childhood music, was mentioned by the professionals to provide relief from grief related distress.

The Irish Hospice Foundation (2016) recognised a need for awareness of grief in people with dementia and their caregivers. They created an easy-to-read but thoroughly cited guidance document, for health care workers to greater understand and develop techniques for support grief in people who have dementia. It suggests that appropriate care requires first being aware that grief is an inevitable part of dementia and understanding the types of losses that people with dementia may experience. The article encourages practitioners to put deliberate thought into their actions, as the difficult behaviour of a person they are caring for may be a grief reaction. The Irish Hospice Foundation (2016) argues that people with progressed dementia still exhibit responsive behaviours, and state that all emotional reactions, actions, sounds, and words should always be treated as communication.

Similarly, Boyle (2014) argues that behaviours that are commonly considered behavioural and psychological symptoms of dementia (BPSD) are ways that people with dementia exercise agency and try to influence their surroundings. In a qualitative research analysis of observations, nonverbal communication analysis and interviews of five people living with dementia and their loved ones, Boyle (2014) concluded that people with dementia do experience emotion, such as loss. From the findings, Boyle (2014) argued that people with dementia use their emotions to form a judgement, and respond relationally. Boyle claimed that these relational actions can tell another person about the strong emotions a person with dementia may have and how they feel about an antecedent, marking this responsive action as a form of communication. Whether a person aims to deliberately influence their surroundings or communicate to others, it is a form of agency. Boyle (2014) hoped the research would encourage carers to react in an according way to the responses of those they cared for.

A Supportive Approach to Dementia Care

As described by K. Allan and Killick (2011), the term *support* suggests encouragement, or adding reinforcement and greater strength to something. This is preferable to *care*, which places the receiver into a passive, receptive role. *Supportive* describes a resource-oriented, person-centred approach, where the remaining strengths and individual interests of a person are emphasised. In their comprehensive book outlining supportive care for dementia in a variety of contexts, Hughes et al. (2011) claim that a truly supportive, person-centred approach to dementia care includes knowing and supporting the person's spiritual and psychological needs (including comfort and the therapeutic relationship). This care approach focuses on maintaining personhood (from the view of the carer) and selfhood (within the individual), but not to the detriment of a person's physical issues. Supportivism is, by this definition, a holistic approach to dementia care, where the individual is in charge of their care where at all possible.

As no current medicine is found to reverse dementia, dementia care needs to incorporate end of life care. A supportive approach can be maintained into palliative care (Hughes et al., 2010). The values of palliative care have been increasingly incorporated in dementia care, recognising that it is a life limiting illness. Palliative care focuses on maintaining quality of life right up to the moment of death. This suits the progressive nature of dementia, although providing appropriate care can become increasingly difficult with cognitive and communication loss (Casey et al., 2011). To maintain quality of life³, palliative care physically focuses on encouraging enjoyment alongside pain management, psychological and spiritual support, including for family and love ones (Hughes et al., 2011)

Art therapies and Dementia

Art therapies, such as drama, dance, visual art, and music allow people with dementia to communicate and express themselves more adeptly, using notions of emotion and metaphors. The arts can offer a means of expression and communication which does not require verbalisation, or organised thought (Cheng et al., 2013; Jaaniste, 2011). Arts-based research has also become a way of researching the dementia experience, where the art becomes the participant's voice, allowing them to speak for themselves (Sakamoto et al., 2017). More empirical research has been done on music therapy for people with dementia than any other art therapy (Jaaniste, 2011). Music therapy research has focused on issues such as reducing behavioural agitation and stress, encouraging spontaneity and

³ Hughes et al. (2011) describe, from a palliative context, that *quality of life* is a certain amount of psychological and spiritual contentment.

reminiscence, and promoting family-based therapeutic interventions (Aleixo, Santos, & Dourado, 2017; McDermott et al., 2013; Vink, Birks, Bruinsma, & Scholten, 2004)

Music Assisted Reminiscence

People with dementia may experience anticipatory or present grief around the loss of their memories. Memories are necessary for knowing who one's self is, and memory loss may contribute to a sense of confusion around one's identity. Tomaino (2002) notes that even in advanced dementia, music can trigger memories associated to familiar music. Tomaino (2002) suggests music's assistance of memories may increase a person with dementia's sense of self. Dassa (2018a) created a *Music Autobiography Interview* (MABI) technique, where a person with dementia is interviewed about their musical history and what music is associated with their salient memories, before being encouraged listen to or create the familiar music. Dassa (2018a) found that MABI reminded the elderly of who they were previously by eliciting distant memories. The musical reminiscence was found to help the participants to reflect on and express their identities. It also promoted their identity by allowing those around them to learn more about their history and memories.

Dassa (2018b) in another exploration of reminiscence, encouraged the families of people with Alzheimer's disease to engage in reminiscence with their loved one. In this study the reminiscence was not specific to one's musical history, but their entire life. Counselling perspectives suggest that such reminiscence of old memories and life review can be even more effective when accompanied by familiar music (Cheng et al., 2013; Kampfe, 2015). Dassa (2018b) equipped families with an individually compiled database of personalised music, photos, memories and significant artefacts. The database was used to engage with a person with dementia and facilitate their memories when their loved one visited them in a care home. The assisted reminiscence facilitated communication and connection between the person with dementia and their family. The positive socialisation served to support the person with dementia's quality of life. As previously mentioned, engaging with loved ones may defend against depression and sadness (Selbaek & Borza, 2015).

Music Therapy and sadness in dementia

Evidence of music therapy's effects on prolonged sadness is discussed here, as sadness is a greater researched and more quantified topic than grief. Sadness and depression can result from loss and are highly prevalent among people living with dementia (, 2017; Berenbaum et al., 2017). The most common symptoms include apathy, indifference, and loss of motivation (Galik, 2016). Non-pharmaceutical approaches to depression (such as music therapy) are particularly useful for people living with dementia, as many antidepressants have been linked to increased risk of falls and/or agitation (Brandt & Mansour, 2016). In a case study by Raglio et al. (2013), a woman with early onset dementia and total aphasia was witnessed by nurses and independent observers, to discharge her emotional and mental stress through establishing an improvised musical vocalisation dialogue with a music therapist. After six months of music therapy, the woman was exhibiting significantly less behavioural and psychological distress, and her Cornell Scale for Depression in Dementia (CSDD) scores had decreased by over 50 percent. A Cochrane review of music therapy literature found that people living with dementia who undertake music-based therapeutic interventions experience moderate reduction of depressive symptoms (van der Steen et al., 2017). There is some evidence that affective benefits of long term music therapy can continue even once the sessions have finished (Jacobsen, Stelzer, Fritz, Chetalot, & Turner, 2015). However, more research needs to be done in this area (van der Steen et al., 2017).

Music Therapy Techniques for Grief in Dementia

There is limited music therapy research on supporting people with dementia through general loss and grief. There has been much more research (including music therapy research) on supporting families who are grieving the changes in their loved one. Over the past decade, increasing amounts of research has focused on the person with dementia experiencing grief, rather than just their loved ones (including titles such as *'Reflections on the under-researched topic of grief in persons with dementia'* (Gataric et al., 2010) and *'Grief and mourning from the perspective of the person with a dementing illness: Beginning the dialogue'* (Rentz et al., 2005)). However this has not yet been reflected in the music therapy literature, except for reflections from Bright (1999, 2002).

Australian music therapist Ruth Bright is well regarded as an authority on music therapy and loss and grief, although her publications are not recent. She has used her previous work as a counsellor in establishing an eclectic and varied music therapy approach, which changes depending on the needs of

her clients (Krout, 2009). Bright (2002) recommends 'supportive' music therapy for people with dementia instead of verbal therapy. She uses music to provide an environment which can help people to express their emotions, as in verbal therapy, but without needing to use words to structure their expression. Rather than setting therapeutic goals which require insight, Bright (2002) focuses on building up the client's resilience, and personal sense of life satisfaction. She believes this helps build the client's defences against illness.

Bright's technique of using a musical environment to express emotion aligns with other literature. Odell-Miller (2017) mentioned that music therapy is uniquely able to help a person with dementia express and access a whole range of emotions – including happiness, sadness, pain, and distress. Ang (2017) in a recent Victoria University MT exegesis, found the violin to be a useful instrument in creating an environment where emotions of grief, loss, longing, and nostalgia could be expressed. Occupational Therapy research suggests that creating an environment with music may be one of the most effective ways of accessing a person with dementia's emotions (Padilla, 2011).

In another therapeutic technique, Bright (1999) creates music with clients which they listened to before an experience of loss. Matching the client's pace, she then derives an understanding of their emotional state from the reminiscent music before creating an improvisation which may validate how the client is feeling (Bright, 1999). Bright notes that, depending on the individual, the unfamiliarity of improvised music may sometimes confuse someone with dementia. In these cases, familiar music can provide comfort for someone with dementia. Familiar music reassures a person with dementia of their personhood through memories, and through opportunities for verbal and nonverbal communication (Bright, 2002).

Aldridge (2000) also claims that familiar musics provide a sense of comfort and security to a person with dementia. He says that music which allows emotional expression may be helpful for people with dementia, as it brings emotions to conscious awareness. He claims that awareness of emotion is a step towards not being overwhelmed by them. He describes the ways which different music therapy orientations can help a person with dementia. Most relevant to grief and loss, are the *humanistic* approach, which works to allow clients to discover their true selves, and equip them for the future; *communicative* where an individual can express themselves and interact with others, and *analogous* which assumes that achievements in the music therapy session can influence their daily life outside of the session. Aldridge (2000) speaks importantly of working in his music therapy sessions to encourage hope in the person with dementia, to help lessen or prevent depression.

It is worth looking at the ways that music therapy can support people living with dementia through loss and grief, as even those with advanced dementia may need help with mourning, and with the

residual effect of loss. Bright (1999, 2002) recommends the use of a comforting environment, improvisation and familiar music to help people living with dementia through the process of grief.

Research Question

Bright (1999, 2002)'s reflections on people with dementia are thoughtful and considered, however sparse throughout her writings. As a developing music therapist, I have wanted more information to help me understand how to support people who are grieving. The research question explored in this study has been:

How can I develop my music therapy practice to support people with dementia experiencing grief and loss?

The present research is a dual process of developing the skills and reflexivity necessary for a being a music therapist, while learning about the specific needs of and ways to support people with dementia experiencing grief.

Methodology

The current qualitative research uses an action research methodology. The method focuses on development, and self-reflection to critically evaluate what is useful and effective for the study's focus.

Theoretical Frameworks

Social Theories examine social phenomena such as relationships and societies. My person-centred approach has been inspired by social theorists who have challenged the existing model of dementia care, in order to implement a socially positive and quality-of-life inducing style of care for people with dementia (Kitwood, 1997; Lipinska, 2009; Mearns & Thorne, 2000). Social theory has influenced action research; the socially pioneered research approach aims to improve actions for the sake of others. It assumes that by improving your own practice, you will improve the situation of your workplace and that of those around you. McNiff (2010) argues that action research for good social order begins with the question: "How do I improve what I am doing for your sake?" (pp.26).

Also underlying action research is **Critical Theory**, which aims to critically examine what society assumes as its norms, in order to create positive social change (Campbell, 2015). Critical theory, pioneered by Marx and the Frankfurt school, argues that research for understanding is not enough – research needs to change the world for the better (McNiff, 2010). Action research's method of critique involves applying critical reflection to a broad question, in order to formulate appropriate action which will benefit the focus (Rickson, Legg, & Reynolds, 2018). The present research aims to critically examine and develop my own practice. Although this research's aim is to critique my own practice rather than social norms, it is greatly influenced Kitwood (1997) and related authors who worked to critique the model of dementia care. The present research adds to the literature which advocates for person-first dementia care, by suggesting supportivism as an approach to dementia care in music therapy.

Action research

Action research is described by Wheeler and Bruscia (2016) as 'study and reflection which leads to change' (pp.1). It is an iterative process which aims to change the perspective and actions of a researcher through continual thought and reflection (Stige & McFerran, 2016). Lewin (1946), the initial pioneer of 'action research', was a social researcher who believed that the best way to

understand something is to attempt to change it. This form of qualitative research has been used by practitioners interested in improving their practice (Rickson et al., 2018).

Action research assumes that the act of continual reflection brings even more insight to the practitioner than the knowledge obtained in the research (O'Leary, 2017). This method of reflection and subsequent modifications aligns with the values of the music therapy profession's, which requires a practitioner to undergo constant personal development and reflection (Music Therapy New Zealand, 2012). Action research's process of reflection invited me to re-evaluate my practice, and challenge the things read about and learned, before deciding whether they were appropriate for my context. By using action research as my methodological approach, I was able learn from evaluation and reflection while I was still with my music therapy participants, rather than solely from the thematic analysis conducted towards the end of my placement.

Reflexivity

While I endeavoured to be reflective as a practitioner, I also aimed to be reflexive as a researcher. Reflexivity is defined by the SAGE Dictionary of Social Research Methods (Jupp, 2006) as *"the process of monitoring and reflecting on all aspects of a research project from the formulation of research ideas through to the publication of findings"* (p.259). I wrote in a reflective journal about my knowledge leading into research, my assumptions, thoughts and experiences in an effort to be aware of my own influence on the findings. These were also sometimes pointed out to me in supervision. As I included my reflective journal in my data, reflexivity was included as part of the research's findings. This was relevant to the *developing practice* part of the research question.

Action research steps

Lewin (1946) developed a 'spiral of steps' metaphor to guide action researchers. This metaphor describes how the steps of planning, action implementation, and reflection begin again at the end of each cycle, as the last cycle's findings spur the next cycle's focus.

I organised my cycles using the three steps of action research, as described by Lewin (1997). These steps were: planning the action's focus; performing the action and generating data; and, finally, reflection and the analysis of the data to find themes. Stige and McFerran (2016) note that although the steps are a defining feature of action research, they are a metaphor and not a procedure which follows a prescribed order. The present study included a final thematic analysis to find common themes throughout the three action cycles.

Diagram 1. The structure of the present research, derived from Lewin's (1946) defining action research steps: 'planning', 'action' and 'evaluation', before a final thematic analysis.

There were three stages to each cycle. In the first stage, the planning step, two to three focuses of action were chosen based on what I had learned from the previous cycle and issues that were pertinent at my practicum. These focuses of action were deliberately broad. They became more refined in the following steps as I collected data, analysed the data for codes, and consequently learned what was important about that focus in my practicum context. During this initial phase, I also began to think about how my action focuses related to external research.

The second step of the cycle involved generating and collecting data. Over the two-week action period, I generated data which included my normal clinical documentation, as well as reflections, brainstorm, and related learning. All the data relevant to a chosen action focus was compiled into a large data set for that action, before undergoing analysis. I worked with seven residents for whom grief was a continual or daily experience. These residents were included often in my data set, but I also included data from sessions with other residents when relevant. The data collected is described further below.

Each cycle was concluded with analysis of the data into codes in order to derive commonalities and find meaning in the data I had created. Upon completing data collection, I wrote down thoughts, criticisms, and epiphanies, before developing codes of common and significant findings in the cycle. Once I had established codes for each focus of action, I began to consider their relationship to other codes, establishing connections in a mind map and then describing them in prose. Clarke and Braun (2016) explain that writing these thoughts is an essential part of the analysis process, as one tries to find direction among the data. An example mind map is pictured in Appendix 3. **Mind Map of Associations between codes and themes** These codes were developed into themes during the final thematic analysis stage of the research.

Data

The data for the present study included:

- My professional clinical notes written in the care homes I visited. These included the Music Moves Me Trust (MMMT)'s slightly adapted Music in Dementia Assessment Scale (MiDAS) (McDermott, Orrell, & Ridder, 2014a), and succinct descriptive notes of standout moments in the session. Although not a very rich source of data, my clinical notes were written independent of my reflections, providing a good reference point to ensure that my reflections and conclusions aligned with what actually happened in the sessions.
- Detailed and reflective notes about each session, written independently at home. Described by Geertz (1973) as thick description, these notes included what I was feeling and my interpretations and thoughts of what the client might be experiencing.
- Notes from a practicum journal where I wrote general and reflexive notes which weren't specific to individual sessions, such as thoughts on my approach, my perspective, and my assumptions.
- In four of my eight overall action focuses, I created a reflective brainstorm to help me understand the action focus.
- Personal notes I had taken from seminars I attended, conversations with my supervisors, and advice and experiences shared with me from RMThs and other therapists.

Thematic analysis

Qualitative thematic analysis (Braun & Clarke, 2006) is a systematic way of organising data into descriptive themes. Thematic analysis was the final stage of the present research, to find common and important themes across the action cycles. While I used a top-down approach to select focuses of

actions, the thematic analysis uses an inductive, bottom-up process (Hoskyns, 2016). Braun and Clarke (2006) describe a series of steps to analysing the data to find themes. This includes naming meaningful selections of texts into 'codes'; which will then be refined and reviewed multiple times before establishing a few encompassing themes. It is the aim of the analysis to create themes which accurately describe the data set and codes. Themes are not necessarily the most commonly occurring codes, but the most significant (Hoskyns, 2016).

Thematic analysis is grounded in a constructivist epistemology, acknowledging that a research's findings are socially constructed and cannot be separated from a researcher's experiences, assumptions, and ideologies (Clarke & Braun, 2016). I carried assumptions into my thematic analysis about what I would find in my research, especially as I was closely engaged with the data, which included my own written reflections and thoughts. Clarke and Braun (2016) state it is a defining feature of thematic analysis that the findings are the researcher's interpretation. However it is necessary for the researcher to be reflexive, open and state their assumptions.

Method of Coding

I used QSR International Pty Ltd (2012)'s NVivo 10 Software to analyse my data set into codes. QSR International's NVivo 10 is a computer programme which makes data more easily manageable to a researcher by holding and filing it electronically. While QSR International's NVivo 10 is a helpful tool for managing data, the interpretation of thematic analysis still entirely belongs to the researcher (Gibbs, 2007). As multiple pieces of data began to fit under one title, I devised subcodes (Clarke & Braun, 2016). The I refined these subcodes and joined similar ones together to create hierarchies, until I felt that I had a succinct collection of codes which accurately described my data (Maguire & Delahunt, 2017). I found I had a mixture of semantic, practical codes and latent codes which described ideological ideas. At the end of each action cycle, I informally began to think about how the codes were connected, through written prose and brainstorming. An example of my QSR International's NVivo 10 coding is in Appendix 4. **Example of coding using QSR international pty's NVivo 10.**

Once I had concluded the action cycles and coded the data, I conducted a large, broad and less structured thematic analysis to identify overarching themes. Although I had found NVivo helpful for structuring the smaller detail of my data set, I did not use it to find the overarching ideas and latent themes in the data. Instead, I engaged in brainstorming, writing, drawing, and scribbling connections to find what felt both prevalent in, and meaningful to my practicum experience. I established five themes and a core theme. I then compared the themes to the data and codes to ensure that the findings did, in fact, define the essence of the data (Clarke & Braun, 2016).

Ethical Issues

The current research's ethical permission was granted using an ethical template for music therapy masters' students conducting secondary analysis, approval number 22131. This ethics template only includes research where a music therapy student analyses their own practice. This is considered low-risk research, as the only participant is the researcher her/himself. Although my research data was comprised of clinical notes and reflections from sessions with clients, the research analysis did not focus on individuals, but on my own practice, experiences, and development.

An exception is the case vignette, and brief vignette in the *spirituality* findings, which describe my interactions with two individuals with whom I worked. I have included these vignettes to demonstrate that my findings were embedded in real-life practice. Verbal assent was obtained from May and Rosie⁴, who are described in the vignettes. People with dementia are considered vulnerable, as cognitive decline can influence their decision-making and consenting ability. Therefore, written consent was also obtained from May and Rosie's guardians who have power of attorney (POAs), who look out for their safety and wellbeing. The letters of assent and consent are included in appendices 1 and 2.

The MMMT was named in this exegesis, to add to the trust's growing collection of research. Specific research may build awareness for the trust's work, and further its reach. However, naming the MMMT poses a greater risk to the anonymity of those written about in vignettes. Rosie, May and their POA's were informed of this risk in the process of consent. I also attempted to mitigate this risk by avoiding the mention of any defining features of their character. Pseudonyms have also been used.

Another ethical consideration for this research is my position as both a researcher and practitioner. Although my research was particularly interested in loss and grief, I reflected on my session notes only where this was an appropriate part of the work. I continued to offer my clients what I felt was the most relevant practice for them, and not every person required grief support. My practice was held accountable by the Music Therapy New Zealand code of ethics (Music Therapy New Zealand, 2012) and the MMMT code of conduct.

⁴ May and Rosie are pseudonyms

Findings

This section presents the findings found in the present research. Firstly, a description of each cycle describes the action's I explored in that cycle and how I selected each focus of action. Then a vignette is included to illustrate the findings and describe to the reader a context for interpreting the findings. Finally, the themes found through analysis are presented in a model of a human hand. The core theme, *valuing the person*, is discussed initially and then considered in the description of each of the themes: *sensing over speaking; human connection; knowing individuals closely; Honouring Spirituality; and therapist self-care*.

Description of cycles

Cycle 1:

For my first cycle, I explored the three issues which I had been considering within the first few weeks of beginning to read and think about my chosen research focus of 'loss and grief'. I focused on comfort, improvisation, and personalised MP3 playlists.

Cycle 1's Actions:

Cycle 1.1

Developing musical and therapeutic resources to provide comfort for residents experiencing grief (Kitwood, 1997).

My exploration of comfort was inspired after reading (Kitwood, 1997)'s model of the six needs of people with dementia, where he explicitly mentions their need for comfort in grief. This action was deliberately very broad, as I wanted to learn iteratively what comfort looked like in this context.

Cycle 1.2

Exploring ways I can use improvised lyrics and improvised instrumental music to support emotional and cognitive complications associated with dementia and grief.

Improvisation to validate a person's emotion was mentioned by Bright (2002) as her main way of encouraging people with cognitive deficit to explore and express their emotions. I used this method as a starting point, wanting to explore whether it was relevant to my music therapy participants.

Cycle 1.3

Developing playlists for residents who might need recorded music for support, comfort or stimulation and using the resources of MMMT to access Mp3 or speakers to make the music available in residents' daily life.

The MMMT resources MP3 players with individualised playlists to selected residents, alongside its service of providing individual and group music therapy in a care home. This action began my considerations of how I could use the playlists to support people experiencing loss and grief. This included considering what my goals for creating playlists were, and whom I thought would benefit most from listening to playlists.

Codes found in cycle 1 (code titles are highlighted in **bold**):

My findings from cycle one were centred in the area of comfort and as I tried to describe and explore what was comforting to multiple different people, I was made acutely aware of the **complexity and diversity** of each person's unique grief journey. I found that some residents found a **legato, and lulling** $\frac{3}{4}$ comforting, while others found comfort in the joy and familiarity of upbeat music, which created a **break from sadness**. I had began my research journey aware of the unique needs of individuals, but I was encouraged to develop further understanding of how other professionals support the needs people of who are encountering loss. In cycle 2, I decided to focus an action on learning about and being inspired by empirical grief models.

Relating to Kitwood's 'comfort': in analysis, I found that I had been singing acapella in emotionally vulnerable moments, which felt like it matched the vulnerability of my client. I decided to further explore acapella voice in cycle 2, to try and understand it further.

It has been acknowledged in research that long-known music may be more comforting or beneficial for people with dementia, who can become confused with unfamiliar music (Bright, 2002; Kampfe, 2015; Clark and Warren, 2015). I found this to be true in my investigation of how I used improvisation during the action period. I used short bursts of improvisation, often to **create a comforting atmosphere**, or to offer containment. Overall, however, I **used little improvised music**, as unfamiliar music didn't seem to capture the residents in the way that well known songs did. When I did improvise, I often **composed familiar sounding songs**, such as using lyric substitution or familiar chordal structure (such as the I-II-IV-V structure used a lot in war time songs). Familiar music's can be comforting but also meaningful, and were the basis for the MP3 playlist's I compiled – with goals of facilitating reminiscence, and providing a resource which might **support emotional regulation**.

While reflecting comfort, I became very aware of a theme which I termed as ‘space’ – which considered where and the way I set up a room for a therapy session, and the way the person I was with and I were oriented in a space. The repeated word ‘**alongside**’ in my data felt important, and physically sitting alongside a person I made music with, often felt appropriately supportive and non-confrontational. I decided to practically explore space and being ‘alongside’ in a cycle 2 focus on **the therapeutic environment**, which had also been an important consideration of where and how the playlists would be listened to.

Cycle 2:

Cycle 2 developed the learnings from cycle 1, by trying to greater understand the theory behind grief, while further exploring comfort, focusing on the therapeutic environment and acapella voice. During cycle 2 I began growing deeper rapport with the people I made music with and many of the coded findings in cycle 2 were based on connection.

Cycle 2.1

Finding practical ways to use the therapeutic environment which may help individuals experiencing loss and grief to feel supported.

During Cycle 1’s action of developing playlists for participants, I had considered how the environment in which a person listened to the playlist may have influenced how the music affected them. This review developed into a more general consideration of the person’s environment, including what was in the space around them, and physical proximity between the two of us.

Cycle 2.2

Exploring when it is appropriate to, and different ways in which I might use acapella voice when being with people who are experiencing loss and grief in dementia.

An action focusing on acapella voice came from my exploration of improvisation. I had found myself humming and vocally improvising more without any music. This felt natural and appropriately tender and vulnerable, so I decided to explore it further.

Cycle 2.3

Finding ways I can use empirical grief (or counselling) models and methods to inform, develop, and/or inspire my music therapy practice.

Following Cycle 1, I wanted to further understand the needs that people experiencing loss and grief may have. I focused on learning more about empirical grief models by reading literature and

attending two seminars. I used the grief models to inform and inspire my practice at the time, and also to reflect upon notes from previous sessions. I included these reflections in the data set.

Codes found in cycle 2 (code titles are highlighted in **bold**):

I reflected regularly in my notes about considering **whether grief models were helpful** in my placement context with people with dementia. Furthering my understanding of grief models did challenge me to consider how norms and expectations of grief are affected by **cultural influences**. I found the '**dual process model**' of grief helpful, in its explanation of how people oscillate between loss-oriented, or resource-oriented coping orientations, and that both ways of coping are healthy. I was also interested to learn about '**continued bonds**', a grief model based on connection, which suggests it's healthy, perhaps even helpful, for bereaved people to maintain connection with their deceased loved ones by talking to, thinking about and/or continuing to learn about them.

Finding connection was often a goal I had while making music. I felt connection was especially important with those who were experiencing loneliness or isolation, sometimes because of the confusion of their dementia. Throughout cycle 2, I repeatedly reflected that using acapella voice both **facilitated connection** and allowed me to deliver rich musical **emotional expression** (vocals are my preferred instrument). During the acapella action, I noted that I felt the lone voice was the most 'human' and vulnerable that my music could be. I also considered how acapella was useful in a practical way, allowing me the **flexibility** to continue the music ('containment') while I held the hand of the person I was with, or went to retrieve a photo of their loved one a wall. Musical expression felt especially important with sad or grieving residents who didn't benefit from verbal communication, but were still very in tune with their, and others, emotions. I realised that creating emphasis on emotional connection with my music therapy participants meant I was experiencing a lot of strong and often sad emotions in a day. I decided to reflect upon issues of personal care for my final cycle, as I felt I wanted to ensure my therapy was sustainable.

Connection became an important extension of my thinking about 'space'. I understood connection on a physical level through the resident's willingness to hold my hand, and make eye contact with me, and I used my own feelings of connection to try and understand if they might also feel the same. I conceptualised this connection, using a **triangle** shape as my go-to set up of the therapeutic space, where I sat physically alongside an individual (a finding in my first cycle), with a shared object of interest, e.g. nature outside a window.

Nature was often a calming addition to our sessions, perhaps because of its familiarity and beauty. I tried to incorporate it into sessions – either by looking outside the window, sitting in the garden, or singing about the outdoors in lyrics (e.g. *Cruising down the river*). I found myself increasingly considering beauty and aesthetic, and how in my sessions I often aimed for a beautiful music. In the acapella action of this cycle, I considered how the **transition from instrumental to acapella** needed to be artistic, smooth and well done or it could startle my participant and **increase their confusion** or agitation. These considerations of what was beautiful and reflective, and made me realise that I had not yet considered the spirituality of people with dementia, beyond singing hymns. I was prompted to focus on spirituality in my next cycle.

Cycle 3:

Cycle 3's actions were inspired by the connection emphasis of cycle 2, focusing on the spirituality of residents and my own personal care.

Cycle 3.1

Further thinking about the spiritual needs of residents experiencing loss and grief and how I use music in spiritual and meaningful moments.

My consideration of spirituality emerged during therapeutic action of Cycle 2. I noticed many of the people I created music with, each in varying stages of dementia, were more at peace in nature. I read about how nature and spirituality may be connected. The more I considered spiritual care, the more I recognised it was essential – to all humans, but particularly those encountering loss and a life-limiting illness.

Cycle 3.2

Finding ways I can ensure personal care and therapist sustainability while in a situation with high emotional demands.

The personal care of therapists was mentioned a lot in grief models' literature, and also came up naturally during my practice, as it was something I had often reflected on in my practicum journal. I wanted to ensure that as I developed my practice, I did so in a sustainable way.

Codes found in cycle 3 (code titles are highlighted in **bold**):

I developed some techniques to inspire me in the moments throughout my practicum when found stillness and being alongside a person with dementia difficult. For example when confronted with strong odours or extreme personal criticism. I was inspired while reading Aldridge (2000) to rely on the **beauty in the music** in difficult situations, to make the situation easier to cope with and help to

find openness toward my music therapy participants. I also found it helpful to regularly reflect on **the meaningfulness of my work**; that working as a music therapist I get to engage with aspects of a person which other people don't see and share moments which are special, important and meaningful. These reflections helped me to continue when the work felt difficult or unfruitful!

During my focus of people with loss and grief, I experienced some of my own bereavement as those I had built relationship with passed away, especially if it was unexpected. In these moments, it was pointed out to me by a peer music therapist that it was essential to **know my emotions** before entering future sessions with other clients. I found it helpful to reflect upon my sessions with the deceased person and to try and **find some closure** to our sessions, be it singing a song and/or writing a final summary of our sessions together. It was also helpful for me to find value in the time I had shared with the person and to remind myself that our music making was important. This felt somewhat similar to the spiritual code '**life satisfaction**', which described how residents would sometimes wish to reflect on how their life had been significant and their most important life contributions. At both the conclusion of a relationship and in aging and disease, it seems helpful to acknowledge and find value and meaning in the contribution one has given.

In this cycle, I noted on many occasions that meditating on, or my listening to a person **expressing their faith** seemed to help them to experience peace in grief. I began to think about how people with more progressed dementia engage with their faith and how music may **make (religious) spirituality more accessible**. Sapp (2010) discusses that symbols of faith (such as crosses and well-known-prayers) are often better understood and more meaningful to people with dementia than conversation about religion is. It seemed important to foster an environment in which people with dementia could still engage with their spiritual and religious identity.

As a person with dementia is less able to consider spiritual concepts such as identity and value, it is up to the person's community to affirm these aspects of them. The more I considered the spirituality of people with dementia, the more I placed an emphasis on the **dignity** of those I was with. For me, treating a person with dignity meant being authentic in my care and ensuring I was always present, genuinely empathetic and invested, and **not just "going through the motions"**. Treating people with dignity let the people I was with know that their lives have value and are important.

Vignette from Music Therapy Practice with May

The following vignette describes a case with a woman with early onset dementia, who experienced grief around loss of ability. It demonstrates a context for the reader to interpret my findings.

May is in her late sixties. She is not yet elderly, yet her hair is now white and she sits permanently in a chair with a slight hunch. I get the impression from her that she has always been a busy woman, as she is quick to act and react. She watches everyone around her astutely and speaks her observations and judgements of them out loud. Her daughter told me that even since before her Alzheimer's dementia, she had always been a woman who was not afraid to speak her thoughts. Throughout her life she walked to stay fit and as an escape to help her cope with stress. May resents that she can no longer walk and is now "stuck in a chair getting fat". She also mourns that she can no longer play piano, a skill she learned from her father. Upon just seeing a piano, she can become upset.

May does not recognise that she has dementia, but she does recognise the loss of her abilities. She frequently voices her dislike of herself. She also experiences delusions and hallucinations, meaning she often doesn't trust people. The psychological effects of her dementia can make her behaviour unpredictable, which makes building and maintaining relationships with staff and other residents difficult. She can be isolated, which is detrimental to her self-esteem.

This year, I began regularly visiting May once a week after lunch. This seemed the best time to visit, as the business of dining room made her very stressed and could leave her agitated and upset for the remaining afternoon. I would often find May in her bedroom, as she had been removed from the lounge where she was screaming at people. However, she would remain agitated in the isolation of her room. Although the noise and movement of the dining room, a stressor for May, had been removed, she was still upset as psychosocial needs had not been fulfilled. One goal for our sessions was to use music to calm her down, as she could no longer use walking to calm herself. As May mourned the loss of her abilities, we also had goals building herself image through utilising her strengths; and creating a relationship which affirmed that despite her losses, she is still valuable and lovable.

Aesthetics, and beauty helped to calm May down. We would often go outside and sing to a fountain, or look at the magnolia tree outside her window together. When I sang to her, she would close her eyes. She particularly enjoyed ¾ songs and classical styled singing, and I found her more responsive when I put more effort into making the receptive music as beautiful as I could. I reflected that the music and nature were sensory experiences which calmed her. As she witnessed beauty it seemed to help her cope with her feelings of loss and the unhappiness she felt with herself. Reflecting and sharing in our surroundings did not require conversation. It came naturally, relaxing her spirits.

May came to trust me, in a relationship built on musical connection and unconditional positive regard (Rogers, 1961). As I began to build relationship with May and began know her more she sometimes shared with me about her very musical history. Her daughter confirmed to me that she had played piano, sang in choirs, and had enjoyed ballroom dancing. One day, May picked up a glockenspiel from a variety of instruments I had laid out in front of her, and played a repeated G scale which I improvised around. In following sessions, I sang 'Do Re Mi'; or 'Somewhere over the Rainbow' as she played scales or octaves. She grinned and seemed to enjoy being a musician again. I believe exercising her musical identity contributed to her self-esteem.

May had been Catholic throughout her life, and it was still very much a part of her identity. However, her faith had recently become tied to her distress, and she often told people that they were going to hell. In our sessions, if May suggested a hymn, we focused on the hope offered by her faith, rather than damnation or shame. She relaxed as we discussed this; it appeared that this element of her faith gave her peace.

One afternoon in August, May was the most upset I had ever seen her. Her chest was heaving, and she had beads of sweat all over her forehead. She was repeating a shrill screech at any residents or staff who came close to her. As I took May outside and began to play music, she closed her eyes, but her rapid breathing didn't slow. I knelt beside her, I held her hand and began to sing acapella *Mull of Kintyre*, and other Celtic songs which are based on the pentatonic scale, to create music which was appropriately ambiguous in mood. Through acapella voice I felt I had the most control over the dynamics and expression of the song. May looked at me in the eyes for around twenty minutes as I sang to her, and she very slowly calmed. My experience of this moment was that it was very tender and motherly. It resonated with Kitwood (1997)'s theme of comfort. The music by itself could not calm May in this moment, but the music allowed connection between her and me. After this, I began to actively seek music induced 'moments of connection' with her in our sessions.

At first, I found it disheartening to have spent time with May, engaging with her humanity, only to find her the next week or a few hours later, screaming or greatly upset again. It was helpful in this situation to reflect on how my work had been meaningful to me as a student practitioner, and hopefully to May herself. She appeared to experience peace, even though it had not lingered. May's carers had seen and sometimes engaged with her humanity as it appeared in music therapy. I was able to share with her carers what I had learned about her in our sessions and use my knowledge of the music she loved to create a playlist with music which relaxed her, for her to listen to once I had finished my placement.

Hand model

After completing thematic analysis, I had found five themes which I felt correctly described the essence of all the codes. A core theme, of *valuing the person*, was a theme which felt like it captured the essence of my work. The findings are modelled on a hand, symbolic of support and hand holding.

Figure 1 Findings of how I supported a person with dementia in grief and loss.

Core theme

The core theme, *valuing the person*, was something I repeatedly considered throughout my reflections. During my thematic analysis it was evidently an essential part of my findings. *Valuing the person* was also coded in the spirituality action.

Valuing the person was integrated into each of the themes, as each theme began with recognising the worth of the person I was with. Genuine care came naturally when I spent time before the session considering the unique value of the individual I was visiting. I believe that all true and genuine encounters came from taking time to honestly cherish the person I was with. *Valuing the person* includes the theme of *therapist self-care* as I feel it is necessary for any therapist to avoid compassion fatigue⁶, for both the music therapist's and their client's benefit. Therefore, each of the other findings first came from the core of the hand and the centre of my work was importantly valuing the person first and foremost.

⁶ See Glossary of Terms

Themes found in the Data:

Figure 2 Map of associations between codes and themes

Sensing over speaking

Sensing over speaking describes a 'way of being' which I observed in my work with people with (particularly advanced) dementia, where emotions and intuition are given precedence over verbal interaction. Here, relationship between participants and me as the student music therapist is built through music and emotional quality. It requires a keen observance and astute awareness of the overall feeling of an interaction. This theme includes sharing in sensory experiences such as observing nature and musical expression.

Table 1 Codes in 'Sensing over Speaking' theme

Codes in this theme:	The code's data set:
Swaying Music	Cycle 1, Improvisation Action
Physical Touch	Cycle 1, Comfort Action
Little use of Improvisation	Cycle 1, Improvisation action
Familiar music	Cycle 1, Improvisation Action
Therapeutic Atmosphere	Cycle 1, Playlist Action Cycle 2, Therapeutic Environment Action
What is lost?	Cycle 2, Grief Models Action
Musical Expression	Cycle 2, Acapella Action
Transition from voice to acapella	Cycle 2, Acapella Action
Nature	Cycle 2, Therapeutic Environment Action
Acapella for expression	Cycle 2, Acapella Action
Increased Flexibility	Cycle 2, Acapella Action
Beauty	Cycle 2, Therapeutic Environment Action

My first cycle quickly revealed that many of the people I worked with were particularly receptive to the emotive power of music and this continued to be a theme throughout my research cycles. I sometimes didn't know anything about a person's grief, or did not fully understand it, without understanding the context of their grief. This was a regular reflection in my research which I coded '*What is Lost?*'. Sometimes, all I knew was that they were sad and that they could not tell me about it. However, I often found that, we could create a musical and therapeutic exchange through our emotional intuition and senses.

"(She) started to fall asleep- or at least close her eyes. I changed my music to softer music... and played in this mood, with her eyes closed, for quite a while. It felt like – the longer that atmosphere was created around her, the more she settled into that mood. When I sang her a

goodbye song “Now is the Hour” and left, she was awake, but very settled.” (Improvisation Action, Cycle 1).

As in Bright (2002), I often used music to match an individual's emotional state, letting them know that they had been heard. This first required being sensitive to how they were feeling. In my first cycle, I wished to find a way of musically expressing comfort. Particularly with those who were non-verbal and more progressed in their dementia, musical and physical associations with love and comfort were my main way of making them feel supported, rather than isolated in their grief. I found that *swaying music* with $\frac{3}{4}$ or $\frac{6}{8}$ time signatures created a sense of comfort. I also particularly focused on *Musical Expression*, recognising that it resonated with the emotional intuition of those I was with.

“With acapella I felt fully in control of the inflection of my voice. I feel Sadie⁷ is very sensitive to this – in an emotional way, which goes beyond what is being said.” (Acapella Action, Cycle 2).

In creating musical containment, I became aware that many of the individuals I musicked with were particularly sensitive to sounds and unexpected noises. Unanticipated noise could give frights, create unease, unfocus, or even distress within those I was with. While using acapella voice, I concentrated on creating a *smooth transition* between instruments and voice, as some of those I was with were particularly sensitive to the instrumental interruption. Smoothness and predictability seemed to create a sense of trustworthiness in the music and contributed to its comforting quality. This may be why I found familiar music to be much more engaging and/or comforting than improvisation (Bright, 2002), which I *didn't use often*.

“My acapella didn't work – because it was in the middle of the song, I just kind of stopped and then jumped in and it felt bumpy, unsupported and not a smooth transition. I did drum a beat – but that beat started once the guitar stopped, it could have been smoother... she looked somewhat startled, however it didn't contribute to her present-ness or reality awareness, in fact it may have contributed to her confusion.” (Acapella Action, cycle 2).

The *therapeutic atmosphere* became an important consideration, coded in both Cycles 1 and 2. My experience was that sharing in nature (either being in it or looking at it), created shared relaxation and calm in both myself and the person I was with. Sometimes singing songs about nature contributed to the outdoors schema, particularly onomatopoeic songs such as “Old Man River” (which has a lulling and rolling melody); and “Mockingbird Hill” (which mimics birdsong). Being in nature also allowed myself

⁷ Sadie is a pseudonym

and others to share sensory impressions, without requiring intellectual or verbal demands. While sitting in *nature*, I found people to be calmer, and sometimes more comfortable sitting with their grief.

“We are usually faced the same way, looking towards nature. I pull up her (curtain) doily layer so she can actually look at what’s happening outside, and then I move a chair to sit alongside her, and we look out, and sing to the trees together. There is something about looking at nature.. she describes it as ‘soothing’.” (Therapeutic Environment Action, Cycle 2).

Taking the time to sit, be patient, feel, sense, and consider the experience of a person with dementia, is a way of **valuing that person**. Although I had not termed the “sensing” way of being until I completed a thematic analysis, it was very much a part of these sessions. Sensing over speaking may have brought greater equality between a person with dementia who I worked with and myself, as I abandoned cognitive and verbal demands to meet them in the realm of feelings and senses, where I felt they might be more proficient and aware than me ⁸.

Human Connection

Human connection includes the techniques I developed to connect with people with dementia. Physical interaction, such as hand holding and the orientation of the therapist and client solidified connection and represented rapport. This theme also included connection with family members and loved ones for whom the resident grieved and missed. This theme is rooted in relationship-based therapy, assuming that connection and communication may help to support a person in their grief and to reduce social isolation, which often comes with loss of cognition (K. Allan & Killick, 2011).

Table 2 Codes in the Human Connection Theme

Codes in this theme:	The Code’s Data set:
Being Alongside	Cycle 1, Comfort Action
Physical touch	Cycle 2, Environment Action
Handholding	Cycle 2, subcode
Residents initiating physical connection	Cycle 2, subcode
Music building relationship	Cycle 2, subcode
Triangle Orientation	Cycle 2, Environment Action

⁸ *The locus of my attention is definitely shifting from my head to my heart. I feel and think about feelings more than I think about thinking.... Sometimes I am very happy, and sometimes I am very sad, and at all times I am aware of all my feelings.” (Taylor, 2007, p. 138).*

Written by Richard Taylor, a psychologist, about his experience of early stage dementia

Continued Bonds	Cycle 2, Grief Theory Action
A Break from Sadness	Cycle 2, Therapeutic Environment Action
Acapella voice for human Connection	Cycle 2, Acapella Action
Humming	Cycle 2, Acapella Action

Physical connection

I understood connection on a physical level through the residents' initiation of touch, their willingness to hold my hand and through eye contact. I coded the importance of *physical touch*, with subcodes of *handholding* and *resident's initiation of physical connection*. I also recognised that as music created further rapport between myself and a resident, physical touch (i.e. hand holding) only *came naturally* after musical closeness had been established. There were residents who did not appreciate physical touch. I was very aware of the connotations which touch may have, and usually held a hand or put my hand on someone's shoulder if they had initiated physical connection first. My finding was that touch was particularly valuable in the context of dementia, because of the unspoken, physical sense of support provided by such contact.

"Initially, she had her hands up at her chest – quite rigid and very protective. But as she became increasingly relaxed, she let one arm down quite close to me – I wondered if this was an invitation. I took her hand gently. It felt like physical reassurance. The DTs tell me she is very responsive to massage." (Therapeutic Environment Action, Cycle 2)

Connection and the therapeutic Environment

The theme of connection was also found in my Cycle 2 exploration of the therapeutic environment. I found that a *triangle orientation* of myself, the individual I was with, and a shared object of interest conceptualised my approach of being alongside an *individual*, in a non-confrontational way. In this orientation I sat to someone's side, either parallel or slightly forward (so they could see me), as we both faced the same way.

Figure 3 A triangular orientation of the resident, student MTh, and object of focus

Sometimes the object of focus was nature, as we **shared in our senses** (as in the previous theme). In other times we shared written music. This shape held a sense of camaraderie and unity, and was less confrontational than sitting face to face. I used this shape especially in initial sessions, as the person I was with and I began to build trust, and in situations when emotions and grief were particularly confrontational.

"I sat on a chair, she sat on the bed. A little triangle, the two of us pointed towards her hymn book. I think this triangle (shape) is the ideal "alongside" space." (Therapeutic Environment Action, Cycle 2)

Connection to loved ones

Continued connection to a loved one is considered to be helpful to the bereaved in their grieving process, in the *Continued Bonds* grief theory. There has been a change in focus from severing ties and 'moving on' after a loved one has passed away, to recognising that a relationship does not conclude at death. For many grieverers, it may be beneficial to stay connected to their loved one by engaging with their memories, and learning how to connect with their loved one in a symbolic and internal way. (Hall, 2014; Klass, Silverman, & Nickman, 1996/2014; M. Stroebe, Schut, & Boerner, 2010). Klass et al. (1996/2014) suggest the relationship may continue through actions such as talking to the bereaved, sensing them and using memories to learn new things about them.

"I know now that Jack⁹ doesn't need to 'move on' but just to re-situate his relationship with his wife. In future, instead, we might spend time thinking about their "precious memories", or, as he is religious, about her in heaven." (Grief Models Action, Cycle 2)

Missing people was a common source of grief in individuals I visited. This included loved ones, both deceased or simply not present during the session. Reminiscence of loved ones, singing relevant music to photographs, and playing songs from before a loss (when it was not too confrontational) were ways of acknowledging the meaningfulness of that person in their life, and creating a sense of connection to them. I note that sometimes perseveration on missing someone meant that a person with dementia benefitted most from redirection, distraction, or creating a *break from sadness*.

⁹ Jack is a pseudonym

However I feel that part of **valuing a person** is to acknowledge the loss they are experiencing as a real source of distress, and not just a ‘symptom of dementia’.

One of the greatest benefits of singing acapella, and perhaps the reason I felt it *facilitated connection*, is that it allowed me *to be more flexible*. I could hold someone’s hand when I wasn’t holding my guitar, while still offering music. It also allowed me to get up and retrieve pictures of beloved family members from the wall. In this way, acapella was a practical way of facilitating connection.

“So I knelt beside her, I held her hand and sang acapella. I paused while she spoke. I made the large notes particularly resonant and long. She looked at me in the eyes – I sang with a lot of light and shade, but primarily it was light. Mostly it was tender, mostly it was gentle.”
(Acapella Action, Cycle 2).

Knowing individuals Closely

Knowing Individuals closely refers to understanding the abilities of those I worked with, and what motivates and is meaningful to them. This theme is based on a person-centred approach (Rogers, 1961). To support an individual in grief, I found it essential to acknowledge how they grieved, their faith, and their culture.

Table 3 Codes in the Knowing Individuals Closely Theme

Codes in this theme	The Codes data set
Diversity of Grief	Cycle 1, Exploring Comfort Action
A Break from Sadness	Cycle 1, Exploring Comfort Action
Goals for pre-recorded Musics	Cycle 1, Playlists Action
Culture	Cycle 2, Grief Models Action
Is the grief model helpful?	Cycle 2, Grief Models Action
Acapella Increasing Confusion	Cycle 2, Acapella Action
What is lost	Cycle 2, Grief Models Action
Dual Process model of grief	Cycle 2, Grief Models Action
Knowing My Own Feelings	Cycle 3, Therapist Self-Care Action

An unanticipated finding I encountered as I explored comfort in Cycle 1, was about the *diversity of grief*. Not only was there diversity between individuals, but the same individuals experienced different types of grief, both between and within sessions. Research on grief models led me to understand that in the diversity of grief, it is best to follow an individual's way of coping.

The *dual process model of grief* (M. S. Stroebe & Schut, 2001) is helpful to create an understanding and acceptance of different types of grieving within an individual. The model offers two types of grief: loss-oriented¹⁰ (L.O), where an individual wishes to openly express their distress, and confront and reflect upon what they have lost. Resource oriented⁶ (R.O) coping describes an individual adjusting to additional changes which result from a loss, which can include constructing a new identity or looking for distraction from L.O grief, such as in my Cycle 1 findings about residents who wanted a musical opportunity to have a *break from sadness*. The dual process model describes that both griefs are normal ways of coping, and predicts that individuals will oscillate between them. An individual may experience more or less L.O or R.O depending on their grieving style. It says that grief has many types of normal, and may only become disordered if an individual feels overwhelmed. This interpretation of grief allowed me to better understand the experience of those I was with. As I learned more about an individual and acknowledged that they might oscillate in their grief, I felt more equipped to recognise their 'normal', and see when I might need to refer them to someone with more expertise than I could offer.

"I have since thought that Elizabeth¹¹ seems to live her life in the L.O, and quite overwhelmed. I think the next step is maybe spending time with her, finding her apparent and effective coping strategies, while maintaining the open-ness we have achieved. I don't know how she could "take time off" (maybe going outside, to get a breather from the care home environment?)" (Cycle 2, Grief Models Action).

Sometimes it was difficult to learn about an individual with advanced dementia, particularly if I could not talk to their families or loved ones. In these circumstances I drew on psychodynamic approaches of transference, letting my own feelings of a situation clue how an individual might be feeling. In these cases it was essential to also *know my own feelings*, as in the therapist self-care theme.

Culture greatly influences social expectations of grief. It may influence what is 'considered 'normal' and how much time is spent in the R.O or L.O. In the present study, I did not create music with any person experiencing grief who identified as Māori. However I did engage with literature, and had

¹⁰ See Glossary of Terms

¹¹ *Elizabeth* is a pseudonym

conversations to increase my personal awareness of tangihanga¹² and Māori approaches to grief, as I feel such an understanding is necessary when considering grief in Aotearoa. During Cycles 2 and 3, I became increasingly aware of cultural attitudes towards grief within groups and facilities. I lead a music therapy group with older men, where I recognised a culture of heavy R.O coping. As we sang about the old times and reminisced, we used metaphors to talk about loss as open grieving was too confrontational and uncomfortable in this group.

“It was a room of all men, of varying ethnicity – but all of the war era ...I was aware how this may have affected how loss and grief were broached in this room. It was as though no particularly expressive emotions were allowed. All except for (one resident) - who spoke quite regularly and occasionally of sadness re. his father and his wife. It was difficult to support him, when it definitely felt there was a façade of “strong” in the group.” (Cycle 2, Grief Model Action).

I believe all people have a desire to be known. In dementia care, I feel it’s important to understand what has been important to an individual, so you can remind them of the life they have lived. But it’s also necessary to know what they respond to, enjoy and find meaningful in their current self, which may have changed in the process of dementia. Truly person-centred care begins with **valuing** an individual enough to be interested in them. Similarly, paying attention to the details of a person is a way of valuing their personhood.

Honouring Spirituality

Honouring¹³ Spirituality is an essential part of providing holistic supportive care, particularly during grief. In dementia, I felt that honouring spirituality meant creating opportunities for residents to engage with their personal spirituality. Reflecting on meaningful life events promoted life satisfaction and was encouraging to the spirit. I argue that being treated with dignity is spiritual, as it helps to affirm the value of someone’s existence.

Table 4 Codes in the Honouring Spirituality Theme

Codes in this theme	The Codes data set
Therapeutic Environment	Cycle 1, Playlists Action

¹² Tangihanga (tangi) is a formal Māori grieving process (Matenga-Kohu & Roberts, 2006)

¹³ ‘Honouring’ refers to respecting resident’s engagement with spirituality which they already associate with; as opposed to exploring new spirituality, or spiritual guidance.

Nature	Cycle 2, Therapeutic Environment Action
Expressing Faith	Cycle 3, Spirituality Action
Spirituality's Accessibility in Advanced Dementia	Cycle 3, Spirituality Action
Life Satisfaction	Cycle 3, Spirituality Action
Dignity	Cycle 3, Spirituality Action
Faith	Cycle 3, Spirituality Action

Although spirituality findings came into my research only in the Cycle 2 reflections about *nature* and the *therapeutic environment*, I recognised that it was an essential part of both dementia care and grief support as I explored spirituality in Cycle 3. Although it may not have been as prevalent in my research, I felt that spiritual needs were unique and important enough have their own theme.

In this cycle, I quickly recognised the importance of expressing faith for many of the people I worked with, even when they were in a confused or agitated state. Some of the resident's I musicked with experienced stillness in religious music; I noted on many occasions how a person's faith had helped them to experience peace. Meaningful hymns were astoundingly powerful if they were close to someone's heart. Also, prayers and Bible verses which were precious to a person could be reflected upon to music. One woman regularly requested the Lord's Prayer sung to the familiar melody of Auld Lang Syne when she was upset, and shared with me that it offered her hope. However, I also worked with a resident who often wished to play a song which expressed their hurt toward God. It was clear to me throughout this action that religious faith could be expressed in our sessions, however I was aware I could only do so much before I might need to refer an individual to someone who specialised in spiritual care.

"I had one particularly moving moment with Rosie¹⁴, who would only ever sit with me for less than one song before standing up to tearfully find her husband. She had been married to him since she was very young, and she clearly loved him very much. One afternoon, she was particularly agitated and tearful. But as I began to sing hymns, she sat next to me for a very long period."

"But as I was going to leave, and she was confused, eventually asking "would you like to stay?". We sang a couple others – Tipperary; You Are My Sunshine; When Irish Eyes (which she

¹⁴ Vignette consent is also held for Rosie.

tells me is her favourite). I believe that the religious songs gave her enough peace to sit and enjoy those songs with me, when she couldn't at the beginning" (Spirituality Action, Cycle 3).

I began to consider how could spirituality be accessible in advanced dementia, particularly with those who could not easily communicate to me their spiritual needs. I quickly learned that, as in my **sensing over speaking** theme, that symbols, images, and sensory reminders of faith were better understood than words. This included musicking while reflecting on crosses or rosary beads an individual owned, or singing Bible verses or proverbs they had displayed. When I was unable to ask person's family about their spirituality, I often looked for signs of it on their walls or bedside table. I also tried to be particularly astute to clues in disorganised speech that the individual might have been speaking about something spiritual.

"I find myself being hyperaware of when someone might be speaking in reference to, or in metaphors about, things that are spiritual." (Spirituality Action, Cycle 3).

I understood spirituality and dementia through two perspectives. Firstly, Sapp (2011) in his palliative approach to dementia care said that religion and faith can be sources of strength among those with palliative illness. He also said that upon facing death, spirituality may increasingly become about understanding what one's life has meant.

"In the absence of religion, I begin to think about how their lives still have, and have had meaning, that they have dignity and worth" (Spirituality Action, Cycle 3).

In the present research, this related to the code of creating opportunities for life satisfaction. Often, residents and I reminisced about times in their life that were particularly meaningful, important roles they had had, and contributions they had given to things which were larger than themselves. This may have included being a mother, their work, etc. Other times, we simply acknowledged that their life had had ups and downs, and reflected that they had lived a full life.

"This began reflection on her life. We began speaking about being the role of a mother, and grandmother, singing "que sera sera" with the lyrics "now I have children of my own...", singing about some of the really important moments in (her) life." (Spirituality Action, Cycle 3).

The second perspective I used to understand spirituality is not palliative, and considers how spirituality can include finding meaning in the present, while living with dementia. Wilson (1999, p. 106), describes that spirituality is related to ontological meaning¹⁵, saying *"Spirituality can be described as a search for that which gives meaning and identity to a person's life and the wider world.*

¹⁵ See Glossary of Terms

Dementia does not destroy the ability to experience and appreciate the world about the person". I felt that dignity was essential to spirituality in the present. While reminiscence may remind an individual that their life had meaning, being treated with *dignity* and being **valued** is an unspoken way of reiterating that their life still has meaning.

Treating a person in my care with dignity required me to be authentic, always present, genuinely empathetic, and invested in the care I was providing, rather than *just "going through the motions"*. Treating people with dignity is a natural expression of an authentically and integrous person-centred approach. It meant honouring the person and their wishes, and taking their experience of grief seriously. That is, trying to understand the person, and what they might be communicating, rather than assuming 'symptoms of dementia'.

"I think dignity is a large part of spirituality. I suppose I personally associate spirituality with insight, deep thinking, and wondering about what is your purpose... but when cognition is limited, I think spirituality becomes about what I find meaningful, what is worth living for, and being treated as though you have a right to be here, your life has value." (Spirituality Action, Cycle 3).

Therapist Self-Care

This theme refers to strategies I developed to care for my own needs while spending a lot of time around grief and sadness. Over my placement, I considered how to maintain genuine empathy, deal with my own losses, and learned the importance of reflecting upon my own feelings, and defences. This theme developed as I realised that caring for both sides of the therapeutic relationship was essential in creating sustainable therapy.

Table 5 Codes in the Therapist Self-Care Theme

Codes in this theme	The Codes data set
Finding Closure to Therapy	Cycle 3, Therapist Self-Care Action
Knowing My Own Emotions	Cycle 3, Therapist Self-Care Action
Not 'Going Through the Motions'	Cycle 3, Therapist Self-Care Action
Beauty	Cycle 3, Therapist Self-Care Action
Finding Closure	Cycle 3, Therapist Self-Care Action

“But I know that the residents can sense if the empathy and invitation to share in their emotions is not genuine.” (Personal Care Reflection, Cycle 3).

The *personal care* theme was evident throughout my placement in my practicum journal, but these reflections were not included in the data until the Cycle 3. In a *personal care* focused action, I engaged with my reflections of self-care, generating data by further writing about my reflections. Most of the personal care strategies I learned were not developed solely in reflection, but also learned from others - in supervision, in speaking to/confiding in music therapists, and in reading.

There were times throughout my practicum that I found being genuinely invested and being alongside a person with dementia to be quite difficult. Sometimes this was when I felt emotionally fatigued, from investing in and supporting several people through sadness in a day. There were also times that I felt uncomfortable around a person with dementia, for example when confronted with strong odours, or harsh personal criticism from my client. I quickly learned that being with dementia required learning techniques to deal with discomfort and recognising that my music therapy participants were often uncomfortable too. I felt I needed to develop strategies for avoiding compassion fatigue. I coded two strategies: *finding beauty in the music* and reflecting on the *meaningfulness of my work*, which I used to look upon my music therapy participant at all times with unconditional positive regard (Rogers, 1961).

Finding *beauty in the music* was inspired by Aldridge (2000), who uses creating the most beautiful music he can as a way of staying open to a client, even in situations he finds difficult to palate. I found that putting all my effort into the light, shade, and tenderness of music required making myself more vulnerable. As I endeavoured to make the aural environment beautiful, I was more open to what was beautiful in my client. I felt that the behaviour and effort of creating beautiful music for someone reminded my mind and defenses that the effort was worthwhile, because this person was worthy of love.

“In this way, the music also keeps me from distancing myself too far. I cannot be superficial and open my heart, keep cool and still play beautifully.” (Aldridge, 2000, p. 190)

I also found that reflecting on *the meaningfulness of my work* helped me to remain inspired and invested when working with those who required a lot of input. Attending seminars and talking with

family members and fellow music therapists about changes seen in dementia care reminded me that moments of quality of life improvement are essential, whether an individual remembers them. I found responsibility in being a 'memory keeper' for those who had lost their memories and charged myself to hold newly created memories from therapy for the resident (Swinton, 2014). I may be the only one who knew about an individual's experiences in therapy and sees what that person responds to and enjoys in the music. I felt it was my duty to hold memories of these sessions and share them with the appropriate staff and family members. I have regularly reflected that working as a music therapist in this context is incredibly special, important, and meaningful. These reflections helped me to stick at it when the work felt difficult or unfruitful!

"I am continually moved by my work" (Reflective Diary, Cycle 3).

During my focus on people with loss and grief, I experienced some grief of my own. I was working with elderly and ill patients, some of whom passed away unexpectedly. In these moments, it was pointed out to me by a peer music therapist that it was essential to *know my emotions*, so I could acknowledge them and not transfer them to my other clients.

I found it helpful to reflect upon my sessions with the deceased and find some closure. For example, this could include taking time to sing them a song and write a final summary of our sessions together. It was also helpful for me to find value in our time together, and to remind myself that our music making was important. This felt somewhat similar to the spiritual code of '*life satisfaction*', where residents and I would sometimes reflect on their most valuable and important life contributions. My own experience of bereavement taught me that at the conclusion of any relationship, it is helpful to acknowledge and find value and meaning in the contribution you have given.

"So I wrote the final report for him. I found a song to represent him in the group. I do feel sad that he is gone. Our sessions were cut short and I was genuinely invested in him. But this was his journey, and I feel privileged to have been there for a period of time." (Cycle 2, Reflective Diary)

Summary of findings

The findings of this research are really core values of my practice. They are area's which have developed my approach, and helped me to understand the needs of both my client and I in the area of dementia

and grief. These themes found helped me to guide my approach to a client and have some ideas about what might be meaningful and important in the therapy sessions I held.

Placing my findings on a human hand is symbolic of developing my practice. I am equipping my hands with techniques to carry into therapy with a person encountering both grief and dementia. Hands often represent skill (i.e. the saying *I want to try my hand at playing piano*), and I envision my hands are my tools: they play the instruments; they hold hands with a weeping person, and they are a personal part of me (and my participant).

The hand metaphor also integrates my findings. The core of the hand, the palm, is *valuing the person*. This is inspired by Kitwood (1997)'s personhood, and Rogers (1961)'s positive regard, and the core of any good music therapy practice. Each of the found themes are connected to this core theme.

Although many of the themes could be beneficial to any music therapy client, the combination of them is what makes it specific to the people I worked with, who were experiencing grief. The emphasis on 'sensing over speaking' and 'knowing individuals closely' may be relevant to all clients with dementia who may not be able to easily communicate about themselves. Conversely, the themes of spirituality and therapist self-care may be more salient considerations in contexts where people are experiencing grief. While *sensing over speaking* supports the cognitive needs of a client, *connection* may support their social and psychological needs through the therapeutic relationship (Hughes et al., 2011). Combined with *spirituality*, these are the beginnings of a holistic supportive grief care, specifically for people with dementia.

Discussion

Of the five themes identified in the findings, three of these, *human connection*, *sensing over speaking* and *spirituality* refer to the needs of a person with dementia, beyond their behavioural or psychological symptoms of sadness. I found that music therapy could support these needs in particular and valuable ways. *Therapist selfcare* and *knowing the individuals closely* were qualities of the therapist which I discovered were necessary to working in this context. Most previous music therapy literature has focused on the emotional symptoms of sadness, but has not considered the particular needs which those experiencing grief might have in dementia. In a unique study, McDermott, Orrell, and Ridder (2014b) aimed to understand *how* and *why* people with dementia experience emotional benefits from music therapy. The present study used a similar premise, reflecting on how a person with dementia may be experiencing sadness because of grief, and considering how music therapy can support this. McDermott et al. (2014b) describes engaging with, and trying to understand the experience of dementia, as a way of valuing that person.

Valuing people with dementia is essential to engaging with their personhood. Kitwood (1997)'s conviction was that the community supporting a person with dementia has an obligation to recognise the value of a person, even in disability, and accordingly treat them with deep respect. Much of the music therapy literature has embraced Kitwood (1997)'s philosophy of dementia, as it aligns with the common music therapy goals of optimising people's quality of life in illness and disability (Ridder, Wigram, & Ottesen, 2009). In a music therapy exegesis to Victoria University, M. Allan (2012) used Kitwood (1997)'s model of needs to guide her in providing holistic care for her Music therapy participants. I feel that the current study's topic is the next step in engaging with and working greater understand a person with dementia, by recognising they have specific needs in loss, as any person.

Connection in the cognitive decline of dementia

It can be helpful to consider the brain mechanisms which may deteriorate or remain in dementia. Although this is very varied within different dementia causes (i.e. Lewy Body's dementia has effect on different brain areas to Alzheimer's dementia), it is generally looked upon that the brain begins to atrophy from the outside in. That is, the cortical and higher thinking areas which govern complex cognitive, social and lingual tasks are damaged, while the "reptilian" or "triune" brain remains (Smith, 2017). These are the areas of the brain which evolved first and are responsible for basic survival such as emotional memories (of what is agreeable and disagreeable), our values, or reactions and judgements (MacLean, 1990). This has been helpful for me in conceptualising why it may be effective to appeal to emotional memories of people with dementia through the emotional quality of music, and to capture a person with dementia's exogenous attention in nature (Chalfont, 2008). A person's

remaining emotional memory and judgement without cortical function may be part of the reason they experience ambiguous loss. This type of theorizing is perhaps beyond the scope of this discussion however as a developing practitioner, I found it helpful in further conceptualizing my client's experience of grief. I also feel it reiterates that a person with dementia requires specially considered grief support. My understanding of triune theory (MacLean, 1990) contributed to the *sensing over thinking* finding.

As in the *sensing over speaking* theme, many authors speak about increased use of intuition while working with people with dementia. Aldridge (2000) describes using his intuition to sense what a client needs, and then creating a musical "*safe environment, where the patient can just be*" (pp.188). 'Just being' perhaps describes existing without the pressures or effort of conversation and structured interaction. Sharing sensory experiences was a way to 'just be' with a person with dementia. Kitwood (1997) suggests that it may be beneficial to the rest of humanity to spend time with people with dementia. By adopting the necessary intuitive and sensory way of being around someone with dementia, a person may become more aware of what they are experiencing. "*Contact with dementia and other forms of severe cognitive disability can – and indeed should – take us out of our customary patterns of over-busyness, hyper-cognitivism and extreme talkativity, into a way of being in which emotion and feeling are given much larger place*" (pp.5).

It is recognised that *physical touch* is a natural, nonverbal way which humans comfort each other in grief (Dolin & Booth-Butterfield, 1993). As pointed out to me by my supervisor, in a therapist role I must be especially careful and sensitive, as I do not know a person's previous experience with touch. However, in my placement, I found that in advanced dementia, hand holding was a way of confirming trust and relationship. Touch is mentioned by both Aldridge (2000) and Bright (2002) in their music therapy with people with dementia. Although this needs attention and careful observation, I felt that within safe boundaries (such as only on a hand, or shoulder), touch may have been an appropriate way of supporting a person with dementia

Physical touch was coded in the present research under the theme of *human connection*, as was the code *acapella voice*. Aldridge (2000) suggests that touch and singing are connected with early schemas of being sang to and patted as we cried, so we experience them as comforting. Aldridge discusses the comfort and connection of singing, saying "*Singing provides desirable emotional contact and intimacy that gives comfort, and alleviates fears without speaking*" (pp.90). Similarly, Bruun (2012) discusses that listening to vocals is a relevant form of therapy for someone throughout all stages of their life, from providing comfort as a baby up until the moment they are in palliative care. She describes this is because of the intimacy of the voice, something which we are born with, which is

sustained by our breath (Baker & Uhlig, 2011). Early schema's and the intimacy of the human voice perhaps explain some of the reason I found touch and acapella voice to facilitate connection.

Supporting Spirituality

The spiritual care of people with dementia has previously been considered in music therapy. Kirkland et al. (2014)'s research of a co-led 'spiritual care and music therapy' (SCMT) group of people with moderate to advanced dementia aligns with the current study's findings of spirituality. Upon premising their research, they mentioned Kitwood's personhood and valuing of the persons with dementia, describing that it helped people with dementia to live fulfilling lives. To care for spirituality, the chaplain and music therapist who ran the SCMT group paid particular attention to the environment, and nonverbal communication (as in the present study's *sensing over speaking* finding). The study emphasized that to understand what is a meaningful kind of spiritual care for residents, one first must understand who the clients are (as in the *knowing individuals closely* finding). Kirkland et al. (2014) felt that music therapy and spiritual care provided opportunity for the resident's to experience beauty and wonder; and provided opportunities for them to express and share in their grief with others. The alignment with Kirkland et al. (2014)'s research provides some validity to the present study, and perhaps emphasizes the importance of spiritual care in caring for grief in dementia.

Strengths and Limitations of the research

Both a strength and limitation of action research, is the data and analysis are a product of the researcher's work and world view. This research's aim was to provide an authentic account of a music therapy student's experience and to contribute to my own growth and the improvement of my practice. I am hopeful that other practitioners and music therapy students working in similar context's recognise parallels in their findings with their own work, which may affirm things to consider when working with dementia and grief. This research may be particularly applicable to music therapists and volunteers with the MMTT, and future music therapy students working with people with dementia.

A possible weakness of the present study is that it has not considered musical techniques enough. I was more interested in learning about common needs of people with dementia experiencing grief and developing an approach to guide my practice. There was so much diversity in the musical tastes, the types of loss and cognitive abilities of those that I worked with, that it was difficult to find musical techniques which worked for multiple people. I note that I had considerable learning from readings in counselling and psychology about approaches and communicative processes which were new to me and inspired further thinking. This perhaps made me have a more generic focus on therapeutic approach rather than ideas specifically musical. However, in future music therapy research it may be

beneficial to include musical resources such as reciprocal musical communication, specific songs and instruments and techniques which therapists can draw upon.

This exegesis includes a part of music therapy research which has not been considered very specifically in the literature for over a decade. It builds on Bright (1999, 2002)'s instigation of how music therapy might approach grief in dementia and applies recent grief theory developments. One major consideration is Bright (1999) focuses on resolving and 'moving through' grief, when more recent thinking in grief therapy is to support an individual in finding ways to live with their grief, recognising they may never 'resolve' it (Doughty, Wissel, & Glorfield, 2011; Hall, 2014; Smit, 2015). Although this is one student's study with small numbers of residents, I am hopeful it may contribute to a growing recognition of grief and people with dementia. Particularly in music therapy research, as it is uniquely positioned to support people with dementia through its emotional and sensory qualities.

Future research may also consider terming music therapy with people with dementia as 'supportive'. A supportive approach is embedded in *person-centred*, and *resource-oriented* care, which aligns with many music therapist's approaches.

Conclusion

A person's journey through dementia involves multiple losses, including cognitive, physical, and musical abilities. Grief of personal disability, loss of the familiar and bereavement may be even more complicated when experienced with cognitive decline. Given the rising population with dementia, and the Ministry of Health (2013)'s recommendation for high quality non-pharmaceutical care for people with dementia, it is a suitable time for music therapy research to consider how best to support people with dementia.

The present study focused on how to develop my music therapy practice to support people with dementia through loss and grief. I aimed to greater understand what needs people with dementia may have while experiencing grief, and how I could use music to support those needs. I used an action research methodology, based on epistemologies of social theory, and critical theory, shown through the critical self-evaluation of my practice. Through action research cycles, I focused on developing specific areas of my practice which felt relevant. Some areas of focus included: using acapella voice; considering how models of grief could inform my practice; exploring how the therapeutic environment could support feelings of grief; and considering the spiritual needs of the resident's I visited. The data from each cycle was analysed to find codes. All of the data and codes were then considered in thematic analysis, to find salient and important themes.

The themes derived from the data were values of my practice, which had been important in sessions with people experiencing grief. These themes were modelled in a human hand, symbolising support and the hands I had held during my sessions. Each finger represented a theme, including *sensing over speaking*; *human connection*, *knowing individuals closely*, *honouring spirituality* and *therapist self-care*. These were tied with a core theme, *valuing the person*, inspired by Kitwood (1997)'s personhood. I felt that each of the fingers needed to stem from a genuine and unconditional appreciation and respect for the person with dementia. Spending time considering the value of a person meant I was more likely to act in a way which was empowering to the client and motivated my practice.

Considering the experience and perspective of a person with dementia is a way of valuing them, and acknowledging their personhood (McDermott et al., 2014b). Although a person with dementia may lose cortical function, they may be still be capable of experiencing emotions, making judgements, and experiencing the emotional complications of grief (Smith, 2017). Other authors have stated they place increased emphasis on their intuition and emotions when with a person with dementia, as found in the *sensing over speaking* theme in the present research (Aldridge, 2000; Kitwood, 1997). I found

handholding and acapella singing helpful for facilitating connection between myself and individual, perhaps because it is associated with early experiences of comfort (Aldridge, 2000).

Kirkland et al. (2014)'s research of a spiritual care and music therapy (SCMT) group found the group facilitators placed emphasis on the therapeutic environment and nonverbal communication, as in the present study. Kirkland et al. (2014) mentioned that sharing and expressing grief with others was a particular goal of their group. They found the SCMT group allowed residents to live with more fullness of life, and the music therapy allowed a spiritual care which engaged with the residents in a way which no other group at the care home could. Although different in its aims, Kirkland et al. (2014)'s research aligns with, and may provide some validity to the present study's findings.

This study was to develop my own practice and equip myself as a music therapy student to work with people experiencing both dementia and grief. Its findings suggest that music therapy literature may benefit from further considering the support of loss and grief in dementia.

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Appendices

Appendix 1. Information sheet and assent form for residents

Appendix 2. Information sheet and consent form for POA/NOK

Appendix 3. Mind Map of Associations between codes and themes

Appendix 4. Example of coding using QSR international pty's NVivo 10.

Appendix 5. Permission Request Letter to Facility

Appendix 6. Permission Request Letter to Care homes

Appendix 7. Bibliography of songs referenced throughout the work

Appendix 1. Information sheet and assent form for residents

Developing Music Therapy practice to support people with dementia
experiencing loss and grief.

Information Sheet for Residents

17th September, 2018

Dear [REDACTED]

My name is Alicia (in the picture), and I am a music therapy student with the Music Moves Me Trust, I have been doing music with you at [REDACTED] in Hamilton. I have been doing this for university, towards my 'Master of Music Therapy' at the New Zealand School of Music.

For my degree, I have been researching how I can use music with people who are feeling grief and sadness because they have experienced loss. This is because I believe from my own experience music can help us to relax; or to express our sadness; or maybe give us a break from sadness by reminding us of good times.

This letter is to ask for your permission to write a story in my research book which describes our music sessions together. I will use this story to show what I have learned during my research. I will not include your name, or the name of [REDACTED]. This is to protect your privacy. However I will use the name of the 'Music Moves Me Trust', and people who are reading the story may know that it was written about a care home in Hamilton. You are more than welcome to

Appendix 1. Information sheet and assent form for residents

read the story if you would like, however it may not be finished for another six months.

If you have any more questions about the story or my research, please ask the person who is reading the letter with you, or ask me, at any time. If I am not at [REDACTED], I'll come and see you next week when I'm in and you can ask the staff to let me know. We can talk with Sarah, my supervisor at the University, if there is anything you are worried about.

Thank you for the time you have taken to read this letter.

Please sign the consent form attached by October 20th, 2018.

Yours sincerely,

Alicia Stewart

Student Music Therapist

Email: [REDACTED]

Phone: [REDACTED]

Supervisor:

Dr. Sarah Hoskyns

Research Supervisor at the New Zealand School of Music

Email: [REDACTED]

Phone: [REDACTED]

Appendix 1. Information sheet and assent form for residents

Developing Music Therapy practice to support people with dementia
experiencing loss and grief.

Written Assent form for Residents

- [REDACTED] has read the information letter, and it makes sense.
- I know that my name, and the name of [REDACTED] will be changed, so that I am more anonymous.
- I know that the Music Moves Me Trust will be named in Alicia's research book.
- I know that I will get a copy of the story once it is written.
- I know that I can say "no" if I would like. I also know that I can change my mind if I say yes, up until October 20th, 2018.
- I have had enough time to make this decision.
- I know that I can ask more questions from [REDACTED] or Alicia at any time.

I give Alicia permission to write about our music sessions in her research, as explained in the information sheet.

Signature: _____ Date: _____

Full name/s printed: _____

Appendix 1. Information sheet and assent form for residents
Developing Music Therapy practice to support people with dementia
experiencing loss and grief.

Visual Assent form for Residents

- [REDACTED] has read the information letter, and it makes sense.
- I know that my name, and the name of [REDACTED] will be changed, so that I am more anonymous.
- I know that the Music Moves Me Trust will be named in Alicia's research book.
- I know that I will get a copy of the story once it is written.
- I know that I can say "no" if I would like. I also know that I can change my mind if I say yes, up until October 20th, 2018.
- I have had enough time to make this decision.
- I know that I can ask more questions from [REDACTED] or Alicia at any time.

I give Alicia permission to write about our music sessions in her research, as explained in the information sheet.

Full name/s printed: _____

Appendix 2. Information sheet and consent form for POA/NOK

Developing Music Therapy practice to support people with dementia experiencing loss and grief.

Information Sheet for Enduring Power of Attorney (EPOA) or family member

28th September, 2018

Dear [REDACTED]'s loved one,

My name is Alicia, and I am a second year Master of Music Therapy student at the Victoria University of Wellington. I am completing my clinical placement hours with the Music Moves Me Trust in Hamilton. This year, I have been providing Music Therapy services to your loved one, [REDACTED], at [REDACTED].

I am required to research about music therapy as part of my training. After being particularly moved by stories which residents have shared with me, I have decided to focus my research on exploring and developing music therapy approaches and techniques that can help people with dementia who are experiencing loss. Examples of loss could be in their physical function, independence, musical ability or bereavement. Some goals for the music therapy may include: encouraging joy and a break from sadness, finding ways they feel supported, or helping their grief to be heard.

My research question is:

How can I develop my Music Therapy Practice to support people with dementia who are encountering loss and grief?

I would like to ask you to give written permission for some of the materials written in my notes and reflections to be included in this research. This information contains specific musical and personal experiences with your loved one during music therapy sessions. I will not use names or other information that could potentially identify him in any publication or presentation of this research. All the records and consent forms for this research will be

Appendix 2. Information sheet and consent from for POA/NOK

stored in a locked cupboard and kept for ten years at New Zealand School of Music. However, there is a possibility of [REDACTED] being recognised, as the Music Moves Me Trust will be named in my research, which does pose a greater risk to the anonymity of anyone written about. However, the Music Move trust is currently in eleven different care homes, which will not be named. I will make every attempt to protect [REDACTED]'s privacy and confidentiality.

I will provide a summary of the results of the study to you if you wish to see the findings of this project, but please note that this study may not be ready for publication until later in 2019. I will be happy to discuss with you about this study during and/or after the study.

Please feel free to discuss with my clinical liaison from the Music Moves Me Trust, or me about my research and/or giving permission to use the music therapy materials in the research. If you feel you have obtained sufficient information about this research and happy to give permission, please sign the enclosed consent form. There will be no changes to the ongoing music therapy even if you decide not to give your permission, and rest assured that I can approach other families if you do not feel able to give consent. You can also contact my research supervisor Dr Sarah Hoskyns if you have any concerns or questions relating to this research.

This project has been reviewed and approved by the New Zealand School of Music Postgraduate committee. The VUW Human Ethics Committee has given generic approval for music therapy students to conduct studies of this type. The music therapy projects have been judged to be low risk and, consequently, are not separately reviewed by any Human Ethics Committees. The supervisor named below is responsible for the ethical conduct of this research. If you have any concerns about the conduct of this research, please contact the supervisor or, if you wish to raise an issue with someone other than the student or supervisor, please contact the Victoria University of Wellington Human Ethics Convenor AProf Susan Corbett, email [REDACTED], telephone [REDACTED].

Appendix 2. Information sheet and consent from for POA/NOK

Dr. Sarah Hoskyns, Research Supervisor at the New Zealand School of Music:

Ph: [REDACTED] or email: [REDACTED]

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

Yours sincerely,

Alicia Stewart

Student Music Therapist

Email: [REDACTED]

Phone: [REDACTED]

Appendix 2. Information sheet and consent form for POA/NOK

Developing Music Therapy practice to support people with dementia experiencing loss and grief.

EPOA or Family Member's Consent Form

- I have read the information sheet and have obtained sufficient information about the study.
- I am aware that the Music Moves Me Trust will be named in the research, which may lessen the anonymity of the findings.
- I understand that my family member's name will be changed and that the location and name of the setting will not be identified.
- I also understand that the research data will be kept in a locked cupboard at the New Zealand School of Music for a period of 10 years.
- I acknowledge that the study will be published in the library at Victoria University and may be presented in a conference or published paper
- I understand that I can contact the student music therapist and her research supervisor Dr Sarah Hoskyns if I have any concerns or questions relating to the research.
- I also understand that I can contact the Victoria University of Wellington Human Ethics Convenor if I have any other concerns about this research

I therefore give consent for materials recorded in music therapy student's clinical notes and reflective journal that are related to my family member's music therapy to be used in a case vignette to illustrate the findings of the research.

Signature: _____ Date: _____

(EPOA/Family member/s)

Full name/s printed: _____

Appendix 3. Mind Map of Associations between codes and themes

Appendix 4. Example of coding using QSR international Pty's NVivo 10.

The screenshot displays the NVivo 10 interface. On the left, the 'Nodes' pane shows a hierarchical tree of codes. The 'Nodes' pane includes a search bar and a table with columns for Name, Files, and Referen. The table lists the following nodes and their associated file counts and reference counts:

Name	Files	Referen
Keeping your own issues s	1	4
Transference	1	1
not just 'going through the m	1	3
Spirituality	0	0
Explore spirituality	1	2
Making spirituality accessi	1	13
Faith	1	19
Meaningfulness	1	5
Spirituality and loss and grief	1	4

Below the table, a message reads: 'Drag selection here to code to a new node'.

On the right, the 'c3 data set' is open, showing a text segment with several lines of text. The text is as follows:

Things that I have found important in fostering spiritual care for the one's I am with:

- Being hyperaware of when someone might be speaking in reference to, or in metaphors about, things that are spiritual. We tend to skirt around these topics.
- Speaking with particular gentleness, tenderness, and agreement, so the individual knows that they can share their personal experiences and thoughts on spirituality without their truths being opposed, or judged.
- Recognising their spirituality as 'their truths'.
- For myself, being truthful about my own spirituality (e.g. with P.B)
- Looking for meaningful things in their rooms (especially if they can't speak). Allowing their gaze to tell you if it's important.
- Spend time in thought and reflection when something meaningful does come up. Unless the individual is very clearly uncomfortable.
- That nature, memories and music all create a spiritual and reflective environment.

Appendix 5. Permission Request Letter to Facility

Dear [REDACTED]

Letter requesting formal permission to undertake Master of Music Therapy Research at MMTT

As you know, over the course of this year I am completing research focused on people living with dementia and my work as a student music therapist with the Music Moves Me Trust. I have recently been granted approval for my research proposal from the Victoria University NZSM Postgraduate Committee. The committee commented that this proposal included: “an abundantly referenced related works section, a generally well considered methodology and a suitable timeline to completion”. A few changes were recommended, and the amended proposal is attached. This letter is to inform you about my research, and to request formal permission to undertake the study with the Music Moves Me Trust.

My research question is: *How can I develop my music therapy practice to support people with dementia through grief and loss?* My research is to inform my own personal practice about methods, techniques and approaches which I, a music therapy student, can use to help support my clients experiencing loss and grief. This may include bereavement or any form of grief regarding disability, loss of independence, loss of familiar surroundings etc. The research will use an action research methodology.

Ethical approval has been provided by Victoria University of Wellington Human Ethics committee through an ethical template for Master of Music Therapy students: approval number 22131. This research has no formal selected resident “participants”. That is, I am not specifically focussing on particular residents who have experienced loss and grief. Rather my study is on my own approaches to practice when I inevitably encounter grief in my sessions. I am interested to provide sensitive and careful musical service to residents, and to critique and learn from my exploratory journey. I would like to include occasional case stories as examples, but this will only happen if I am able to access informed consent from appropriate sources and to include seeking assent from residents, if they have a guardian. Otherwise, I will only write about my personal practice. During my research I will be adhering to the Music Therapy New Zealand Ethical guidelines and the Victoria University research ethical guidelines.

Appendix 5. Permission Request Letter to Facility

I will also be accountable to my NZSM Postgraduate supervisor, Associate Professor Sarah Hoskyns
(Email: [REDACTED])

I would like to request formal permission to run my research. Please could you reply to this request, if at all possible, by April 13th 2018? Let me or my research supervisor know if you have questions about the study.

I appreciate your consideration,

Alicia Stewart

Email: [REDACTED]

Phone: [REDACTED]

Appendix 6. Permission Request Letter to facility

Tēnā koutou,

This letter is to inform you about Alicia Stewart's research, and to ask for formal permission to access the Music Moves Me clinical notes kept at

I am currently completing the second year of my Master of Music Therapy (MMusTher) degree at Victoria University. Over this year, I am completing the 750 hours of clinical work with the Music Moves Me Trust. [REDACTED] is one of the facilities where I am delivering music therapy services.

Over the course of this year, I am also completing research focused on people living with dementia and my work with the Music Moves Me Trust. This research aims to inform my own personal practice about methods, techniques and approaches which I, a music therapy student, can use to help support clients who are experiencing loss and grief. I am interested to provide sensitive and careful musical service to residents, and to critique and learn from my exploratory journey. This involves documenting and learning from what I experience and what I find to be useful when working with clients. My research question is: *How can I develop my music therapy practice to support people with dementia through loss and grief?*

The method of my research is 'action research'; which involves cycles of generating data and then analysing this data using thematic analysis. Sources of data include personal reflections on my own password-protected laptop (where I do not keep any of the client's or facility's names); and the Music Moves Me Trust MIDAS scales and clinical progress notes, which are kept in the client's folders at on site.

I would like to ask for formal permission to access the Music Moves Me Trust MIDAS scales and progress notes which I have written, and are kept at [REDACTED]. I plan to analyse these regarding my strategies and approaches to support residents. These approaches won't identify any clients, and my analysis will be kept on my password protected laptop. In discussion with the Music Moves Me Trust, it has been decided that no clinical notes or identifying information will be taken off site from the facilities. All analysis will be performed at [REDACTED], when I am finished at the end of the day.

Ethical approval has been provided by Victoria University of Wellington Human Ethics committee through an ethical template for Master of Music Therapy students: approval number 22131.

Appendix 6. Permission Request Letter to facility

During my research I will be adhering to the Music Therapy New Zealand Ethical guidelines and the Victoria University research ethical guidelines. I will also be accountable to my NZSM Postgraduate supervisor, Associate Professor Sarah Hoskyns (Email: [REDACTED])

I would like to reiterate that the present research is focused on my music therapy practice and approach, and not on individual participants. At all times, pseudonyms will be used for the clients and care homes, and any personal or identifying information will be avoided. I would like to include occasional case stories as examples, but this will only happen if I am able to access informed consent from the clients and their next of kin, and [REDACTED] will be informed. It is worthwhile noting that the “Music Moves Me Trust” will be named in my research, which does make my research less anonymous.

Please could you reply to this request, if at all possible, by June 15th 2018. Do not hesitate to contact me or my research supervisor, Sarah Hoskyns, if you have any further questions.

Ngā mihi,

Alicia Stewart

Email:

[REDACTED]

Phone:

[REDACTED]

Appendix 7. Bibliography of songs

This bibliography of songs references the singer or performer who's style I used.

1. *Auld Lang Syne*, traditional Scottish Folk melody to Robert Burns's poetry, 1788
2. *Cruising down the river*, sung by Lou Preager, 1946
3. *Danny Boy* sung by Elsie Griffin, 1915
4. *Do-Re-Mi*, performed in the musical *Sound of Music*, 1959
5. *Home on the Range*, sung by Bing Crosby, 1933
6. *It's a long way to Tipperary*, sung by John McCormack, 1914
7. *Mockingbird Hill*, sung by George Vaughn Horton, 1951
8. *Now is the Hour / Po Atarau*, sung by Maewa Kaihau, 1928.
9. *Old Man River*, performed in the musical *Showboat*, 1927
10. *Que Sera Sera*, sung by Doris Day, 1956
11. *Sad Movies (Make Me Cry)* sung by Sue Thompson, 1961
12. *Somewhere over the rainbow*, performed in the musical *Wizard of Oz*, 1939
13. *Show me the way to go home*, sung by Irving King, 1925
14. *The Tennessee Waltz*, sung by Patti Page, 1950
15. *When Irish Eyes are Smiling*, sung by John McCormack, 1916
16. *You are my sunshine* sung by Jimmie Davis, 1939