'I'D RATHER HAVE MUSIC!': the effects of live and recorded music for people with dementia living in care homes, and their carers

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I declare that none of the work contained within this thesis has been submitted for any other degree at any other university. The contents herein have been composed by the candidate, Claire Elizabeth Garabedian.

Claire Elizabeth Garabedian.

In loving memory of:

My grandfather Norman Morris, who was the first person I had the honour and privilege of playing cello at his nursing home bedside many years ago.

Orin, Bill, and mama Johntz, for allowing me the honour and privilege of playing the cello at their bedside during their final days and moments of life.

My loyal companion, Odar.

The participating residents from this study who have since passed-away.

Abstract

The objectives of this thesis were to explore the effects of receptive individualised live and recorded-music on interactions within participating dyads consisting of a person with dementia who was in their final phase of life (resident), and a person with whom he or she shared a close connection (carer), as well as on each individual participant. A 'Receptive' music intervention is one where participants are not required to do anything but listen.

Methods

The conceptual frameworks of realist evaluation, ethnography, symbolic interactionism, and dramaturgical actionism influenced the design of this study. There were two phases: during phase-1, fifteen semi-structured interviews were conducted with 'key-consultants', who were specialists in topics related to this thesis, to inform the design of 'phase-2'. During 'phase-2', musical interventions were conducted at five non-NHS care homes in Scotland over a period of nine-months. Each intervention consisted of either individualised live-music (3 sessions) or the same or similar music pre-recorded (three sessions); all music was played by the researcher on the solo cello. Interventions took place in residents' private bedrooms, and lasted between fifteen and seventy-minutes.

The order of live and recorded-music interventions was switched for approximately half the dyads. Each intervention was video-recorded for later observation.

Semi-structured interviews and Visual Analogue Scales (VAS) were administered with each participating carer before and after the conclusion of their series of interventions, to compare their expectations with their actual experiences and to better understand their experience. Whenever possible, key-staff and managers were also interviewed to learn what their perceptions of this study had been: its effects on them and on participants.

Analysis

Analysis required repeated visits to the raw data: beginning with thickly-describing all video-footage; then thematically coding all thick-descriptions and transcribed audio-interviews; and lastly revisiting all video-footage via a self-modified version of an evaluative observation instrument; 'Person Interaction Environment Care Experience in Dementia' (PIECE-dem).

Findings

Findings support prior research regarding the beneficial effects of individualised receptive music on listeners who have dementia. This study suggests that both live and recorded-music promote wellbeing, and enhance dyad interaction in the moment of listening. These findings demonstrate the potential for receptive music to create an embodied sense of 'haven' for people with dementia who are nearing the end of life and for those sharing the experience with them: by capturing and holding their attention, and transporting them either back in time, or entirely out of time into a state of 'flow', or into an 'intense musical experience'.

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Prologue: Getting to here from there

This research represents a convergence of key experiences and interests in my life. I began playing the cello from an early age, culminating in a lengthy career as a professional cellist: performing, teaching, lecturing, and directing various ensembles. Over the years, I also have had the privilege and honour of playing my cello at the bedsides of several dear friends when they were very near to death or dying. These experiences opened my eyes to the raw and intense intimacy of death and dying - and to a purpose for playing music entirely separate from as a 'performance'. My growing interest in this form of music making led me to a US-based organisation; the 'Music in Transitional Healing Program' (MHTP) (http://www.overallmusic.com/aboutMHTP.html), where I was trained and was certified as a 'music practitioner' (CMP). As a CMP, I was employed through hospices to play cello at the bedsides of people nearing death or dying. Upon relocating to Scotland in 2007, I sadly discovered that there were no similar opportunities for this type of work.

I also worked as a senior research assistant for over seven years at a public health research centre in the USA before moving to Scotland. While at this job I worked on a number of large-scale longitudinal studies; including one that brought me into considerable contact with spouses of people with dementia.

On moving to Scotland and learning of the regrettable absence of employing music within palliative care approaches for people nearing the end of life, I determined

to learn more about the research side of what I had personally witnessed during my work in the USA as a CMP: which led to my completing a postgraduate diploma in Enhanced Palliative Care at the University of Stirling and to the subsequent study described in this PhD thesis.

CHAPTER 1. INTRODUCTION

Modern western societies are facing a curious dilemma; average life expectancy is increasing, but so too is the prevalence of age-related conditions such as dementia (Chatterjee, 2008; Small et al., 2007; Birch & Draper, 2008). 'Dementia' is an umbrella term that encompasses more than 100 conditions that affect the brain and which are characterised by similar symptoms, including memory loss and cognitive impairment.

Dementia is frequently reported to be the most feared health condition of our time (Innes, 2009). One reason that dementia causes such concern is because it forces our youth-driven culture to acknowledge inevitably growing segments of society; those who are ageing, and those who are dying (Emanuel & Emanuel, 1998). Dementia is incurable and difficult to diagnose due to the many ways it can manifest (Burgess, 2004; Chatterjee, 2008). Perhaps the most frightening aspects of dementia are the compromising affects it has on short-term memory, and also on verbal communication (Burgess, 2004; Chatterjee, 2008). Consequently, people with dementia are often stigmatised and increasingly isolated as they lose their ability to effectively communicate (Bond & Corner, 2004; Cox & Watchman, 2004; Small et al., 2007). This isolation often extends to those who care for and about a person living with dementia, due to mounting frustration at the inability to effectively communicate and connect, often resulting in increased distancing from previous social interactions. Thus, all involved experience correspondingly diminished wellbeing and quality of life (Sweeting & Gilhooly, 1997).

Discovering new ways of effectively connecting with people living with advancing dementia (who may also be physically frail) has become a primary aim of dementia researchers and practitioners. 'Frailty' is a complex topic in its own right; for the purposes of this thesis, 'frailty' is primarily a shorthand way of expressing that the resident participants in this study required considerable support and generally were experiencing multiple physical and cognitive issues. Intriguingly, creative arts of all types have repeatedly been shown to be especially effective for reaching people living with dementia (Brotons, 2000) although there has been little progress in determining and evidencing the mechanisms for these effects. Though interest in the use of creative arts and especially in the use of music with people who are living with dementia is increasing, funding, training, and implementation of creative arts approaches remain inaccessible for most people with dementia in the UK. Research exploring the use of creative arts for enhancing communication between people living with dementia and those who care for and about them is also wanting. Paradoxically, this dilemma is precipitating an unexpected association between two historically disparate groups; medical professionals and creative artists:

> "It is here that the humanities and medical science can be most fruitfully integrated and in ways in which they are posed as equal partners with shared problems and concerns" (DeNora, 2013:137).

Thus the following research questions guided this present study:

- **What effect does individualised live or recorded-music have on a person with dementia who is in their final phase of life?**

- **What effect does individualised live or recorded-music have on their carers?**

How does individualised live or recorded-music affect the level or quality of interaction within each participant dyad?

The rest of this chapter comprises an overview of the structure of this thesis.

A. Thesis plan

Having provided my personal background and interests and briefly situating the relevance of this research within the present state of dementia and the creative arts, the structure for the remaining chapters of this thesis is as follows:

Chapter 2: Perspectives

Chapter 2 contextualises the need for this study; providing background information regarding historical and current societal perspectives on people with disabilities, with particular foci on dementia, ageing, and people who are in the final phase of their lives. This chapter also situates this present study within prior and current disability, dementia, and end of life research. This chapter concludes by highlighting the importance of 'relationship', and the specific difficulties faced by people living with dementia and those who care for and about them due to difficulties with communication.

Chapter 3: Music and medicine

This chapter presents an overview and critical assessment of relevant music-related research. The focus is on research into the use of music within dementia and end of life care, but research that explores the effects of music within other

health settings and other health conditions are also examined. This chapter concludes with reiteration of the research questions guiding this current study.

Chapter 4: Methods

This chapter details the design of this present study, and provides context and explanations for the specific methods chosen.

Chapter 5: Interaction

The first of two findings chapters chronicles ways in which music affected participants during interventions. Examples from thickly described observations and participant and staff interviews help illustrate these findings. Two major categories of interactions are described: dyad and triad interactions.

Chapter 6: 'Haven'

This chapter uses the conception of 'haven' to holistically describe the impact that these music interventions had on participants. 'Haven' was achieved via a combination of effects resulting from elements of the intervention format and characteristics of the music played. Examples from thickly described observations and participant and staff interviews help illustrate these findings. Examples of how aspects of these interventions and the music played may have impeded an experience of 'haven' for some participants are also presented.

Chapter 7: Discussion

This chapter discusses and situates this study's findings within relevant current academic literatures.

Chapter 8: Conclusion

This chapter begins with a brief summation of the previous three chapters; reviewing the effects of specific elements of the interventions on participants and reflecting on the data analysis process. A summary of implications and suggestions for future related practise and research follows, concluding with personal reflections and final comments regarding music's potentially beneficial power.

CHAPTER 2. CONTEXT

1. Introduction

Though this research topic is somewhat unusual, it is nonetheless highly topical given current demographic and health-related trends in the UK and elsewhere. This chapter provides the backdrop for this study by presenting an overview of prevalent past and present societal attitudes towards populations to which participants in the present study belong. The first section explores why and how people who are old, are in the final phase of life, who have dementia, or who are otherwise deemed as having a disability are often stigmatised within our society. This section argues that there are parallels between disability activists' struggles to shift societal attitudes and perspectives, and the political journey that people living with dementia are currently undertaking, and that this process is informing and shaping current dementia research.

The second section concentrates on the concept of 'relationship', specifically focusing on the importance of interaction and the barriers that can impede interactions involving someone who is living with dementia. This section discusses the two related conceptual frameworks of 'symbolic interactionism' ('SI') and 'dramaturgical actionism' ('DA') before providing an overview of issues specific to communication and dementia. The last part of this section discusses matters unique to the triadic interactions, particularly common within the arena of dementia care.

2. Ageing and dying

Innes (2009) suggests that old age is increasingly viewed as; "…a problem to be resolved rather than a stage of life to be embraced and accepted" (Innes, 2009:22). Modern western society's growing emphasis on external fitness is creating increasing discordance between our ageing external selves and the youthful self that exists within (Harding & Palfrey, 1997).

Rapid technological advances in health care mean that people in modern western societies are living much longer, and are more likely to die from protracted illnesses rather than from infectious diseases (Emanuel & Emanuel, 1998; Zimmermann & Rodin, 2004; Woods, 2006). Meanwhile, dying has predominantly come to be perceived as a sterile, technical, and impersonal process; shifting away from an unavoidable part of living, towards a cloistered activity that frequently occurs within hospitals (Zimmermann & Rodin, 2004; Cox & Roberts, 2006). Medical advances have also resulted in the line between 'living' and 'dying' becoming more blurred; thus provoking increased debate regarding the rights of the 'terminally-ill' and their allies (Emanuel & Emanuel, 1998; Walters, 2004; Zimmermann & Rodin, 2004).

3. Dementia

In most if not all developed countries the number of people diagnosed with dementia is increasing; primarily due to improvements in medical technology and practices and better living conditions which are helping people to live longer (Small et al., 2007; Chatterjee, 2008; Birch & Draper, 2008; Hennings et al., 2010). As a result, the fastest growing segment of most developed countries is the 'oldest

old' (e.g. 85 or older) (Davies et al., 2010:65). 'Dementia' is an umbrella term for a cluster of terminal degenerative disorders of the brain usually affecting older people (De Vries, 2003; Small et al., 2007; Chatterjee, 2008). As dementia progresses, a person loses various brain functions including memory, motor, and intellectual skills (Burgess, 2004; Kaasalainen, 2007; Chatterjee, 2008).

Because dementia is most commonly found in older people, it is more likely that other medical issues may mask or even overshadow dementia symptoms (Small et al., 2007; Chatterjee, 2008; Sloane et al., 2008). Although diagnosis of dementia continues to improve via MRI/CT scans, it still primarily relies on results of cognitive tests that may feel demeaning for the person being tested (Harding & Palfrey, 1997). While these cognitive test scores can tell us about some aspects of a person's abilities or impairments, they fail to depict how a person interacts and experiences the world around them (Harding & Palfrey, 1997; Kontos & Martin, 2013). MacRae (2011) suggests that, "...persons who live with dementia are not always given an opportunity to use their abilities, demonstrate their competence, and remain socially engaged" (MacRae, 2011:454).

A. Embodiment and dementia

17th century philosophers championed the mind as the defining attribute of what it is to be 'human' (see Descartes, 1640). The 'Cartesian' viewpoint continues to be both influential and contentious to this day, and is considered to be a primary contributor to society's negative outlook on people who have cognitive impairments (Bartlett & O'Connor, 2007; Dewing, 2008), including people with dementia (Kitwood & Bredin 1992).

In considering people with dementia, Kitwood (1997) rejected Cartesian notions of essential humanity. Indeed, Dewing (2008) suggests that Kitwood came close to describing the more recently developed concept of 'embodiment' in his work. 'Embodiment' denotes a more holistic view of what it is to be human - a 'reconnecting' of the brain to the body. This concept is gaining acceptance as philosophers and researchers alike acknowledge the vast knowledge and memory stored within our physical bodies (Kontos, 2012; Coaten & Newman-Bluestein, 2013; Kontos & Martin, 2013). Recognition that even those with advanced dementia have the ability to access 'embodied' knowledge and memories is also steadily gaining traction (Aggarwal et al., 2003; Kontos, 2012), prompting some dementia researchers to assert that understanding embodied forms of cognition is crucial for those who work with people living with dementia (Dekker, 2011; Downs, 2013).

Zieler (2013:135) uses the expression; 'monadic body-oriented conception of personhood' to define the belief that we all develop mannerisms, both cultural and individual, which define us as human and which we retain throughout our lives. Clear examples of the embodied knowledge commonly retained by even by people who have severe dementia, include food preferences, and idiosyncratic gestures and mannerisms (Kontos, 2012). Indications of embodied knowledge include: "...locomotion, posture, eye contact, facial expression, gestures; manoeuvring the body; balance; social mores, social graces, etiquette; and mannerisms, clothing, accessories, hair" (Kontos, 2012:333). Hughes (2001:88) asserts that, "...it is our bodies that place us in a historical context of time and place." Dekker (2011:292)

states that this bodily sense, "...does not derive its agency from a cognitive form of knowledge," and compares this bodily knowing with an inner sense of being 'home': "Our experience of being at home in a bodily way is as essential to our nature as being in the world" (Dekker, 2011:293).

Whilst the concept of 'embodiment' is generally accepted, there is some philosophical debate regarding the application of 'embodiment' to people with dementia. Dekker (2011) poses the question of whether having dementia is akin to being internally 'homeless'; to having lost one's sense of 'home' (Dekker, 2011). Phinney and Chesla (2003) speculate that we cannot truly ascertain that dementia does not physically compromise both the brain *and* the body simultaneously. These types of questions highlight the seemingly boundless layers of philosophical complexity and mystery surrounding the subject of the experience of having dementia and of what it is to be 'human'.

B. Social constructionist view of dementia

Rather than seeing people with dementia as having a 'disease', social constructionists focus on the complexities that make up dementia within an ever-evolving societal, bio-medical and cultural world. Social constructionist theory centres on how the relationships between people impact on each other and also on our perceptions of the world around us. Sabat (2001) proposes that we are primarily defined by how we position ourselves or conversely are positioned within the society in which we live. Hence, once a person is labelled as having dementia, all their subsequent behaviour is assessed through this label for the remainder of their life (Harding & Palfrey, 1997). Ironically, many of the

'challenging' behaviours commonly ascribed to people with dementia may result precisely from the ways in which they are treated after being identified as having dementia (Innes, 2009). Because people with advancing dementia usually have difficulty communicating, they are frequently ignored or at best discounted - possibly causing greater confusion and frustration (Wendell, 2006).

Sabat (2001) writes of the particular vulnerabilities that the person with dementia faces in regard to what he labels as 'self 3', which is dependent upon others in the external world recognising one's own self-perception. Sabat also refers to the concept of a 'personal present': the perception that each of us has regarding who we once were, who we are now, and who we will be at any given moment. Awareness of these self-perceptions obliges carers to not invalidate a person with dementia as, for example, she may still perceive of herself as the professor - mother - daughter they have always been, rather than simply as a person who now has dementia. The self-worth of a person with dementia therefore can easily be damaged by others focusing on only what has been lost, positioning him or her only as a person who has dementia, who must therefore be constantly 'managed' (Sabat 2001). Thus, Sabat argues, it is evident that a person with dementia will only thrive when the people surrounding him or her are willing to collaborate with these self-perceptions.

C. Dementia care and palliative approaches within the UK

Palliative care endeavours to provide comfort to the person who is dying, and to help aid him or her towards a 'good death' via approaches that are holistic, person-centred and designed to achieve pain-free dying (Small et al., 2007; Chatterjee,

2008; Living & Dying Well, 2008). The concept of 'total pain' is central to palliative care, and recognises that a terminally-ill person often suffers from forms of pain beyond the physical; including social, emotional and spiritual pain (Clark, 2000) and care thus requires a 'holistic approach' (Nyatanga, 2002:240). This 'holistic approach' is often facilitated through the use of multidisciplinary palliative care teams consisting of doctors, nurses, specialists, physiotherapists, social workers, chaplains, and volunteers (Emanuel & Emanuel, 1998; Nyatanga, 2002) who work together to optimise the quality of life for the person who is dying (Nyatanga, 2002; Field & Froggatt, 2003; Chochinov, 2006).

Payne (2010) provides a detailed description of the history and current definition of 'palliative care' as understood within Scottish care. Although 'palliative care' in the UK originally was aimed at providing comfort and wellbeing to people in the final months of terminal cancer; palliative care is currently available, "…at any stage following diagnosis of a relevant illness or condition, and not solely in the last few days, weeks or months of life" (Payne, 2010:10). Also, eligibility for 'palliative care' has opened-up to include, "…those living with and dying from a wide variety of non-malignant conditions, including dementia…" (Ibid.).

The excerpt below highlights several relevant aspects of the World Health Organization's (WHO) current list of crucial elements for successful 'palliative care':

- "Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process…;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;

- Offers a support system to help the family cope during the patients' illness...;
- Uses a team approach to address the needs of patients and their families...;
- Will enhance quality of life..." (WHO, 2014)

Dementia's classification as a life-limiting condition from which there is no cure has prompted both researchers and medical professionals to suggest that a palliative approach should begin upon diagnosis (Burgess, 2004; Birch & Draper, 2008; Chatterjee, 2008; Living and Dying Well, 2008; Sloane et al., 2008; Chang et al., 2009). This suggests that the easing of physical, social, emotional, and spiritual pain should be of primary importance when caring for a person living with dementia (Clark, 2000).

Appropriate advocacy is important in providing effective and appropriate palliative care for a person with advancing dementia. With diminishing ability to communicate verbally, he or she becomes more reliant on others to advocate on their behalf (Potkins et al., 2000; Hughes & Baldwin, 2006; Sloane et al., 2008; Chang et al., 2009). Without such advocacy, "...there is clearly a danger that those who are no longer able to express needs are assumed to have none..." (Orchard, 2002:73).

D. Person-centred care (PCC)

Kitwood's model of 'person-centred' dementia care (PCC) has hugely influenced the manner in which people with dementia are perceived and cared for. A central premise of PCC is that 'love' is the quintessential of all basic human needs. Kitwood's definition of a 'need' is, "...that without which a human being cannot function, even minimally, as a person" (Kitwood, 1997:19). This need for 'love' is

satisfied when the five inter-related basic human needs of 'comfort-attachment-inclusion-occupation-identity' are satisfactorily fulfilled (Kitwood, 1997). Brief descriptions of each of these basic needs, as they specifically pertain to people with dementia are provided below:

Comfort: "...tenderness, closeness, the soothing of pain and sorrow, the calming of anxiety" (Kitwood 1997:19). "Comfort promotes relaxation" (Brooker, 2007:96).

Attachment: "Ours is a highly social species, and this is clearly shown in the forming of specific bonds or attachments...There is every reason to suppose that the need for attachment remains when a person has dementia; indeed it may be as strong as in early childhood" (Kitwood, 1997:19). Brooker (2007:98) adds that we have a particular need to "...feel attached to someone or something familiar..." when we are anxious – as people with dementia often are.

Inclusion: "The social life of people with dementia tends to dwindle away...The result is that people with dementia often have no group to belong to - not even the family of which they were once a part...When this need is not met, a person is likely to decline and retreat, possibly into vegetation" (Kitwood, 1997:20). Brooker (2007:99) adds that: "Inclusion is about being in or being brought into the social world, either physically or verbally. It relates to facilitating engagement where there would otherwise be none, and making a person feel they are part of the group, and are welcomed and accepted."

Occupation: "To be occupied means to be involved in the process of life in a way that is personally significant, whether this consists of action, reflection or relaxation. At the opposite extreme lie states of boredom, anomie and apathy. One may be occupied in the company of others, or in solitude...sometimes...it consists of play, which in its purest form has no external goal and is concerned simply with the enjoyment of the present. In dementia, the need for occupation still persists, but many of the avenues through which the need might be met have been removed..." (Kitwood, 1997:20).

Identity: "To have an identity is to know who one is; it involves maintaining a sense of continuity with the past, and some kind of consistency across the course of present life. To some extent, others confer identity, as they respond to a person and convey subtle messages about how that person is perceived. Many of the sources of identity are taken away in dementia...If identity is to be maintained, then, it will be depend largely on the basis of what others provide" (Kitwood, 1997:20).

Love: "...to love and be loved is arguably one of the most powerful and fundamental driving forces for sustaining self-esteem and self-identity, and the need for reciprocal loving does not necessarily diminish with age" (Wilson et al., 2009:84).

PCC focuses on the individuality and individual needs of each person. This differs considerably from common medical and residential practices of grouping people with dementia together solely based on their diagnosis (Brooker, 2007). Echoing social constructionist values, PCC moves the focus from the *condition* of dementia to the *person* who is living with dementia (Kasayka, 2002) and to each person's innate right to a good quality of life (Kasayka, 2002; Brooker, 2007). Hence PCC stresses the importance of meeting each person with dementia where they are in the 'here and now' (Shustik & Thompson, 2002), and also the importance of providing him or her with familiar 'touchstones' of their cultural identity (e.g. familiar food and music) (Brooker, 2007).

Brooker's (2007) 'four essential elements of PCC' expand on Kitwood's 'five basic human needs':

1. "Valuing people with dementia and those who care for them...
2. Treating people as individuals...
3. Looking at the world from the perspective of the person with dementia...
4. Recognising that all human life, including that of people with dementia, is grounded in relationships..." (Brooker, 2007:12-13).

In PCC, "...connection, interaction and communication...[are] at the top of the list of priorities..." (Kasayka, 2001:9). This resonates with the core ethos of 'Symbolic Interactionism' (which will be discussed): that meaning is created through interaction with others. Therefore, because one can only be empathic (the third of Brooker's 'essential elements') if one is relating with another person, empathy

leads directly into what Brooker considers the fourth 'essential element'; 'relationship' (Brooker, 2007). These values also correspond with the values put forth in 'relationship-centred care', as will be discussed presently.

Much has been written regarding PCC's merits and weaknesses: fulfilling Kitwood's five basic human needs remains a constant struggle for those who care for people with dementia, particularly within busy care homes.

4. Disability

> "Disability is a form of social oppression involving social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being" (Thomas 1999:156).

A principal motivation for choosing this research topic was to provide a voice and greater recognition to people who, despite their numbers increasing, continue to remain on the margins of society. Dementia is a 'hidden' disability. The following subsections provide background regarding 'stigma' and disability, disability activism, the links between disability and dementia, and how disability and dementia research have been informed by disability activism.

A. Stigma

Given the previous discussion regarding the societal (mis)perceptions of people who are old, in the final phase of life, or who have dementia, it seems likely that people who have overlapping 'membership' within all three of these groups are especially susceptible to social isolation (Bartlett, 2000; Wendell, 2006). Though the topic of stigma and its ramifications for people with disabilities including dementia runs well beyond the scope of this thesis, it is appropriate to provide

some background regarding stigma in relation to these two populations. Kitwood and Bredin (1992) refer to the 'them and us' attitude exhibited by medical professionals in relation to people with dementia:

> "We are basically sound, undamaged, competent, kind. They are in a bad way, for they are afflicted with a primary degenerative disease in the grey matter" (Kitwood & Bredin, 1992:272).

While this divisive attitude has broadly improved since the early 1990s, it does still exist.

Oliver (1996) suggests that the act of ostracising people who are different is a regrettably common human aspect of human society; implying that this singling-out of a person or group of persons as being the 'other' is usually the result of those in power's sense of security being threatened. Therefore, "…any attribute can become a stigma" (Coleman, 2006:148). Consequently, people with externalised impairments often strive to 'pass as normal' by disguising their impairment (Coleman, 2006). It is worth noting that stigma associated with 'disability' is contextual, meaning that a person or group may experience stigmatisation in one society or culture and none whatsoever in another (Coleman, 2006; Barnes, 1996; Oliver, 1996). Ultimately, the act of stigmatising a person or group is fear-based. Those who stigmatise others incorrectly believe that greater society's 'order' and thus their 'safety' to be threatened by those who are 'different' (Harding & Palfrey, 1997; Coleman, 2006).

Wendell (2006) theorises that the 'irrevocable' nature of the attributes shared by people with dementia, nearing death, or who are very old (e.g. physical weakness, cognitive impairment, loss of body control, and communication difficulties), leads

to people who are in one or more of these groups to be viewed as symbolic of medical and societal failings. The societal barriers that these types of stigmatising attitudes generate for people in one or more of the three above-mentioned populations renders it all the more crucial that carers, researchers, and others in positions of power make an extra effort to provide support by helping to have people's voices heard and improving the quality of their lives.

B. Disability activism

Parson's 'sick role' theory of the 1950s is believed to have ignited what would become known as 'disability activism' (Oliver, 1996). The 'sick role theory' effectively states that when someone is ill, they should, "…be relieved of all normal expectations and responsibilities" and should strive to become a 'useful' member of society as quickly as possible (Oliver 1996:20). This implies that society should simply discard people who are deemed to be no longer 'useful', with no distinction made between people who are chronically ill and those who are not actually ill, but are physically (or otherwise) chronically impaired (Oliver, 1996). By the late 1960s, people with disabilities in North America were actively campaigning for the right to live independently (Oliver, 1996). This activism engendered the 'social model of disability'; the aim of which was to do away with the medicalised perception that people with disabilities needed to be 'repaired' (Barton, 1996) while espousing the awareness shared by most people with disabilities that they were perfectly fine - excepting for externally constructed barriers and prejudices (Shakespeare, 2006).

Perhaps because most of the pioneering disability activists were young and highly intellectual, issues related to ageism and mental capacity were basically overlooked (Wendell, 2006; Katz et al., 2013). Nonetheless, the somewhat simplistic perception of disability solely being an external issue has evolved towards recognition of the immense impact that impairment and chronic illness can have on one's everyday life (Bartlett, 2000; Thomas, 2004; Shakespeare, 2006;). This evolution in perception means that the premium placed on independence is being re-evaluated by people with disabilities. Greater understanding and appreciation is emerging regarding the ways in which some impairments result in greater dependency on others. For example, there is increasing recognition that old age; "...a condition most of us will reach" (Wendell, 2006:253) often requires greater 'inter-dependency'.

C. Disability, dementia, and dementia research

Dementia is another disability where 'inter-dependence' is generally required. Greater awareness of the connections between embodiment and dementia is also inspiring closer scrutiny of the "...links between vulnerability, social rights and embodiment..." (Kontos & Martin, 2013:296). While these shifting perspectives challenge the traditional independence-focused aspirations of the disability movement (Bartlett, 2000), dementia activists strive to highlight the rights of each individual with dementia, as well as the collective rights that people with dementia constitute as a growing segment of greater society (ibid).

There is understandable wariness within the disability community towards research perceived as being done *to*, as opposed to collaboratively *with* people

with disabilities (Barton, 1996; Oliver, 1996; Thomas, 1999). Barton (1996:4) urges researchers to work with marginalised groups, whilst also advising that researchers ask themselves several important questions before undertaking research that includes people from marginalised populations:

- "What right have I to undertake this work?
- What responsibilities arise from the privileges I have as a result of my social position?
- How can I use my knowledge and skills to challenge forms of oppression that people with disabilities experience?
- Does my writing and speaking reproduce a system of domination or challenge that system?"

Until relatively recently, even people with mild levels of dementia were assumed to be unable to directly communicate their experiences (Nolan et al., 2002; Katz et al., 2013). More recently, groups such as the 'The Scottish Dementia Working Group (SDWG)'; whose membership consists entirely of people with a diagnoses of dementia, have begun contributing critically needed first-hand insight into the experiences of having dementia; informing policy and assisting researchers towards more effective inclusion of people living with dementia within their studies (the SDWG kindly contributed their thoughts about this research early in the study). The insights and assistance that groups such as SDWG provide are invaluable - particularly as researchers have generally been slow to include people with advanced dementia in studies, primarily due to potential difficulties with communication (Cook, 2002), and challenging ethical issues (as will be discussed later in this thesis). Because half the participants taking part in this present study were living with dementia, I took Barton's aforementioned research criteria quite seriously prior to conducting my fieldwork, striving to always receive and acknowledge the experiences of each participant living with dementia.

5. Relationship

Having contextualised societal perceptions towards people who have dementia, who are old, who are in the final phase of life, and people with disabilities generally, this section concentrates on another central topic of this thesis: 'relationship'. One of the major reasons that people with dementia are often excluded from interactions is because of difficulties with verbal communication. Yet, interaction is an essential element of relationship, and relationship is an essential part of what it is to be human (Allan, 2006). This need for relationship does not diminish as we grow older (Hubbard et al., 2003; Katz et al. 2013).

This first set of subsections focuses on 'interaction' by providing a brief overview of two influential and related conceptual frameworks: 'symbolic interactionism' ('SI') and 'dramaturgical actionism' ('DA'). The final subsection considers barriers to communication commonly experienced by people living with dementia.

The second set of subsections concentrate on the experiences of those who care for and about a person with dementia (e.g. family carers in home settings, and carers in care home settings). The final two subsections describe the triad dynamic commonly found within dementia care (i.e. a person with dementia, a family member or friend, and a professional), and introduces the dementia care model known as 'relationship-centred care (RCC)', which directly addresses interaction issues specific to this triadic dynamic.

A. Symbolic interactionism (SI)

The roots of what was to become the theory of 'symbolic Interactionism' originated in the United States during the 1950s. There are two main strands of SI: the 'Chicago school', and the 'Iowa school'. The former lineage (e.g. Mead, Blumer and Goffman) is the one referenced in this thesis.

SI contends that meaning is created through interactions between people engaging with a shared stimulus, and that interactions are exchanges of shared symbols conveyed through physical and vocal gestures (Blumer, 1969). These gestures are not intrinsically meaningful, but rather are interpreted by whoever is sharing in the interaction (Manis & Meltzer, 1978). These interpretations are either influenced by one's past, or can be unpredictable responses generated in the here and now (ibid.). Thus, people continually reference themselves by how others who are present define them (Manis & Meltzer, 1978), and it is through these social interactions that the 'self' emerges and is sustained (MacRae, 2011).

A 'symbolic' interaction happens when a shared stimulus is not simply reacted to, but instead is synthesised within the mind and *then* responded to (Manis & Meltzer, 1978; Blumer, 1969). In contrast, a 'non-symbolic' interaction occurs when a response is reflexive and bypasses the interpretation phase (Blumer, 1969). This is where the importance of verbal language and interaction surfaces in SI: Mead proposed that verbal language lifts human interactions to a higher level

as compared with interactions between other animals (Atkinson & Housley, 2003). Verbal language allows humans to interact:

> "...in ways that are decontextualized, not limited to the here-and-now of the stimulus-response gesture. By virtue of language...I not only engage in a dialogue of symbolic signification with my fellow men and women; I also engage in an inner dialogue..." (Atkinson & Housley, 2003:120-121).

SI's emphasis on interaction as the source of meaning has great resonance with this present study. However, inferences regarding the significance that verbal language and self-reflection have in creating meaningful interactions are not only a contentious issue in itself, but particularly for this study, which focuses on interactions with a person living with dementia who may have particular difficulty interacting verbally.

Critics argue that SI pays too little attention to the potential impact that social structures may have on interactions (Craib, 1984; Meltzer et al., 1975). Whilst this critique is perhaps warranted, SI clearly states a primary interest in the micro-level of person interaction:

> "It is the social process in group life that creates and upholds the rules, not the rules that create and uphold group life" (Blumer, 1969:19).

Likewise, this present study is focused on the micro-level of personal interactions, which will ideally serve to inform future practice within the larger societal structures where interactions take place.

Although SI is also criticised for not providing clear guidelines regarding how to interpret observed interactions (Meltzer et al., 1975; Craib, 1984), the enigmatic nature of this issue equally explains why SI is sometimes credited as having

established qualitative methodology within the social sciences (Holstein & Gubrium, 2000; Atkinson & Housley, 2003). Indeed, Craib (1984) sees this lack of clear guidance as:

> "...a necessary aspect of the [SI] approach's distinctive contribution to sociology...if it is the case that social interaction is in constant flux, then the starting point must be flexible...or we would lose vital aspects of what we are studying" (Craib, 1984:77).

B. Dramaturgical actionism (DA)

> "...Interaction...may be...defined as the reciprocal influence of individuals upon one another's actions when in one another's immediate physical presence" (Goffman 1959:26).

Though Goffman began his career within the 'Chicago school' of SI, his primary interest of "...exploring the central role of language in social life..." (Appelrouth et al., 2008: 178) spurred development of his theory of DA, in which the metaphor of drama is used as a means for explaining interactions (Goffman, 1959). Goffman uses the term, 'impression management' to describe the varied roles we each assume during interactions, suggesting that these roles are entirely circumstantial (Melzer et al., 1975; Applerouth et al., 2008). Goffman also posits that human interactions are never 'automatic' (Applerouth et al., 2008); this view directly conflicts with Blumer's (1969) above-mentioned concept of 'non-symbolic' interaction, and helps refute common assumptions that people with dementia are unable to engage in meaningful interactions. DA is widely respected for having drawn attention to the importance of observing human interactions within the context of real-life, rather than in artificially constructed situations set-up specifically for research purposes. In doing so, DA is seen as providing sociology significantly greater credibility as a 'real' science (Melzer et al., 1975).

From a DA perspective, we are all actors assuming numerous shifting roles during any given interaction (Goffman, 1959). Whilst a performer's physical features cannot be altered (e.g. age, race) other less tangible features (e.g. facial and bodily gestures, speech) can (Goffman, 1959). The 'performer' and 'audience' are viewed as implicitly acting together: thus the 'audience' willingly accepts the impression given by the 'performer', and will generally try to support a struggling 'performer' by playing-along even when they are being subjected to something demeaning or patronising (Goffman, 1959). It is vital to the success of any 'performance' (interaction), that the 'performer' not break out of character, as any chinks in his or her current character risk weakening or at least altering their established relationship with the 'audience' (Goffman, 1959). In fact, "…an unanticipated disruption can throw an entire social interaction into complete disarray" (Goffman, 1959:235). The other relevant DA 'roles' are:

- The 'shill': a person who has been 'planted'; who has an inside understanding of the goal of the 'performance', who thus can instigate the response that the 'performer' is looking for (Goffman, 1959).

- The 'non-person': a person who is at the 'performance' but does not assume an actual role (Goffman, 1959): Goffman states that servants and "…the very young, the very old, and the sick…" are examples of 'non-persons' (Goffman, 1959:151).

- The 'outsider': a person who is neither a member of the 'audience', nor a 'performer' (Goffman, 1959).

Goffman views the setting wherein interactions take place as integral to informing the 'roles' that each person adopts during an interaction (Goffman, 1959). When there are repeated 'performances' between people in the same space, a social relationship is likely to arise even when there has not been one previously (Goffman 1959). The 'front' is the location of the 'performance' (interaction) and is where decorum is maintained. Whereas SI sees individual interactions as the primary unit of change within society, DA recognises that there are some 'fronts' that are pre-formed by society rather than created by the 'performers' (Goffman 1959). Thus, from a DA perspective the impact that society's perceptions of people who have dementia, are elderly, or are perceived to have disabilities, cannot be overlooked when endeavouring to understand the nature of interactions amongst and with people from these populations.

Critics of DA contend that the 'roles' described are only relevant within western cultures (Atkinson & Housley, 2003). Although this may be true, this criticism has no bearing on this present study. DA and SI share several criticisms, amongst which is the tendency to depict people as two-dimensional, non-emotional beings whose primary objective during interactions is to persuade others (Melzer et al., 1975; Craib, 1984). It is difficult to gauge the meanings of people's external behaviours or to truly know what is happening internally during any given interaction; particularly when interactions involve a person who has dementia. Thus, although these may be valid criticisms, they are not terribly relevant to this present study. Like SI, DA is also criticised for putting too much emphasis on the micro-level of individual interactions rather than on the society within which interactions take place (Melzer et al., 1975). Again, this issue has no bearing on

this study. Finally, SI and especially DA are criticised for a lack of attention to the historical context of interactions (Melzer et al. 1975). The focus of this research is the 'here-and-now' interactions occurring during each music intervention. As people with dementia primarily live in the 'here-and-now', this is where my interest lies regarding assessment of the effects of these interventions.

C. Communication and dementia

Effectively communicating with people who have dementia requires awareness of embodied knowledge and memory, which if tapped, can uncover new ways to interact (Coaten et al., 2013; Downs, 2013; Hughes, 2013; Kontos & Martin, 2013; Martin et al., 2013). This subsection considers issues involved in effective communication involving people with dementia.

Reiterating what was said earlier, communication is at the core of relationship, and relationship is at the foundation of humanity (Killick & Allan, 2001; Allan, 2006; Ward et al., 2008). Humans are innately social beings who rely on social interactions in order to thrive (Hargie & Dickson, 2006). Dementia presents specific obstacles to successful communication (e.g. reduced vocabulary, word-finding difficulty, problems with reasoning, repetition of thoughts, lack of coherence, losing track of topics, and distractibility). These obstacles often result in exclusion from social interactions (Hubbard et al., 2002; Murphy et al., 2007) which can lead to isolation and depression (Hargie & Dickson, 2006; Alm et al., 2007; Ward et al., 2008). Kontos (2012) posits that a major barrier to communicating with people who have dementia is that "...the bodies of those with

dementia have failed to be seen as an important source of agency for sociability"
(Kontos, 2012:330)

People with dementia commonly lose their ability to verbally communicate, hindering their ability to clearly indicate what they are feeling and what their wishes are (De Vries, 2003; Burgess, 2004; Chatterjee, 2008; Powers & Watson, 2009). Inability to express one's experienced physical or psychological pain is now recognised as a principle reason for the so called 'challenging behaviours'(e.g. yelling, mood shifts, agitation, wandering) often associated with advanced dementia (Burgess, 2004; Smith, 2005; Small et al., 2007; Van der Geer, 2009). These 'challenging behaviours' were previously (and sometimes still are) treated with heavy sedation and restraints (Birch & Draper, 2008). However, there is increasing demand for non-pharmaceutical, compassionate approaches towards assuaging the underlying experienced frustration (Svansdottir & Snaedal, 2006; Park & Specht, 2009; Van der Geer et al., 2009).

There is also a growing awareness that:

> "Arenas of care in which the interpersonal relationships of older people are encouraged through nonverbal forms of communication may provide pathways in which older people with dementia maintain a sense of personhood" (Hubbard et al., 2002: 163).

Less than 20% of human communication is transmitted verbally (Hubbard et al., 2002; Hargie & Dickson, 2006; Hobson, 2008; Nazarko, 2009), with the remaining 80% conveyed via sight, smell, sounds, and touch (Hubbard et al., 2002; Hargie & Dickson, 2006). Nevertheless, verbal language is widely viewed as the most important form of human communication and is considered a primary element

separating us from other species (Killick & Allan, 2001; Hughes, 2013). Because people with dementia generally become increasingly reliant on nonverbal means of communicating (Ward et al., 2008; Kontos, 2012; Hydén, 2013), it is crucial that more attention be paid to the individual ways that embodied communications are expressed (Kontos, 2012). Embodied expressions of self usually present as gestures, which may be "…as subtle as the breath…" (Coaten & Newman-Bluestein, 2013:677). Thus, perhaps the most important route towards effective interaction with a person who has dementia, is to be aware of all expressed gestures, to empathise with the person's experience, and to respond in a fully-present and holistic manner (Coaten & Newman-Bluestein, 2013; Hughes, 2013; Hydén, 2013).

As inferred above, consideration of the physical and sensory environment where communication involving a person with dementia is to take place is also important (Aggarwal et al., 2003; Adam & Gardiner, 2005; Hargie & Dickson, 2006). Matters such as the appropriate use of public versus private space (Killick & Allan, 2001; Allan, 2006), and the level of background noise and distraction (Powell, 2000; Heine & Browning, 2004; Bryan, 2006; Hargie & Dickson, 2006; Goldfein, 2007; Hobson, 2008) can greatly affect the success of interactions involving a person with dementia.

People labelled as having dementia are often excluded from general discourse; principally due to a general lack of understanding of how best to effectively communicate with a person with dementia on his or her terms. In reality, the person with dementia is not very different from anyone else; indeed, as Killick and Allan (2001) remind us, we all stand a good chance of being in their shoes later in

life. It is also important to bear in mind that while there has been an increase in strategies aimed at improving communication with people who have dementia, each person will have his or her own individual ways of coping and communicating (Walker, 2007; Hobson, 2008).

D. Carers

As the number of people diagnosed with dementia rises, so too do the number of people who are directly connected with a person who is living with dementia – through kinship, friendship, or caregiving. Formal and informal carers cite difficulties with communication as the most stressful aspect of caring for a person with dementia (Bryan, 2006; Ripich & Horner, 2006; Weinrich et al., 2006; Alm et al., 2007; Murphy et al., 2007; Astell et al, 2010). Having previously highlighted verbal communication challenges common in dementia care, this section begins by drawing attention to other issues prevalent among caregivers of a person who has dementia. The following subsections consider communication and relationship issues specific to informal and formal carers of people with dementia.

i. Informal and formal carers

Caring for a family member who has dementia can be very rewarding, but also quite taxing – largely depending on the carer's perceptions of the person with dementia (Innes, 2009; Van't Leven et al., 2013). The unsought role of caring for a person who has developed dementia can have negative impacts on all aspects of the carer's life, often leading to 'caregiver burden' (Sweeting & Gilhooly, 1997; Clair, 2002; De Vries, 2003; Burgess, 2004; Papastavrou et al., 2007; Sakamoto et al., 2013), which in turn can lead to serious stress-related illnesses (Downs et al., 2006; Chatterjee, 2008). Residual effects of these illnesses can continue long after

the person with dementia has moved into a care home (Burns & Rabins, 2000; Papastavrou et al., 2007). Hence it is equally important for family carers of people with dementia to be offered access to "…emotionally supportive interventions…" (Burns & Rabins, 2000).

As detailed in the following chapter, all fieldwork for this study took place in non-NHS care homes in Scotland. Despite increasing efforts to keep people with dementia living and ultimately dying at home, many people with dementia in the UK will likely spend their final months or possibly years in a care home (Downs et al., 2006; Froggatt & Payne, 2006; Powers & Watson, 2008; Sloane et al., 2008; Hennings et al., 2013).

Successful relationships are core to a thriving care home. However, due to frequent understaffing, restrictive timeframes, and the heterogeneity of resident populations (e.g. different backgrounds and different impairments), creating successful relationships within care homes can be particularly challenging (Katz et al. 2001; Wilson, 2009). Thus, care home residents often lack opportunities for social interaction - particularly residents who are especially frail who have cognitive impairments (Hubbard et al., 2003).

The numbers of people either formally or informally diagnosed with dementia residing in care homes has dramatically increased; with some care home managers stating that nearly all of their residents currently have some level of dementia (Froggatt & Payne, 2006; Volicer, 2008). This is particularly difficult for residents with dementia living in care homes managed by someone who is not necessarily

comfortable dealing with dementia, and who may not feel that care homes are an appropriate place for them (Stanley, 2009). This potential discomfort expressed by some care home managers towards residents with dementia may be due to perceptions that people with dementia are unable to express their needs despite growing evidence that, if given appropriate time and support, even people with quite advanced dementia *can* indicate their wishes (Stanley, 2009; Wilson et al., 2009).

'Caregiver burden' is the most common reason for a family carer to eventually and usually reluctantly place their family member with dementia into a residential home (Field & Froggatt, 2003; Small et al., 2007; Chatterjee, 2008). Care homes are faced with a particularly difficult undertaking, as they are required to accommodate long-term residents who are living, and also tend to those who are dying (Field & Froggatt, 2003). Innes (2009) suggests that one of the chief difficulties that institutionalised care for people with dementia presents is the social construct of pairing marginalised, underpaid and undertrained staff hired to care for a stigmatised and equally marginalised group of people who were likely not happy about moving from their personal homes. To compound this situation, care home staff who usually have the most consistent contact with people with dementia are generally low-paid, lack training and support, are transitory, and are responsible for too many residents at one time (Field & Froggatt, 2003; Smith, 2005; Chatterjee, 2008; Froggatt et al., 2009; Kontos & Martin, 2013).

The common practise of clustering people diagnosed with dementia together can present additional difficulties, because they may have little else in common (e.g.

social class, ethnic and cultural background etc.) (Innes, 2009). The generic time-structure common to most care homes (e.g. when to sleep, eat, get dressed etc.) also does not accommodate residents' individual internal time clocks, which can potentially add to frustration for residents and hence for formal carers (Kontos & Martin, 2013).

The outcome of the above noted impediments is that regardless of the good intentions that an institutional carer may have, the physical demands required for accomplishing regular tasks such as bathing and feeding leaves little energy or time for acquisition of the skills necessary for successfully providing person-centred care (Kovach, 2003; Innes, 2009; Kontos, 2012). These issues are beginning to be directly addressed through government policies including 'Living and Dying Well' (Scottish Government, 2008) and the 'National Dementia Strategy' (SG, 2010). These documents do not merely acknowledge the need for improvements, but also provide specific guidelines regarding care specifically tailored for people with dementia.

E. Relationship-centred care (RCC) and the dementia triad

Whilst PCC concentrates on the care of each *individual* living with dementia, RCC concentrates on caring for the *relationships* between each person living with dementia, those who care about that person (e.g. family members and friends), and those who provide care (e.g. professionals) for that person (Nolan et al., 2002; Nolan et al., 2003a; Ryan et al., 2008; Dewing, 2009). Care home residents who have dementia often have little control over their life choices. RCC focuses on inter-dependency, or the reciprocity of giving and receiving care, as key to

successful care within these populations (Nolan, 2002; Adams, 2003; Wilson, 2009). Hence, RCC emphasises the importance of providing activities that include not only the person with dementia, but also people with whom they have a shared affinity (Ryan et al. 2008).

Despite the prevalence that the constellation consisting of a professional, a visiting friend or family member, and a person living with dementia occurring within dementia care, there is little research exploring the nature of interactions within these triad formations (Adams & Gardiner, 2005; Quinn et al., 2013). Triadic interactions and dynamics are particularly fascinating because their inherent instability involves continual shifts of attention, power, and alliances between members (Adelman, 1987; Adams, 2003; Quinn et al., 2012). A study exploring the triadic relationships between spousal caregivers, people with dementia, and Admiral Nurses reported that, "...health care professionals can have a critical role in shaping the interactions between the caregiver and care-recipient" (Quinn et al., 2012:590). The authors add that though roles and allegiances within each triad were in constant flux, problems only resulted when a family member was too rooted in his or her long-established roles, making it difficult for them to 'try-on' new ways of interacting with the triad member with dementia (Quinn et al., 2012). These findings suggest the possibility that the presence of a third person who is less emotionally involved (e.g. a professional or musician) may assist the family member to perceive the person with dementia in new ways and consequently to find new ways of interacting. The professional triad member must also take special care not to exclude the triad member with dementia, who may be highly

susceptible to exclusion within this dynamic due to difficulties with communication (Martin & Younger, 2000; Adams, 2003; Adams & Gardiner, 2005).

6. Conclusion

This chapter located the relevance of this present study by providing an overview of prevalent past and present societal attitudes towards populations central to this study. Supplying background history regarding the origins of these societal perspectives and discussing approaches developed towards allaying these often damaging viewpoints serves as the foundation for the remainder of this thesis.

Older people, people in the final phase of life, and people living with dementia represent three steadily growing and often overlapping populations who are especially vulnerable to being stigmatised due to societal misperceptions and resistance to identifying with possible future membership within one or more of these groups. Other societal barriers such as a general lack of knowledge regarding nonverbal communication and not allowing ample time to connect with people who are extremely frail - especially if they also have difficulty expressing themselves verbally also cause exclusion for members of these groups. These include. Thus, the importance of recognising the embodied intelligence retained by each of us, and the need to develop methods for accessing this embodied intelligence dwelling within each person living with dementia is emphasised.

People who care for and about people how are members of one or more of these three populations also frequently speak of feeling isolated. Family carers are highly susceptible to 'caregiver burden' resulting from exhaustion stemming from

difficulties with communication and a lack of training and proper support. Formal carers are generally undertrained, underpaid, and lack sufficient time to make satisfactory connections with people from these populations. Both carers and residents are vulnerable to isolation within the care home environment, with the latter largely dependent on the particular ethos of care predicated by each care home manager.

Communication and relationship are central to this present study. The conceptual frameworks of SI and DA provide a helpful foundation for interpreting the interactions within these populations, and will be revisited throughout this thesis. PCC was introduced both to provide background for one of the most influential and positive approaches to caring for people with dementia, and also to help situate RCC, which shifts the focus from the individual with dementia to the quality of their relationships with those surrounding them. RCC also addresses the common triadic configuration (a professional carer, a person with dementia and a family member) commonly found within dementia care, and the necessity for greater attention to be paid to facilitating and enhancing interactions within this specific triadic dynamic.

The next chapter introduces music and its importance within society, and its historical and present-day use as a respected agent for healing through review of relevant research.

CHAPTER 3. MUSIC MEDICINE

1. Introduction

Until relatively recently music was not so much something that was performed, but an activity that everyone took part in either as an instrumentalist, singer, or dancer (Levitin, 2006; Turino, 2008). While the origins of music are uncertain, music has been recognised for its healing properties since the beginning of known human history and within all cultures (Hays & Minichiello, 2005; Grocke & Wigram, 2006; Sixsmith & Gibson, 2007; Särkämö et al., 2012).

There has been a resurgence of interest in the healing properties of music in modern western societies, partly due to growing interest in its potential to help palliate and improve the wellbeing of people living with long-term incurable conditions including dementia. This chapter provides an overview of the history of employing music as an agent for healing through to the present. This chapter begins by explaining selected terminology related to this topic: differentiating between 'healing' and 'curing'; 'music therapy' and 'music medicine'; and the various practitioners specifically trained to conduct different types of music interventions. Two important physiological effects of music are also defined: 'entrainment' and the 'iso-principle'. This chapter concludes by presenting research regarding the use of music in a range of contexts, including at the end of life; with people who have dementia; and in other medical arenas. By doing so, this chapter positions the relevance and need for this current research.

2. 'Healing' and 'curing'

Music interventions are generally organised either for 'curing' or for 'healing' the recipient(s). Although these two terms are often used interchangeably, their ethos is actually quite different. For western medical clinicians, 'curing' is synonymous with 'fixing' or 'repairing' the patient. Conversely, 'healing' focuses on providing comfort and improving wellbeing for recipients irrespective of whether or not he or she is 'curable' (Boudreau et al., 2007; Hutchinson et al., 2009). Whilst both objectives are equally valid, 'healing' can benefit *all* people regardless of their health status (Fachner, 2007). Indeed, there are times when conducting a music intervention with the sole intention of curing a recipient might actually have a negative impact, for instance when the recipient is actively dying (i.e. within hours or days of death (Hui et al., 2014), or has a condition that is no longer 'fixable'.

Simply listening to the music one enjoys has been shown to significantly improve people's wellbeing across all populations and in all settings (Grocke & Wigram, 2006). When music listening is used within an intervention, it is referred to variously as 'music medicine' (Janata, 2012; Archie et al., 2013), 'music listening' (Raglio et al., 2013), and 'passive listening' or 'receptive listening' (Spiro, 2010; Black & Penrose-Thompson, 2012). For the sake of clarity, the term 'receptive listening' will be used in this discussion to describe such interventions. During receptive music interventions, recipient(s) need not do anything other than listen to the played music (Sherratt et al., 2004a; Grocke & Wigram, 2006). Music interventions requiring interaction between recipients and music played are often referred to as active' or 'interactive' (Janata, 2012; Raglio et al., 2013). For this

discussion, such interventions will henceforth be referred to as 'interactive music' interventions.

A recognised profession since the 1950s, music *therapists* (MTs) are specially trained to help meet a variety of physical, cognitive, social, and emotional needs within a wide range of medical and non-medical settings (Grocke & Wigram, 2006; Janata, 2012). The British Association for Music Therapy describes music therapy as:

> "[A] psychological therapy which uses the unique qualities of music as a means of interaction between therapist and client..." (BAMT Fact Sheet, n.d.).

The following quote found within a Cochrane review of music interventions at the end of life, is indicative of general misunderstandings regarding two main forms of music interventions, and who is best suited to conduct them:

> "... interventions are categorized as 'music medicine' when passive listening to pre-recorded-music is offered by medical personnel. In contrast, music therapy requires the implementation of a music intervention by a trained music therapist, the presence of a therapeutic process, and the use of personally tailored music experiences..." (Bradt & Dileo, 2010:3).

I question whether listening to music is actually ever a truly 'passive' activity, and also the implication that 'medical personnel' are the only appropriate people to conduct pre-recorded-music interventions. The above quote also implies that only MTs are capable of providing 'personally tailored music experiences'. It should be noted that whilst interactive music interventions are the most common form of music therapy, MTs *also* conduct receptive music interventions; but *always* with an intended specific *therapeutic* goal (Grocke & Wigram, 2006).

As previously mentioned, interactive forms of music therapy are not always a viable, or even best option depending on what cognitive and physical impairments a potential recipient might have (Black & Penrose-Thompson, 2012; Sakamoto et al., 2013). Receptive music interventions consist of live *or* recorded-music, and require nothing of the recipient(s) (Sherratt et al., 2004a). Receptive music interventions conducted for healing purposes need not involve a MT. Alternative avenues available for those wishing to obtain appropriate training for conducting receptive music interventions will be discussed presently. As will become apparent, while it is important that an *appropriately* trained person be present while the music is playing, employing pre-recorded-music during interventions opens-up the potential for people to benefit from music at times (e.g. to aid in sleep, or at times of increased stress) when a MT may not be available (Janata, 2012).

3. Entrainment and the iso-principle

Used appropriately, music can serve as a powerful tool. By first matching the tempo or mood of music played to the indicated temperament of the listener and then gradually changing the pace and mode or key of the music, the recipient can be guided towards an altered physiological or neurological state. For example, frenetic music would be played to capture the attention of an agitated listener, and then the music would gradually be slowed-down and softened towards bringing a listener into a more peaceful temperament (McCaffrey and Locsin 2002; Lee et al. 2005). Such actions rely on the physiological effects of music known as 'entrainment' and the 'iso-principle'.

The human body is comprised of many elements and systems (e.g. the heart, circulation, respiration, hormone secretion etc.) that generate rhythms that naturally synchronise or 'entrain' with each other (Clayton et al., 2005). 'Entrainment' refers to listeners' internal body rhythms matching with the rhythms of the played music (Fachner, 2007; Khalfa et al., 2008; Black & Penrose-Thompson, 2012). The 'iso-principle' refers to the mood, emotion, or psychological state of a listener matching with the temperament or mood of the played music (Hilliard, 2000; Bradt & Dileo, 2010).

Whilst music is widely recognised for its ability to convey and evoke moods (Grock & Wigram, 2006; Hunter et al., 2010), the specific impact of different moods depicted in played music (usually via major or minor keys) on participants is difficult to pinpoint. A study exploring emotional responses to music (Hunter et al., 2010) found a strong relationship between people's emotional responses and particular characteristics of the music: fast-paced music in major keys made people feel happy and slow-paced music in minor keys made people feel sad; fast-paced songs in minor keys and slow songs in major keys resulted in mixed responses. The authors also found that although the mood of the played music clearly affected the moods of listeners, there were many other factors that contributed as well. These included: pre-existing mood-states; pre-existing associations with the music being listened to; the attitude towards the music of others present; and also characteristics of the music such as tempo, mode, and instrumentation.

4. 'Flow' and 'Intense Musical Experience' (IME)

Two additional phenomenon warrant consideration: 'flow' and 'intense musical experience' ('IME'). An in-depth discussion about these two associated, rather nebulous concepts is beyond the scope of this present thesis. However, their relevance to this research prompts a brief overview.

Individuals have described their experience of 'flow' as:

> "…states of seamless absorption, high-level focus, and…effortless immersion in a pleasurable task" (Diaz, 2013: 43).

Explaining the difficulties associated with gathering data on which to base a definition of 'flow', Diaz (2013) speaks of 'flow' as:

> "… an event that occurs in time, and thus summative accounts based on either interview techniques or questionnaires do not provide sufficient information relating to the temporal characteristics of the experience" (Diaz, 2013:45).

Schafer et al. (2013) define an 'IME' as a sensation that music listeners sometimes experience when their perception of time is altered to the extent that they describe having a feeling of 'transcendence':

> "…people leave their ordinary experience and enter a world "that is not comprehensible in rational terms…Spatial dimensions and chronological structure ceased to exist" (Schafer et al., 2013:13).

Both of these concepts describe an experience of having one's perceptions of reality and time altered as a result of being deeply absorbed in the pleasurable and stimulating activity of listening to music.

5. Music at the end of life

Researchers suggest that as hearing is generally the last sense retained at the end of life (Haig, 2009), receptive music may be uniquely suited for playing at the bedside of someone nearing or actively dying (Freeman et al., 2006; Hogan, 2003). There are two types of specialists specifically trained to play music for people near the end of life or who are actively dying: 'certified music practitioners (CMP)' and 'Certified Music-Thanatologists (CM-Th). I was specifically trained as a CMP. The job of a CMP is to play music at the bedside of a person who is chronically or terminally ill, or actively dying; solely aiming to meet him or her where they are in that moment, and to provide comfort or palliation as warranted within that moment.

CM-Ths play and sing 'prescriptive' music that is free of rhythm during 'vigils', with the sole intention of easing the dying process of the person who is dying (Cox & Roberts, 2006; Black & Penrose-Thompson, 2012). Researchers suggest that because "...nonverbal behaviour is an essential method to convey warmth, love and support" (Caris-Verhallen et al., 1999:809) music may be especially beneficial during this most intimate of times; perhaps particularly for people who are near death.

The value of interventions performed by CMPs and CM-Ths are steadily gaining recognition as reflected in increasing employment of people with these qualifications in hospices and hospitals in the United States; though this has yet to take hold within the UK.

6. Music and dementia

Music is recognised as a powerful form of non-verbal communication surpassing all language barriers (Gallagher et al., 2006; Sorrell, 2008; Gerdner & Schoenfelder, 2010), and as "…a unique stimulus, because it can induce both physiological and psychological responses in the listener" (Chlan & Tracy, 1999:35). Music can also reduce the agitation that is often expressed by people with dementia (Van der Geer, 2009; Cohen-Mansfield, 2013; Music Therapy in Dementia Care, n.d.), and can also provide points of reference for the phases and important events in one's life - thus helping people with dementia reconnect with past memories (Gallagher et al., 2006; Janata et al., 2007; Gerdner & Schoenfelder, 2010).

Researchers have also discovered the ability of music to reach uninjured parts of the brain, thereby enabling people with dementia to interact better with people within their environment, and helping to alleviate the isolation often attributed to dementia (Hubbard et al., 2002; Sorrell, 2008; Gerdner, 2009; Music Therapy and Dementia Care, n.d.). Sixsmith and Gibson (2007:132) found that many people with dementia "…enjoyed music as an activity in and of itself …". In a study looking at the effects of music on people with dementia living in a residential home, McCaffrey (2008:41) cites participants "…describing the ability to close their eyes, listen to familiar music, and be transported to their own homes." Recent studies (Särkämö et al., 2012; Vink et al., 2013) showing that people with advanced Alzheimer's disease still respond to music even after they have ceased responding to other sensory stimuli warrant further investigation. Vink (2000a) suggests that people with advanced dementia benefit most from individualised receptive music

interventions; however, this study does not provide enough evidence to support this statement, nor has any other related research.

Growing recognition of the physical, mental, and emotional pain experienced by people with dementia has precipitated increasing interest in discovering effective non-pharmaceutical palliative approaches such as acupuncture, massage, and music (Witzke et al., 2008; Cohen-Mansfield, 2013). Music has been shown to reduce many forms of pain (Krout, 2003), while also effectively distracting listeners from their experienced pain (Gerdner & Schoenfelder, 2010). Music interventions may also cost less than pharmacological interventions, and do not involve side-effects common to some of the latter types of interventions (Archie et al., 2013).

Significantly, researchers advise paying particular attention to the musical preferences and demographics (e.g. age, culture, and religion) of prospective music recipients living with dementia in order to avoid exacerbating agitation and discomfort (Cuddy & Duffin, 2005; Gerdner, 2009). Concern over possible negative effects can be seen as an acknowledgement of the potential power that music can have on listeners.

Successfully applying to people with dementia the palliative methods that until recently have applied almost exclusively to people dying of cancer requires fresh attitudes and innovative approaches. Though there has been some progress, there remains considerable need for improved education and greater dissemination of information about dementia and dementia care within palliative care settings.

While there is a clear need for more exploration into better ways of implementing palliative person-centred care for people with dementia and their families, it is encouraging that innovative research is emerging. This trend will be illustrated later within this chapter.

Having provided a general overview of the uses of music within dementia and end of life care, the next section provides a review of research into the effects of music on people with dementia, who are nearing the end of life, or who have various other medical conditions.

7. Music research

Proponents of 'realist reviews' suggest that there are many valuable sources for information - including so-called 'grey literature' (e.g. research that has not been peer-reviewed prior to being published) (Pawson et al., 2005). As this study explores under-researched topics, I have included 'grey literature' in my literature review. Likewise, I found traditional keyword searches to be of limited value, but that using the realist review tool known as 'snowballing' (i.e. finding pertinent references within relevant papers (Pawson, 2006) to be more helpful.

Although music interventions conducted within various medical settings are generally acknowledged to be beneficial, much is yet to be learned and evidenced about the most effective ways to utilise music (Black & Penrose-Thompson, 2012; Särkämö et al., 2012). These gaps in knowledge are quite apparent when reviewing research about the effectiveness of music interventions for people

nearing the end of life (EOL) and for people with dementia, as is demonstrated in the following subsections.

A. Music-related medical research

There has been considerable research (albeit of fluctuating quality) exploring the effects of music interventions on people with various medical conditions. As the focus of this present study lies elsewhere, this subsection presents only a brief synopsis of the general state of this strand of music research through assessment of a representative sample of research, including a meta-analysis and three bio-medically based studies.

Aragon et al. (2002) explored the effects of music on anxiety and pain levels of patients in the recovery phase immediately following vascular or thoracic surgery. Seventeen patients were electronically monitored for heart rate, blood pressure, respiratory rate, and oxygen saturation during a single twenty-minute live-music intervention consisting of improvisatory live harp music. Participants self-reported their level of 'satisfaction' with the music on a Visual Analogue Scale (VAS): all participants expressed 'satisfaction' with the music intervention. Participants reported that the music generally reduced anxiety and pain levels, with effects lasting for at least ten-minutes after the intervention. It is difficult to assess these conclusions because this study relied on data from a single music intervention and there were no comparative interventions. The harp can also be problematic for some recipients due to its association with heaven and therefore with the prospect of dying. The meaning of the term 'satisfaction' was not

elaborated on, and it is not clear just how alert these participants might actually have been given they had just undergone ostensibly major surgery.

Bernardi et al. (2006) explored how different genres and tempi (speeds) of music in combination with random periods of silence affected the cardiovascular rates of twenty-four healthy younger people, half of whom had played musical instruments. Several bio-medical responses were continuously monitored throughout two twenty-minute interventions consisting of pre-recorded-music played in:

> "…random order with no intervening pauses, presentations of two minute periods of (1) slow classical, (2) fast classical, (3) dodecaphonic, (4) techno, (5) rap, and (6) raga music …Then the tracks were repeated in a different random order but this time for four minutes…" (Bernardi et al., 2006:446).

These two versions of the music were then re-run with two-minutes of silence randomly added between musical selections. Monitored responses indicated that tempo had greater effect than genre or individual music preferences, and that the interspersed silences added a relaxing effect. Participant musical background made no discernible difference. This study is helpful in that it explores the effects of specific music characteristics. However, it perhaps evokes more questions than answers; such as what impacts other music genres, or individualised preferred music might have had on these participants.

Aiming to determine what types of music positively affects cardiovascular health, Trappe (2011) reviewed an undisclosed number of almost entirely bio-medically based studies. Trappe concluded that it is important to consider what to play for related music interventions; finding that classical music (particularly by Bach,

Mozart, or 'Italian composers') showed the most overall benefit overall whilst meditation music was more effective for sedation. Heavy metal and similar music were declared to be:

> "…ineffective or even dangerous. This music encourages rage, disappointment and aggressive behaviour while causing both heart rate and blood pressure to increase. Breastfeeding mothers should avoid this music because there is a negative influence on milk flow" (Trappe, 2011:1871).

While these conclusions are intriguing, they are too simplistic and insufficiently evidenced.

Tang and Vezeau (2010) conducted a meta-analysis of thirty-three music-related studies towards determining which specific populations and medical conditions were utilising music interventions, what specific music was being played, what methodologies and measurements were being used, and the effectiveness of these music interventions. They found that music interventions were being used across diverse populations for alleviating wide-ranging symptoms and conditions, and that the music chosen for these interventions was equally diverse. Tang and Vezeau noted gaps in the literature, including general omissions of information regarding theoretical or conceptual frameworks, and a general lack of rigour primarily due to omission of explanations behind research choices such as the length and frequency of interventions. Most of the reviewed studies also lacked descriptions of, and explanations for the settings of music interventions. Whilst no comments were offered regarding the 'alternative treatments' provided to control groups, very few of the included studies compared truly analogous music interventions.

Regarding people with dementia or people who are nearing death, Tang and Vezeau's meta-analysis suggests that interactive group music interventions might be more effective because interaction and engagement are encouraged. Tang and Vezeau also caution that allowing participants to choose the music that is played can present complexities for researchers due to participants' potentially wide-ranging preferences, and difficulties ascertaining these preferences. However, the studies included in this meta-analysis provide insufficient proof regarding the greater effectiveness of group activities, and do not provide valid reasons for denying any participant the right to choose which music he or she prefers to hear. Rather, it only shows that it is often more difficult to do so when participants have cognitive impairments and difficulties with communication.

B. Music-related research for people who are nearing the end of life

When a person is nearing death, music can be comforting and can also be used to accompany a person through the process of dying; the emphasis is no longer on curing. Indeed, Renz et al. (2005) suggest that:

> "Music is the medium that transcends consciousness and is therefore uniquely able to reach patients within borderline states between life and death" (Renz et al., 2005:962).

This subsection reviews research concentrating on the use of music during this intensely intimate time.

The effects of music on people who are nearing the end of life are under-researched, possibly due to difficulties with recruitment (Bradt & Dileo, 2010) and potential problems obtaining ethical approval. A Cochrane meta-review of music interventions for people nearing the end of life (Bradt & Dileo, 2010) found it

difficult to evaluate existing relevant research due to the considerable diversity of settings, participant medical conditions, people present, and music used during interventions. The few studies I found which focused on the effects of music on the recipient's wellbeing:

Wlodarczyk (2007) explored the effect of music on 'spirituality' with ten hospice patients. Each participant took part in either a thirty-minute interactive live-music therapy intervention or a thirty-minute intervention consisting of no-music. Wlodarczyk concluded that:

> "...spirituality is truly an integral topic to be addressed with terminally ill patients and their family..." (Wlodarczyk, 2007:1999).

This conclusion is difficult to assess, due to its ambiguity.

Using secondary data captured during a single music intervention, Freeman et al. (2006) explored the effects of live harp music played for sixty-five people who were very near to death. Lacking complete primary data for review, speculative results implied that there was a reduction in agitation and that patients were more restful at the conclusion of their intervention. There was no significant effect on participants' pulse rates. As previously discussed, harp music has various connotations for people, which might affect their response, and incomplete data from a solitary intervention makes these findings difficult to assess or to validate.

Horne-Thompson and Grocke (2008) measured and compared the effects of one interactive music therapy intervention with twenty-five terminally ill people with the effects on a similar cohort who were visited by a visitor but who had no music.

Using 'The Edmonton Symptom Assessment System (ESAS)' and pulse measurements, agitation was found to have significantly lowered in those participating in an active music intervention, but pulse remained unaffected. With only solitary interventions of interactive music being compared only with an intervention which included no music, this study's findings are once again difficult to fully assess or validate.

Hilliard (2003) explored the effects of a series of live-music interventions on the 'quality of life' of eighty hospice cancer patients. Half received at least two live-music interventions, with the other half receiving two no-music interventions. Analysing data accrued from self-reports using the Hospice Quality of Life Index-Revised (HQOLI-R)', Hilliard found that participants who received music interventions had a significantly higher 'quality of life'. Whilst this study compared participant responses during two interventions instead of just a single one, the two types of interventions were not truly comparable, and ' quality of life' was not clearly defined. In addition, because this report lacked detail it is difficult to properly assess or validate the findings.

Each of the above studies chose to evaluate the effects of live-music compared with 'no-music'. Exploration of the comparative effects of analogously different music interventions (e.g. live vs. recorded) was not undertaken. Research aims, results, and study methods were also generally rather ambiguous, with the only agreement being that live-music garnered a more beneficial response than no-music, and that pulse-rates measurements apparently did not produce any significant data.

i. Research: music and interaction for people nearing the end of life

Two small studies were identified that explored the effects of music on family members present at interventions conducted near the end of life. Krout (2003) presented five case studies to illustrate how individualised live-music can facilitate communication and emotion between a family member and someone who is terminally ill. Magill (2009) interviewed seven bereaved caregivers who had been present during an unspecified number of music-therapy sessions with terminally ill cancer patients, resulting in four loosely defined propositions: "music is a conduit – music gets inside of us – live-music makes a difference – music is love" (Magill 2009:36).

The lack of research exploring this important topic is emblematic of a general lack of music-related research involving people nearing the end of life. The solitary (Cochrane) meta-analysis focusing on the effects of music interventions conducted near the end of life (Bradt & Dileo, 2010) found only five studies (including two unpublished Master's theses) that met their inclusion criteria (i.e. music interventions conducted by a MT, and involving a control intervention for comparison). Exclusive use of medically-based search engines (MEDLINE, PSYCINFO, CINAHL etc.) may have contributed to Bradt and Dileo's (2010) difficulty in finding relevant studies. Their inclusion criteria also imply a belief that the only 'legitimate' music interventions are those conducted by MTs. This view omits effective music interventions conducted by other appropriately trained practitioners (e.g. music practitioners, family carers, music-thanatologists). Bradt

and Dileo (2010) tentatively concluded that, pending results from 'more conclusive' large-scale RCTs, MT might benefit terminally ill patients.

A literature review of end of life music interventions conducted by two nurses (Black & Penrose-Thompson, 2012) focused on the practical use of receptive music interventions; incorporating brief case studies to demonstrate specific ways that music has been successfully employed to help manage physical, emotional and spiritual pain. Their review also includes examples of the various ways that music (especially familiar music) can facilitate communication between family members and a person who is dying. Citing the Cochrane meta-analysis, Black and Penrose-Thompson echo the call for larger quantitative RCTs.

This overview of research focusing on the effects of music for people nearing the end of life reveals a clear need for further research; especially regarding the effects of music interventions conducted by practitioners *other than* MTs, and also the effects of music on *interaction* during this most intimate of life's phases. There is plainly a need for better-documented studies incorporating truly analogous music interventions aimed at obtaining clearer information about the best use of music in similar situations. I found just two studies (Krout, 2003; Magill, 2009) exploring the effects of music on others who are present during interventions for a person nearing death. Both of these studies were exceptionally small and lacked methodological as well as other important information (e.g. what music was played, for how long, how were participants recruited, etc.), which further confirms the considerable gap in the evidence-base around these important issues.

C. Research: music and dementia

The increasing number of people being diagnosed with dementia (Small et al., 2007; Birch & Draper, 2008 Chatterjee, 2008; Hennings et al., 2010) has generated a considerable upsurge in recognition and interest in the potential beneficial effects that creative arts, and particularly music, can have for people with dementia. This section considers the state of research focusing on the effects of music on people who have dementia, particularly in relation to agitation, wellbeing, and interaction.

i. Agitation

As discussed previously, the high level of agitation frequently expressed by people with advancing dementia may be caused by difficulties in communicating and the subsequent isolation and boredom commonly experienced particularly by people with dementia who are living in care homes (Piechniczek-Buczek et al., 2007; Kelly, 2010).

Individualised music is the most commonly utilised and researched form of intervention for mollifying agitation in people with dementia. Gerdner (2000) pioneered research into the effects of playing individualised music for people with dementia towards reducing agitation. Over an eighteen-month time period, thirty-nine participants with dementia living in a 'long-term facility' received either thirty-minutes of individualised commercially recorded-music or thirty-minutes of classical 'relaxation' music weekly for six-weeks. This was followed by a two-week 'washout' period, and then by a reversal of these interventions. Assessment of participant agitation levels required certified nursing assistants to be trained in

the use of the 'Temporal Patterning Assessment of Agitation' ('TPAA') and the 'Cohen-Mansfield Agitation Inventory' ('MCMAI') observation instruments. Gerdner found that individualised recorded-music more effectively reduced agitation and also had a longer-lasting effect when compared with the provided generic recorded-music.

Ragneskog et al. (2001) also investigated the use of individualised music for reducing agitation as well as for eliciting emotional responses from people with very advanced dementia. Four participants were video-observed during four different thirty to forty-five-minute interventions (no-music; commercial recordings of Pachelbel's Canon with sea sounds; and two sessions of individualised commercially recorded-music). Every participant received four or five repetitions of each type of music intervention. In addition to video-observation, still-camera facial close-ups were taken at five-minute intervals and later analysed using 'Facial Action Coding (FACS)'. This study found that individualised music was considerably more effective than the classical-music intervention; the two participants with the most advanced dementia reacted least to the music; and the music interventions used did not improve a participant's initially bad mood.

Park and Specht (2009) explored the effects of individualised music on fifteen people with dementia living in their own homes. This required training family caregivers to measure agitation levels using an observation instrument ('MCMAI-II'). Researchers prepared and supplied each caregiver with a CD consisting of

commercial recordings of each participant with dementia's preferred music, and a CD player:

> "Each participant listened to recordings of their preferred music for 30-minutes, two times per week for two weeks, followed by two non-music weeks, and then the cycle was repeated once" (Park & Specht, 2009:50).

Agitation markedly decreased during, and for a while after each music intervention.

Sung et al. (2006) looked at the effects of individualised music on agitation in "…institutionalized elders with dementia in Taiwan" (Sung et al. 2006:999). Participants were divided into two groups, one of which (n=32) received thirty minutes of individualised recorded-music twice weekly for six-weeks, while the control group (n=25) received 'usual care' with no-music. Levels of agitation were assessed using CMAI at baseline and at the end of week-six. Agitation levels significantly decreased in participants receiving the music interventions compared with the no-music controls.

Gerdner (2000) mentions the need for more rigorous quantitative testing and the risk of rater-bias as she both conducted the music interventions and analysed the data. The authors of the other three studies cited no limitations. However, a major limitation in the design of the two studies that incorporated comparative music interventions was that they did not compare analogous music. Gerdner (2000) compared the effects of listening to commercial recordings of individualised music with undisclosed music from an album vaguely entitled: "…Meditation – Classical Relaxation…" (Gerdner 2000:55), and Ragneskog et al. (2001) compared the effects of listening to "…a New Age recording of classical music and ocean

sounds..." (Ragneskog et al. 200l: 149) with individualised, commercially recorded-music, and no-music. Individualised music is very likely to be universally preferred to generic 'relaxation' music, especially because (as is discussed in detail later) the listener may not be in the mood to enjoy 'relaxing music' at the time of his or her intervention. Moreover, these researchers seemingly have an agenda, which is at best questionable. Gerdner (2000) states that:

> "A preference of classical music by one subject warranted an alternative selection that included an anthology of instrumental Lawrence Welk music" (Gerdner 2000:55).

This quote implies that Gerdner purposely substituted music that a participant might have enjoyed for a genre of music tha tthis participant was almost certainly *not* going to appreciate! Meanwhile, Ragneskog et al. (2001) report that:

> "If a patient was drowsy during one entire recording, that recording was repeated" (Ragneskog et al. 2001:149).

This statement suggests that 'drowsiness' was for some reason deemed an inappropriate response from listeners.

Ragneskog et al.'s (2001) use of a series of repeated similar interventions makes for more credible findings. However, four participants is quite a small study sample. There is a risk that within such a small total number of related studies, apparently negative findings based on extremely tiny numbers could have unhelpful future repercussions regarding access to similar interventions for people within similar populations (i.e. people with more advanced dementia). The authors also provide little information regarding what happened during the 'no-music' interventions, and precise details regarding the content of the commercial recordings are also lacking.

The use of repeated interventions also makes Park and Specht's (2009) findings more credible. However, whereas involving carers in research can be beneficial for the carer, the design of this study risked causing additional stress for caregivers required to be trained and to conduct what appear to be fairly intensive observations. It is also nearly impossible to evaluate how rigorous their observations actually were, as these observations were unmonitored.

Gerdner's (2000) decision to both conduct the music interventions and analyse all of the data herself without using an interrater for greater reliability seriously weakens the credibility of her findings. This research design limitation is particularly pertinent because of its similarity to the research design of this present study. Further discussion of how this design limitation is addressed in this present study can be found in the chapters that follow.

Though all of the above studies concur that (individualised) music effectively reduces agitation, numerous and sometimes substantial design limitations mean that there remains a significant gap in the research literature regarding what it is precisely about music that can successfully reduce agitation in listeners who have dementia.

ii. Wellbeing

'Wellbeing' is another frequent aim of studies involving the creative arts and people with dementia. 'Wellbeing' has been defined as:

> "How a person derives meaning from their everyday activities...happiness and life satisfaction...being involved in activities that are personally meaningful and valued..." (Sixsmith & Gibson 2007:129).

This subsection provides an overview of music-related research focusing on the effects of music on the wellbeing of people living with dementia.

Sixsmith and Gibson (2007) conducted in-depth interviews with twenty-six people with dementia to learn more about the impact that music had on their 'wellbeing'. These interviews occurred in community-dwelling and residential settings, with carers occasionally present. Most participants reported that they enjoyed music "...to the extent of 'being lost' in its hearing" (Sixsmith & Gibson, 2007:132), and that music promoted interactions via non-verbal communication including physical touch. These findings affirm the potential impact that music can have on the wellbeing of people how have dementia.

Holmes et al. (2006) compared the effects of live-music, recorded-music, and silence on thirty-two people with dementia who were all considered particularly prone to apathy. Both music interventions consisted of:

> "...a mixture of favourite songs appropriate to the age group, including music from the swing era, popular classics and Scottish dances" (Holmes et al., 2006:625).

One live and one recorded-music intervention took place in a public area within a residential home, and each lasted for 1.5 hours. Each participant was filmed for thirty-minutes with the sound muted during these interventions. The resulting video-footage was analysed in three-minute segments using Dementia Care Mapping (DCM) (Bradford Research Group, 1997). Researchers found that live-music was the most effective at rousing listeners, particularly those listeners who

had severe dementia. The authors reported regretting having muted the video recordings, as this prevented their being able to hear verbal reactions. They also speculated that perhaps simply watching a live-musician could have accounted for the greater responses to the live-music. This is difficult to assess as only one intervention of each type was conducted.

Because 'wellbeing' is a rather abstruse expression, it is difficult to evaluate the credibility of the findings of these studies.

iii. Interaction

Although interaction is widely considered an indicator of 'wellbeing', just two studies were located that considered the potential of music to enhance interactions involving a person with dementia.

Sherratt et al. (2004a) looked at the perceived quality of social interactions between twenty-four people with mid-to-advanced dementia, and also between each person with dementia and attending staff members. Four types of interventions (no-music; preferred commercially recorded-music; the same music pre-recorded by a singer-guitarist; and the same music played live by the same singer-guitarist) were conducted. Participants were divided into five small (n=8) groups based on musical preferences and received one-hour each of all four types of interventions. There was a 1:1 ratio of observers to participants and all interventions were recorded and analysed using 'continuous time sampling (CTS)' (Sherratt et al. 2004a). Researchers found that live-music evoked the most

interaction and had the longest lasting effect, followed closely by both types of recorded-music.

The design of this study is noteworthy because of its use of analogous music interventions (i.e. same or similar music played by the same musician pre-recorded and live). However, the other two interventions (i.e. no-music and commercial recordings) were not analogous; no information was provided regarding the musical background or training of the musician; and there was no detailed information regarding the chosen commercial recordings. The authors cited limitations regarding the ability of CST to pick-up the more subtle responses of participants; video-observation might have proven more useful as researchers could have revisited their original observations. Conducting individual interventions that included one person familiar to each person with dementia may have also provided clearer information about the effects that the different interventions had on interaction. The authors also do not address possible participant bias due to participant's increased familiarity during their latter interventions.

Clair (2002) focused on music's effects on interactions between a person with advanced dementia (i.e. no longer able to verbally communicate) and their spousal caregiver. Eight dyads participated in eight weekly, forty-minute interventions. A music therapist conducted each videotaped intervention, which took place in the same private space, at the same time each week. Interactive music interventions based on the preferences of each couple were utilised: some selected dance (e.g. commercial recordings of each couple's preferred music), others chose singing (e.g. live singing initiated by the music therapist). Interactions increased

throughout the series of music interventions, and sometimes this increase in interactions continued during subsequent non-music interventions. The main limitation cited by the author was the small-scale of this study. This is an excellent study in many ways, and one of very few focusing on interactions between a person with dementia and their carer. There is however no mention of possible dyad bias during latter repetitions of their interventions. Also, the two types of music interventions used during this study do not necessarily account for people with advancing dementia who may no longer be able to dance or sing.

These two studies represent some of the strongest research involving the effects of music on interactions involving a person with dementia, due to their use of somewhat analogous music and repeated interventions, well-described methods, and clear reasoning for the methods chosen. These studies also illustrate the potential for music to appreciably enhance and perhaps facilitate interactions involving people with dementia. This is important because the most commonly cited difficulties related to caring for someone living with dementia are barriers related to communication.

8. Conclusion

This chapter situated this present study by providing background about the use of music as an agent for 'healing' and curing' and explanations of the aims and intentions of, and the training for, various types of music practitioners. This chapter also defined two physiological listener responses to music; 'entrainment' and the 'iso-principle', and described how they can affect music listeners; sometimes to the point of listeners experiencing 'flow' or an 'IME'.

The remainder of this chapter helped locate this study within related music research by presenting and assessing prior research regarding the effects of music for various physical medical conditions, for people nearing the end of life, and for people with dementia. In addition, it considered research exploring the effects of music on interactions involving people nearing the end of life, and people with dementia.

Alongside dementia swiftly coming to the forefront of society's attention, there has been a commensurate upsurge in dementia research. Arts-based and especially music-based interventions show great promise, particularly for effective palliation of the psychic and emotional pain linked to the 'challenging behaviours' frequently expressed by people with advancing dementia, for reducing apathy, and for generally improving wellbeing.

As can be appreciated from this review, there is much still to be learned about how music can most effectively be utilised for people with dementia, people nearing the end of life, and for enhancing interactions involving people from within these two growing populations. Despite Von der Geer et al. (2009) equating the effect of music on people with dementia to that of frequent interpersonal contact, there is little research exploring its effects on interactions between people with dementia and those who care for them. The recognised stress that people with dementia and their carers experience due to difficulties with communication, and the possibility that music might facilitate connections between people with advancing dementia who are nearing the end of life, and their carers makes this an especially crucial

topic for further study. There has been no prior research considering the effects of music on interactions occurring within the triadic configuration commonly found within dementia care, and this too warrants examination.

The aim of this present research is to add not only scientific, but also practical knowledge towards filling the noted gaps in related research. With this in mind, the following research questions guided this study:

- **What effect does individualised live or recorded-music have on a person with dementia who is in their final phase of life?**
- **What effect does individualised live or recorded-music have on their carers?**

  How does individualised live or recorded-music affect the level or quality of interaction within each participant dyad?

The next chapter details the methods chosen to address these research questions, as well as providing explanations for the specific methods selected.

CHAPTER 4. METHODS

1. Introduction

Developing a research design for this study required delving into a sizeable volume of literature, in order to learn from past researchers successes and failures, whilst also gaining knowledge of different methodological frameworks previously utilised within related research. 'Phase-1' of this study consisted of seeking the insights and recommendations of people with expertise in relevant topics via semi-structured interviews. The design of this present study evolved to include playing music tailored to the individual preferences of each participant with dementia ('resident'). Six music interventions were conducted in the resident's private-bedroom. Three consisted of live-music, and three consisted of recorded-music. The music was the same or similar for each of the six interventions, and was all played by me on solo cello. Each intervention was shared by a 'carer', who was someone identified as having a close connection with the resident. The targeted length for each intervention was thirty-minutes. All interventions were video-recorded for later analysis.

This chapter is divided into four major sections: the first describes the methodological frameworks guiding the design of this study; the second section details and explains the reasoning behind each phase of the study design; the third section details and explains the reasoning behind the methods employed for analysis of the accrued data; the final section reflects on the barriers, limitations, and general knowledge acquired through implementation of this study design.

2. Influential methodological frameworks and guidelines

A. Complex interventions

The Medical Research Council's (MRC) guide to evaluating complex health interventions describes complex interventions as being comprised of "…a number of components, which may act both independently and inter-dependently" (MRC, 2000:2). This present study included several interrelated 'components': live and recorded-music; residents and carers; myself as both researcher and musician; issues surrounding dementia; frailty; end of life; and care homes. Although the MRC guidelines are mainly aimed at providing guidance towards the design of larger randomised trials of complex medical interventions, many suggestions were applicable to this present study: e.g. maintaining a flexible approach throughout the research process, and counsel regarding not taking a generic approach towards designing a complex intervention (MRC, 2006). These guidelines also emphasise the importance of piloting innovative approaches to complex interventions, which led me to view this study as a springboard towards informing future larger-scale related studies.

B. Realist evaluation

Realist evaluation (RE) is a theory-driven methodology originally developed for evaluating complex social-policy interventions and programmes. It is based on the enquiry: "What is it about this kind of intervention that works, for whom, in what circumstances, in what respects and why" (Pawson et al., 2005:31). RE takes a more iterative approach towards complex interventions compared with the MRC guidelines discussed above. Whilst they both suggest a sequence of steps or phases

towards successfully researching a complex intervention, RE invites and combines the uncertainties and complexities of human interactions with the hypothetical theorising methodology of the natural sciences (Pawson & Tilley, 1997). This means that a 'programme' (e.g. individualised live or recorded-music) is administered without any expectation of a specific 'outcome' (Pawson & Tilley, 2005), or simply for obtaining more scientific knowledge. Instead, RE aims to improve and change practice (Pawson & Tilley, 1997). The RE custom of using multiple qualitative and quantitative methods (Pawson & Tilley, 1997; Pawson & Tilley, 2005), and of consulting key stakeholders during the formative stages of a study (Pawson & Tilley, 1997; Pawson & Tilley, 2005) also informed the design of this present study.

Critics of RE contend that it is time-consuming, and that one of its pivotal components; 'mechanisms', is not clearly defined (Marchal et al., 2012). There is also considerable debate between proponents of 'randomised controlled trials (RCTs) and proponents of RE. RCTs focus on results from research conducted within rigidly controlled environments, whilst RE research is conducted in the natural and thus uncontrollable environments of real-life (Bonell et al., 2012). However, there is growing momentum towards discovering ways that the main principles of RE might work in combination with RCT methodologies to create better evidenced, less limited, and more inclusive 'gold-standard' models of social research (Bonell et al., 2012).

C. Ethnography

Originally employed exclusively within anthropological research, ethnographic methodology refers to research requiring extensive time spent at field site(s), observing and engaging with small numbers of people within their 'natural' environment (Silverman, 2000; Hammersley & Atkinson, 2007; Bryman, 2008). Primarily aimed at learning first-hand about a culture and how people behave within that culture, ethnography has been described as "...an ambitious journey through the complex world of social interaction" (Fetterman, 1998:ix). Thus, ethnographic fieldwork usually encompasses a number of complex elements such as negotiating access via gatekeepers, ethical issues, recording live observations, plus interpreting and managing large amounts of qualitative data (Hammersley & Atkinson, 2007). Long stints in the field engaged in participant observation are the mainstay of ethnographical research, but equal value is also given to frequent visits to fieldwork sites (Jeffrey & Troman, 2004). This is particularly relevant to fieldwork at care homes, where building trust and establishing relationships with staff and residents requires repeated contact (Dewing, 2009; Wilson et al., 2009; Davies et al., 2010). Both approaches to fieldwork permit the ethnographer to obtain a deeper understanding of fieldwork sites and the people living within those sites, resulting in greater integrity in their findings (Creswell, 2009). Atkinson and Hammersley (2007) describe ethnographers as being:

> "... simultaneously concerned to make the strange familiar, so as to *understand* it, and to make the familiar strange, so as to avoid *misunderstanding* it" (Hammersley & Atkinson, 2007:231).

Like RE, ethnography is based on the idea that similar stimuli can evoke different responses or engender different meanings within each individual, and that the same person may also respond differently to the same stimulus at different times (Hammersley & Atkinson, 2007). Ethnography and RE also share the key aim of increasing knowledge for the sake of knowledge, rather than seeking or expecting positivist outcomes (Pawson et al., 2005; Hammersley & Atkinson, 2007). 'Participant observation' (PO), is a core method used in ethnographical research, which requires researchers to be closely connected with the people who are being observed (Fetterman, 1998).

While not strictly adhering to any of these three conceptual or methodological frameworks, pertinent aspects of each one helped inform the methods chosen for this present study. All three frameworks suggest the need for the researcher to remain flexible and resilient, and to apply a mixed-methods approach. RE and ethnography are founded on the importance of obtaining greater knowledge, and taking the time necessary to obtain an empathetic understanding of observed participants. Ethnography advocates researchers to become 'participants' while at the same time maintaining an observational stance. In essence, the principles of ethnography and PO guided the fieldwork phase of this study (e.g. fieldnotes, live observations as an active participant, and extensive time in the field), whilst the principles of RE helped provide a framework for understanding what I saw during the video-analysis phase or, 'what worked for whom in what circumstances'. The following subsections detail the specific methods chosen for this study.

3. 'Phase-I': key-consultant interviews

This thesis encompasses several distinct, complex and intangible concepts, including 'music'; 'dementia'; 'relationship', and 'the final phase of life'. As advocated within all three of the frameworks discussed above, I conducted open-ended interviews with fifteen experts in areas related to these topics before formally designing the core phase of this study. Relevant comments and suggestions are included throughout this thesis, with a 'C' followed by their identification number used to designate each consultant. Table 4.1 below provides a brief overview of the key-consultant's specialty background.

Table 4.1: Phase I participants

Identifiers	Grouping - Occupation/Specialty
C1 – C4 – C5 – C10 – C12 – C15	Academics: professors and senior lecturers specialising in dementia – dementia care – elderly care – care homes – older people – mental health – end of life – disability.
C2 – C3 - C7 – C11 – C14	Senior researchers: specialising in neurology and music therapy – music therapy and end of life/palliative care – music and dementia – communication with people with various communication impairments – dementia.
C3 – C6 – C9 -	Therapists: music and end of life/palliative care – creative arts and dementia.
C13	Group of people living with dementia who actively campaign and contribute to research involving people with dementia.

4. Research Design

The research design for this present study, the methods chosen to complete each of the phases, and the context for why these methods were chosen are presented in the following subsections. A table summarising the phases of this study can be found in the appendices (see Appendix 6.A).

A. Fieldwork sites

All fieldwork was conducted within care homes in rural Scotland. Although there is increasing importance being put on keeping people living in their own homes, most people with dementia who are in their final phase of life tend to reside in care homes (Living and Dying Well, 2008). It took approximately five-months to identify twelve eligible residents in five care homes. Although most contacted care home managers expressed interest and support for this study, very few were able to identify residents meeting the inclusion and exclusion criteria set for this study (see below), in combination with the strictures set by the Scottish REC-A as is presently discussed.

i. Research in care homes

Previous research suggests that the leadership and attitude of each manager generally informs the ethos of the entire care home (Froggatt & Payne, 2006; Harmer & Orrell, 2008; Dewing, 2009; Wilson, 2009). Integrating into the distinctive 'social community' of each care home generally takes considerable time, involving regular and repeated interactions with all residents, families, and staff; regardless of each person's direct involvement with the subsequent research (Dewing, 2009). It is wise for researchers to be mindful that:

> "Care homes are complex social environments. They are places where people live, work and visit: and these people are continually changing" (Wilson et al., 2009:78).

Recruitment within care homes; particularly recruitment of participants with dementia who are especially frail, requires substantial time and perseverance (Davies et al. 2010): Table 4.2 below provides an overview of the recruitment

process for this present study, followed by a series of subsections elaborating on this process.

Table 4.2: Phases of recruitment

Task	Purpose	Process
Identify and make initial contact with potential care homes.	To determine which care homes within a reasonable radius of my home would be willing to consider being part of this study.	Ask colleagues familiar with nearby care homes. Read inspection reports for nearby care homes. Prepare an introductory letter (including a self-addressed stamped envelope and brief contact form) to send to care home managers. Followed-up with a varying number of phone calls to care home managers.
Provide information packets for care home managers.	To introduce the study and myself to the family of each prospective resident - to obtain initial family signed consent - to obtain contact details for potential carers.	Prepare a letter of introduction - information sheet – consent form – potential carer contact information form – self-addressed stamped return envelope for each identified potential resident participant to be sent out by care home managers.
Multiple informal visits to care homes residents.	To become familiar to and with each potential resident participant.	Informal visits within the communal areas of each participating care home – occasionally including my playing cello.
Obtain consent from residents and carers.	To obtain informed direct signed consent from each participant.	Conducting an extended meeting in a quiet space, using appropriately designed information sheets and consent forms for residents (see appendix 2&3), with a staff member present to witness and sign each resident's consent form (direct informed consent).

ii. Ethical approval and vulnerable populations

The ethical issues involved with including people living with dementia presents major obstacles for researchers (Calveley, 2012). Though the scope of this thesis does not permit the extensive discussion merited for this important and complex subject, this subsection presents some background and discussion of the ethical issues directly related to this study.

Similar to the goals of ethnographical research, a this present study sought to amplify "…the voices of those on the social margins…" (Hammersley & Atkinson, 2007:97). My intention to include people who were deemed to be particularly vulnerable due to their having dementia and also being considered to be within the last six-months of their life, justifiably required compliance with stringent ethical rules and oversight. Thus I was required to seek and obtain ethical clearance from the highest level of ethical 'gatekeepers' (Dewing, 2009:235) for researching people from 'vulnerable' populations within Scotland; The Scottish National Research Ethics Service (NRES). This necessitated my completing a lengthy and detailed 'Integrated Research Approval System' (IRAS), and defending my application before a NRES committee meeting composed of lay people and professionals. Despite my assertions regarding the importance of including people from this growing segment of society, the very low risk involved, the very high chances for benefit, and the potential benefits that findings from this study might have for people within similar populations (Adults with incapacity Act http://www.legislation.gov.uk/asp/2000/4/part/5: 51.4), I was only granted permission to include people able to provide *direct* informed consent. This decision meant that a number of residents that had previously been identified by

care home managers and staff or families could not participate in this study because he or she lacked the ability to provide direct informed consent. This also meant that the recruitment process was considerably more difficult and time consuming, because identifying care home residents believed to be within the final six-months of life, whose dementia had not advanced beyond an ability to provide direct informed consent proved quite difficult. My experience concerning obtaining ethical approval corroborates Dewing's (2009) observation that:

> "...the process researchers are expected to undertake in research submissions, particularly in relation to ethics, may limit creativity...necessary for developing alternative consent methods where persons with dementia are excluded from informed consent" (Dewing, 2009:236).

Upon hearing about the NRES ethics committee's decision, C1 commented:

> "...there's almost more of a moral imperative...to find ways of connecting and communicating with people [who are unable to give informed consent] than there is...with people who can give fully informed consent and can therefore probably achieve a better quality of life on their own behalf anyway. What a shame..." (C1, 2011).

Whilst this topic is revisited later in this thesis, the importance of providing opportunities for people who are most often disregarded for inclusion in research, whose 'voice' is seldom heard, and who are least likely to benefit from more standard forms of care home entertainments and activities, cannot be overstated. And there is no better opportunity than in a study such as this, where there is virtually no risk of harm and every possibility of benefit for those who take part.

iii. Inclusion and exclusion criteria

The inclusion and exclusion criteria for this study are presented below. The purposes of these criteria were to simultaneously demarcate the targeted study population, while maintaining as much inclusivity as possible.

Inclusion and exclusion criteria for residents

Inclusion criteria:
- Have a diagnosis of dementia
- Deemed by care home managers to be in his or her last six-months of life
- Able to provide direct informed consent
- Have someone closely connected with them that meet carer criteria listed below
- Have access to a private room
- Have some level of hearing
- Use English as their primary language

Exclusion criteria:
- Have no awareness of his or her surroundings (Murphy et al., 2005)
- Unable to provide direct informed consent
- Is profoundly deaf

Inclusion and exclusion criteria for carers

Inclusion criteria:
- Identified as someone familiar to and connected with a resident participant
- Able to provide direct informed consent
- Have some level of hearing
- Use English as their primary language

Exclusion criteria:
- Unable to provide direct informed consent
- Is profoundly deaf

a. Determining a resident's dementia diagnosis

Because many people currently living in care homes may not have an official diagnosis of dementia (Scotland's National Dementia Strategy, 2013), I relied on the opinion of care home managers regarding the dementia status of residents (Aragon et al., 2002; Sixsmith & Gibson, 2007). Thus, if a resident met all other inclusion and exclusion criteria, I sought the opinion of care home managers, or occasionally a senior nurse staff regarding a prospective resident's dementia status as the final word on their eligibility pending consent. As per the REC

stipulations discussed above, all residents were able to provide direct informed consent as detailed below.

b. Determining whether a person is nearing the end of life

While medical professionals generally concur about some indications that a person is nearing death (Shega & Tozer, 2009; Makery et al., 2010), no one truly knows precisely when a person will die and this trajectory can be especially difficult to determine for someone who has dementia (Burgess, 2004; Chatterjee, 2008). Consequently I decided to apply a modified version of the 'surprise question' (Moss et al., 2008), meaning that I asked care home managers whether he or she would be surprised if the resident in question died within the following six-months. The original 'surprise question' extends these parameters to one-year, which I modified because I wanted to concentrate on people who were truly in the final stage of his or her life,, and a year seemed too broad a timeframe.

c. Inclusion and identification of a carer

In this study, 'carer' refers to a person who cares *about*, but was not necessarily *actively* caring *for* a care home resident with dementia (Henning et al., 2013). Family carers frequently report feeling disoriented after a family member has moved into a care home because they have essentially lost their familiar 'role' as carer (Henning et al., 2013). Inviting a carer to share interventions with their family member thus provides the possibility for him or her to share 'expert' knowledge of a resident by helping to interpret the sometimes idiosyncratic gestures expressed by a person with dementia (Downs, 2013; Hydén, 2013). This can also help carers to feel valued and useful (Nolan et al., 2003; Smith, 2005). Inclusion of a carer also provides an opportunity for a unique shared experience to

unfold between the carer and their family member (Ryan et al., 2008). As discussed previously (see chapter 3.7.C.iii), very little research exploring the effects that activities shared by a person living with dementia and their 'carer' have previously been conducted.

iv. Consent

Having successfully identified residents and carers meeting this study's inclusion and exclusion criteria, the last phase of recruitment was the consent process. Table 4.3 below provides an overview of the rather complex consent process involved for this study, followed by an explanation of this process.

Table 4.3: Consent process

Task	Purpose	Process
Care home manager signed consent.	To ascertain that care home managers were fully informed about this study and to obtain full permission to conduct my fieldwork on their premises.	An extended meeting with each care home manager to review information sheets and sign consent forms.
Signed consent from families of potential resident participants.	To inform the family of each resident about this study and obtain their permission to approach and invite their family member to participate in this study.	A packet including a letter of introduction - information sheet – consent form – potential carer contact information form – self-addressed stamped return envelope to be sent out by care home managers.
Witnessed direct informed signed consent: resident.	To fully explain this study to each resident and obtain his or her direct, informed, signed consent as witnessed by staff member.	Extended meeting in a quiet space - specifically designed information sheets and consent forms (see appendix 2&3). Signed by resident and by witnessing staff member.
Signed consent: carer.	To fully explain this study to each carer and obtain his or her signed consent.	Extended meeting in a quiet space with each carer for review of information sheets (see appendix 2&3) and signing the consent form.

Having obtained signed permission from a prospective resident's family, I began informally visiting and spending time with each resident within the communal areas of her or his care home (Davies et al., 2010). These visits generally started with me introducing myself and asking if it was okay for me to sit and chat for a while. If this was acceptable, we would engage in varying levels of unstructured interactions, and I occasionally played my cello during these visits for all who were sitting in the communal area. As I only initiated the consent process when I felt a resident had become sufficiently familiar and comfortable with me, the number of these visits varied. In ethnographical research this process is known as, 'selective intermittent time mode' (Jeffrey & Troman, 2004), and allows time for relationships to develop and to foster better collaboration with participants.

The formal direct consent process for each resident occurred either in his or her private bedroom, or in another quiet part of the care home. A member of staff was always present to witness and sign the consent form confirming that the resident understood what was required during this study, was consenting of her or his own freewill, and comprehended that he or she was free to discontinue at any time (Cameron & Murphy, 2006). The resident information sheet and consent form were tailored specifically towards easier comprehension for a person with dementia (see appendix 2.B & 3.A), and each resident was allotted whatever time required to fully review and ask any questions they had before signing the consent form (Cameron & Murphy, 2006). This consent process addresses the IRAS ethical guidelines stating that each consenting participant must:

• Understand the purpose and nature of the research.

- Understand what the research involves, its benefits, risks and burdens.

- Understand the alternatives to taking part.

- Be able to retain the information long enough to make an effective decision.

- Be able to make a free choice.

- Be capable of making this particular decision at the time it needs to be made (IRAS, 2009)

'On-going consent' was also verbally reaffirmed with every participant prior to the start of each music intervention (Hubbard et al., 2003b; Cameron & Murphy, 2006; Allbutt & Masters, 2010; Astell et al., 2010).

Upon successfully obtaining a resident's consent, I next contacted their prospective carer, and if amenable, I met and conducted a similar (non-witnessed) consent process with him or her using more detailed information and consent forms (see appendix 2.A & 3.B).

Having explained the recruitment process and the impact that the NRES decision regarding direct informal consent had on this process, the following subsections describe my methods for collecting fieldwork data.

B. Data-collection

The complexity of the topics involved in this study necessitated a multifaceted approach to data-collection in order to obtain a comprehensive understanding of how both versions of the music affected not only each individual listener, but also interactions between listeners. The following subsections detail methods used for fieldwork data-collection, which consisted of interviews; fieldnotes; video

observation; biomedical measurements; and visual analogue scales (VAS). A table summarising the data-collection methods used in this study can be found in appendix 6.B.

i. Interviews

I conducted initial and exit interviews with each carer (occasionally joined by their resident partner), and whenever it was feasible, with key staff and managers once all the interventions had concluded. I conducted most of these interviews in person, though some were conducted via the telephone. As with most interviews conducted during ethnographical research, those I conducted with carers and staff were fairly 'informal', meaning that I did not follow a strict agenda. Instead I had a brief list of topics I hoped to cover during each interview (see appendix 8). Topics included carer and staff expectations of the study, personal experiences during the interventions, differences experienced by carers during their live and-recorded music interventions, anything unexpected that occurred, and staff perceptions of the study and its effects on residents (Fetterman, 1998). This interview approach allowed each interviewee the opportunity to express whatever she or he considered significant. Interviewing participants is a central part of ethnographic research (Fetterman, 1998), as it allows researchers to collect additional data that can help inform participant observations (Hammersley & Atkinson, 2007).

ii. Fieldnotes

After each care home visit, I sat in my car and wrote detailed notes about everything I had just experienced. Best written as soon as possible after daily fieldwork (Fetterman, 1998; Hammersley & Atkinson, 2007; Bryman, 2008), Fetterman (1998:114) describes fieldnotes as "...the brick and mortar of an

ethnographic edifice." Fieldnotes are considered vital to ethnographical research because they significantly aid the researcher to remember details of the day's fieldwork that would otherwise likely be forgotten, and also allow the researcher to reflect on how these observations and experiences relate to the current research process (Hammersley & Atkinson, 2007). The process of sitting in my car writing my fieldnotes afforded me an essential way of debriefing and un-picking events that had taken place during interventions; particularly as I was so actively involved during these interventions. Entering my hand-written fieldnotes into my computer each evening further helped me to debrief from that day's experiences; often prompting deep sleep full of images from the day's work.

iii. Participant observation

'Participant observation' (PO) relies on more direct participant involvement than is typically practiced in standard qualitative research as the researcher, "...enters into conversation with some or all of the participants...and discovers their interpretations of the events he has observed" (Becker, 1958:652). I welcomed and indeed encouraged all participants to engage with me throughout this study through soliciting their feedback, suggestions, frustrations etc. Primarily considered an ethnographical tool (Fetterman, 1998; Hammersley & Atkins, 2007; Bryman, 2008), PO is also central to 'Symbolic Interactionism' (SI), because of SI's belief that in order to truly understand a participant, the researcher has got to get inside a participant's experience; to step into his or her shoes (Blumer, 1969). Put another way, SI believes that; "as the anthropologist will live with a tribe in New Guinea, so the interactionist will find and live with a social group in her own country" (Craib, 1984:71).

Some ethnographers use PO to, "...describe and analyse the behaviour of those studied as it would occur without the observer's presence" (Whyte 1989:369), and caution researchers that engaging in regular interactions with participants may cause them to over-identify with their participants, or 'go native' (Bryman, 2008). Conversely, proponents of PO feel that the manner in which a participant reacts to the researcher, and changes that may occur throughout a study, should be viewed as enlightening rather than obstructive, because these changes can inform future research methods and lines of enquiry (Hammersley & Atkinson, 2007). As will presently become apparent, while I did not strictly use PO, it informed my approach of allowing interactions to unfold naturally between participants and myself, and learning from the various changes in interactions that occurred.

iv. Video-observation

Each intervention was video-recorded using two very small video cameras mounted on tripods: one zoomed in on the resident's face to capture facial expressions; the other zoomed out to ideally capture the full-bodies of both dyad participants (Clayton et al., 2005; Husebo et al., 2007; Ersek et al., 2010). These two perspectives were employed to address the communication difficulties common to people with dementia and because it allows for greater flexibility and depth, and the opportunity for the researcher to more effectively assess observed communications (Becker & Geer, 1957; Hubbard et al. 2003b; Götell et al. 2009; Coaten & Newman-Bluestein, 2013).

Ethical concerns regarding participants becoming upset by the presence of video cameras have been mitigated (Lomax & Casey, 1998; Clair, 2002; Götell et al., 2009). Though some researchers posit that participants' apparent indifference to being videotaped might actually be, "...an active state of not paying attention" (Lomax & Casey 1998:2.3), 'non-controllable' behaviours such as, "...head nodding, gestures, foot movements..." can be seen as an indication of the level of unselfconsciousness participants' experience when being video-recorded. Lomax and Casey (1998) state that video-observations "...create and define the event and are therefore fundamentally part of knowledge production" (Lomax and Casey 1998:8.5).

Given the above arguments; particularly the assurance that video-cameras tend to not cause upset to participants, video-observation proved invaluable for this study - especially as I was both the sole researcher and the only person providing the stimulus of music during the interventions.

v. Biomedical measurements

Aiming to add an additional perspective regarding the effects that music might have on participants during their interventions, I decided to measure the blood pressure and pulse of each participant before and after each music intervention via a simple arm-cuff electronic monitor. Though this is not a particularly invasive procedure, the anxiety that some residents expressed, coupled with the difficulty registering measurements from some of the more frail residents, impelled me to quickly curtail conducting these biological measurements with residents. Although some music-related studies (Lee, 2005; Freeman et al., 2006; Horne-Thompson &

Grocke, 2008) found pulse was unaffected by music, Khalfa et al. (2008) suggest that pulse and blood pressure measurements are a reliable, simple to administer, non-invasive, and inexpensive means of gauging of effects of music.

Consultants 2 and 3 cautioned that it would be nearly impossible to pinpoint probable causes for changes in biological measurements; and although I continued taking these fairly nonintrusive measurements from carers, I felt they introduced an unwelcomed and unnecessary sense of a 'laboratory experiment' into these interventions.

vi. Visual Analogue Scales (VAS)

Intending to obtain a 'snap-shot' of the cumulative effect that these music interventions had on each participant's mood, I requested that each participant complete four VASs prior to their first, and subsequent to their final music intervention. Each VAS consisted of a horizontal line anchored at each end by two descriptively extreme words ('worst-best' or 'least-most') between which, the participant was asked to draw a pen-mark indicating their present experience of each of four mood-states: anxiety, apathy (e.g. boredom), depression, and wellbeing (Kertzman et al., 2004). When used for their original intent of self-reporting pain (McDowell et al., 2006; Pautex et al., 2006), researchers have found VAS to be simple and reliable (Boer et al., 2004; Couper et al., 2006; Davey et al., 2007). VAS have also been utilised effectively for the self-report of mood-states (McDowell et al., 2006), and have been shown to be reasonably reliable for self-reporting of various mood-states by people with dementia (Kertzman et al., 2004; Pautex et al., 2006).

vii. Data security

The following steps were taken to ensure that the personal identity and details of every person involved in this study were protected:

- Real names of all persons referred to within this thesis have been replaced with pseudonyms.

- All care home names have been replaced with pseudonyms.

- All audio recorded interviews and video-recorded interventions were only viewed by me, with some brief clips also viewed by my academic supervisors.

- Storage of personal data on manual files was stored in a securely locked archive facility. All identifying information on these files was removed and identified only by pseudonyms.

- Data stored on my university computer was only accessible by me as sole researcher.

- This computer could only be opened and accessed by a password that I was sole possessor of.

- All data was anonymised and all identifying information removed before data was used on any portable device.

- All computer files were stored on password protected network drives.

- All audio and video recordings were kept in password-protected files.

- Any files that were loaded into software for direct analysis were anonymised beforehand.

- All demographic data was kept separately from the names of those who supplied it; in password protected files.

C. Music interventions

Each intervention was targeted to last for approximately thirty-minutes, and consisted of each resident's preferred music played by me on the cello; either live or via a pre-recorded CD. The next set of subsections detail the intervention format used for this study as summarised in Table 4.4 below:

Table 4.4: Phases of music interventions

Task	Purpose	Procedure	Time-frame	Comments
Contact care home.	To alert staff so that each resident was ready for their intervention.	Phone care home.	Approximately one-hour prior to a resident's scheduled intervention.	For various reasons I was not always able to phone, and messages were not always conveyed to relevant staff.
Locate resident in care home.	To reintroduce myself to the resident.	Reintroduce myself and seek their permission to enter their private bedroom to set-up for their intervention.	Approximately fifteen-minutes prior to each intervention.	
Set-up for intervention.	To have the room prepared before inviting the dyad to enter.	Arrange seating for participants, set-up video cameras, position my stool, music stand and cello, or the CD player and speaker.	Approximately fifteen-minutes prior to each intervention.	Some residents were in wheelchairs, or had small rooms; meaning that I did not always successfully capture the entirety of both dyad members' bodies.
Invite participants to the intervention.	NA	NA	NA	Sometimes a resident was hesitant about leaving the communal areas; Elspeth refused two music intervention invitations.

Task	Purpose	Procedure	Time-frame	Comments
Take blood pressure and pulse measurements from carers.	To determine if these biological processes were affected by the music.	Use a simple cuff to measure both blood pressure and pulse before playing music.	Approximately three-minutes.	I initially also took these measurements from residents.
Reintroduce the 'rules' of the study.	To remind residents that they had control of the music and could respond in any way they wished.	NA	A few minutes.	I reiterated these 'rules' occasionally throughout each intervention.
Play individualised music on the solo cello: live or pre-recorded.	To explore and compare the effects of live and recorded-music on individual participants and on interactions.	Approximately half the dyads started with three recorded-music interventions, and half began with three live-music interventions.	+- Thirty-minutes.	Some of these music interventions lasted significantly longer or shorter. Not all dyads and not all the same carers participated in six interventions.
Take blood pressure and pulse measurements from carers.	See above.	See above.	Approximately three-minutes.	I initially also took these measurements from residents.

i. Individualised music

I endeavoured to play music specifically tailored to each resident's tastes, primarily because prior research (Gerdner, 2000, 2009, 2010; Sherratt et al. 2004a; Park & Specht, 2009; Sakamoto et al., 2013), and 'phase-I' consultants (C7, C3, C1) indicate that preferred familiar music is particularly effective for listeners who have dementia. As there were *two* people's musical tastes to be considered during each of this study's interventions, I resolved to keep the focus on each resident's musical tastes, and hoped that some musical preferences might intersect, or that each carer would nevertheless benefit from sharing this experience with someone with whom they were closely connected.

Determining a person with advancing dementia's personal music preferences is usually complicated, often necessitating numerous stages. I began by administering a modified version of a musical preference questionnaire developed by Gerdner (2000) (see appendix 5.B) to each carer, and when possible, also to each consenting resident. I also sought additional input from family and relevant staff members (Ragneskog et al., 2001; Götell et al., 2009). Sometimes these two steps provided enough information for me to develop a good idea of a resident's musical preferences. For others I employed a method used by Clair (2002) and suggested by C1; frequently visiting a resident armed with recordings of popular music from roughly the era when he or she would have been about sixteen to eighteen years of age; and either playing bits of tunes, or simply naming tunes while attentively watching his or her responses (Götell et al., 2009). I also conducted mini-pilot interventions with some residents, which provided an

opportunity to 'test-drive' my preliminary playlist while closely monitoring responses in order to determine if any adjustments should to be made prior to the formal interventions. These mini-pilot interventions also provided an opportunity for residents to 'meet' my cello, as most were unfamiliar with this musical instrument.

ii. Live and recorded-music

It was intended that each of the twelve recruited dyads would participate in six receptive music interventions: three consisting of me playing music live on the solo cello, and three consisting of me playing the same or similar music on the cello via a pre-recorded CD and portable high-quality speaker; with me sitting in approximately the same location during all six interventions. As will be discussed, for various reasons two dyads did not complete all six interventions, and the carer was substituted for one or more interventions in three dyads. Five of the ten dyads that participated in all six interventions listened to recorded-music first; the other five dyads listened to live-music first. I chose to alternate the order of live and recorded-music interventions in order to limit potential participant bias towards either version of the music (MRC, 2006).

Live-music is generally touted as being more effective and beneficial than recorded-music for receptive music interventions (Krout, 2003; Sherratt et al., 2004a; Lee, 2005; Holmes et al., 2006). This is partially due to the flexibility of live musicians to spontaneously respond to reactions of listeners (Aldridge, 1996), which is also likely the chief reason that live-music is generally favoured by practitioners. Indeed live-music may be a necessity for playing at the bedside of a

person who is actively dying, because of the importance of the musician(s) being able to change the music, "...according to physiological changes, breathing patterns, and other observations, synchronizing the music to these changes..." (Freeman et al., 2006:101). Interestingly, only C8 advocated for the sole use of live-music, whereas C14, C6, and C7 spoke of having substantial success using recorded-music. Nonetheless, the conspicuous lack of studies comparing truly equivalent versions of live and recorded-music makes this topic unresolved, requiring further investigation and debate.

iii. Setting

All interventions occurred in the privacy of each resident's private bedroom. Most music-related research with people who have dementia has looked at group interventions within public settings (Holmes et al., 2006; Sung et al., 2006). A meta-analysis by Tang and Vezeau (2010) suggests that interactive group music interventions may be of most benefit for people with dementia. However, my primary interest lies with people who, perhaps due to extreme cognitive or physical frailty may not be able to attend, or to benefit from group music in public settings (Vink, 2000a; Bradt & Dileo, 2010). The private setting chosen for this study's interventions afforded residents an opportunity to benefit from listening to music, with limited extraneous distractions. Coaten et al. (2013:4) suggest that holding interventions within the same familiar setting can also help a person with dementia to have a "...sense of stability and safeness."

iv. Duration and time of day

Prior research has employed music interventions lasting from six-minutes to ninety-minutes, with thirty-minutes being the most commonly used timespan

(Horne-Thompson & Grocke, 2008). Though the targeted duration for the interventions during this study was thirty-minutes, guided by the philosophy of RE, I was always prepared to shorten or extend this timespan depending on the indications and wishes of participants.

Music interventions for people with dementia are frequently targeted at specific times of day, which are often identified by carers, and usually correspond with when the person with dementia is particularly agitated (Cohen-Mansfield & Werner, 1997; Vink, 2000b; Hicks-Moore, 2005; Park & Specht, 2009). I chose instead to base the timing of each intervention on each carer's schedule and the time-structure of each care home; thus taking the RE stance of allowing 'real-life' circumstances to predicate the scheduling of interventions, rather than imposing an artificial timetable on participants.

v. Number of music interventions

Prior related studies have involved widely varied numbers of music interventions, with many studies depending on data collected from a single music intervention (Aragon et al., 2002; Bernardi et al., 2006; Freeman et al., 2006). The six music interventions (three live and three pre-recorded music) I conducted for each dyad during this study were intended to strike a balance between repeating each version of the music enough times to obtain useful data, while also being mindful to avoid overtaxing participants.

D. Data analysis

Making sense of the sizeable amount of qualitative data commonly accrued during ethnographic research is a formidable undertaking; usually requiring numerous

revisits to the raw data over an extended period of time before its full implications are understood (Hammersley & Atkinson, 2007). The iterative nature of this type of analysis puts the researcher at risk of becoming so mired in the minutia of the raw data that he or she loses perspective of the larger picture (Marsh, 2009). This can be particularly problematic because researchers must maintain their perspective regarding the context for all social interactions occurring within the data in order to avoid coming to inaccurate conclusions (Hammersley & Atkinson, 2007).

Guided by earlier discussed approaches (see section 2 above) to analysis common to RE and ethnographical research, I took a multi-dimensional approach towards analysing the sizeable amount of richly diverse raw data accumulated during my fieldwork. The analysis phase was extensive, and required iterative, flexible, and creative tactics towards evaluating multiple data sources. The following subsections begin with a summary Table 4.5, followed by details of methods used for analysis.

Table 4.5: Phases of analysis

Task	Purpose	Procedure	Data source
Transcribe fieldnotes and audio-recorded interviews.	Prepare for thematic coding.	Transcribed using 'Express Scribe' freeware into MS Word.	Handwritten fieldnotes taken throughout my fieldwork. Audio-recorded interviews with residents, carers, and staff.
Thickly-describe high definition (HD) video-footage.	Prepare for thematic coding.	Review of primarily the wide-angle version of interventions using 'VideoLAN Client' (VLC) media freeware while writing down everything I observed, followed by personal reflections.	Converted HD video-footage of music interventions.
Truncate each fully thickly-described set of music interventions for each dyad.	To revisit and familiarise myself with the data, and to focus on most pertinent moments of interventions.	Rereading each thick-description, and distilling down participant responses and interactions.	Full thick-descriptions from each dyad's set of music interventions.

Thematically coding all interview transcripts, fieldnotes, and truncated thick-descriptions.	To develop main themes towards greater clarity.	Three passes of thematic coding using Nvivo software: creating free-nodes - categorising free nodes – recategorising under new main themes.	Thick-descriptions, transcribed interviews from 'phase I' and core phase of the study, and field notes.
Modify an observation tool; 'PIECE-dem'	To create a relevant tabulated video-observation assessment-tool for obtaining a fresh view of the original video-footage.	Modifying and testing random segments of video-footage: including testing inter-rater reliability with a supervisor.	Wide-angle video-footage of music interventions.
Use modified 'PIECE-dem' to revisit and re-observe all (wide-angle) music intervention video-footage.	To revisit the original data via a fresh perspective.	Reviewed all wide-angle video-recordings while tabulating observations in five-minute segments using modified PIECE-dem.	All wide-angle video-footage from music interventions.

Enter all modified PIECE-dem tabulations into Excel spread sheets.	To review data from a fresh perspective.	Created Excel versions of the modified PIECE-dem observation sheets and entered tabulations.	Hand-entered tabulations in modified PIECE-dem data sheets.
Create tables from the modified PIECE-dem data in Excel	To have a visual illustration of the data derived from tabulations.	Experimented with Excel to create easily understandable charts.	Entered tabulations from modified PIECE-dem data into Excel.
Enter all biomedical measurements into Excel and create tables.	To create a visual illustration of any discernible trends.	Entered all biomedical measurements into Excel.	All recorded pulse and blood pressure measurements taken during fieldwork.
Measure and enter all VAS into Excel and create charts.	To create a visual illustration of any discernible trends	Measured marks within each VAS with a tape-measurer (in mm), and entered these measurements into Excel.	Participant self-reported VAS from fieldwork.

i. Validity and reliability

For a study to be deemed credible, the validity, reliability, and generalizability of the methods used for collection and analysis of the data must be clearly communicated. Though attaining this goal is usually a more straightforward process within quantitative research, this does not absolve qualitative researchers from achieving a high standard of accuracy and transparency (Silverman, 1993; Mason, 2002). This subsection discusses the meaning of two related and central research terms; 'validity' and 'reliability', and describes how I went about achieving them within this study.

a. Validity

Mason (2002) defines validity as:

> "...observing, identifying or 'measuring' what you say you are...[and being] able to demonstrate that your concepts can be identified, observed or 'measured' in the way you say they can" (Mason, 2002:39).

Recommended methods for attaining validity in qualitative research include: self-reflection and maintaining transparency regarding potential researcher bias; including deviant findings; allotting enough time for fieldwork (Creswell, 2009); comparing cases; using tabulations; providing raw transcriptions as examples of findings (Silverman, 1993); and thickly describing researcher observations (Fetterman, 1998; Cresswell, 2009).

'Triangulating' data or "... the use of a combination of methods to explore one set of research questions..." (Mason 2002:190), is a commonly used method for validating qualitative data (Silverman, 2000; Hammersley & Atkinson, 2007; Creswell, 2009). However, researchers caution that though triangulating data can

be helpful for gaining different perspectives from the data, no qualitative method will generate absolute outcomes (Mason, 2002; Hammersley & Atkinson 2007).

In chapter 2, I questioned the validity of a study by Gerdner (2000) because one researcher both conducted the interventions and analysed the data. I recognise and acknowledge that this was indeed also an unavoidable (due to PhD requirements) weakness in this present study. However, I intend to clearly demonstrate how, by employing the suggested methods suggested above, I provided validity for this present study.

b. Reliability

Reliability refers to the level to which a study can be replicated: using identical methods and obtaining similar results (Mason, 2002; Creswell, 2009). The reliability of a study is based on the clear and accurate description of each procedure (Silverman, 2000), but qualitative researchers must take care not to put so much effort into ascertaining the reliability of their research that they sacrifice transparency and clarity regarding what they are actually seeking to measure: e.g. the study's validity (Mason, 2002).

Braun and Clarke (2006) declare that:

> "...even a good and interesting analysis which fails to...clarify how it was undertaken, and for what purpose, is lacking crucial information..." (Braun & Clarke, 2006:26).

I sought to build-in as much validity and reliability as possible into this study's design. Regarding reliability, I have striven to clearly and accurately detail

methods used throughout; reflections regarding how well I achieved validity and reliability within this study are discussed in the concluding chapter of this thesis.

ii. Video-observation analysis

Video-recording each intervention proved an invaluable tool, especially because I provided the music during these interventions. Although there was a large amount of video-recorded data to review (approximately 1800-minutes of footage from each camera), I had the luxury of being able to scrutinise details that likely would have been missed during live observations (Heath & Hindmarsh, 2002).

The following subsections describe the methods I employed for analysing the raw video-footage of all the music interventions.

a. Importance of Revisiting Data

Mauthner and Doucet (1998, 2003, 2008) emphasise the importance of qualitative researchers returning to and re-reflecting on their raw data in order to:

> "...keep respondents voices and perspectives alive, while at the same time recognizing the researcher's role in shaping the research process and product" (Mauthner & Doucet, 1998:119).

They also cite time pressures, especially common to qualitative research, as being the major barrier to researchers revisiting data. The following subsections describe the many rounds of revisits to my original data that were involved in this analysis; including my search for and ultimately the creation of a video-observation tool.

b. Thick-description

I applied the recognised ethnographical method of 'thick-description' for my first review of the raw video-footage. Clifford Geertz coined the term, 'thick-

description', in the early 1970s. Although I filmed using two cameras (one wide-angled and one zoomed), I primarily reviewed the wide-angle video-footage in order to observe the entirety of each dyad. Though a similar process to audio-transcription, thick-description is considerably more involved:

> "Thick-description refers to the researcher's task of both describing and interpreting observed social action (or behavior) within its particular context...Thick-description captures the thoughts and feelings of participants as well as the often-complex web of relationships among them" (Ponterotto, 2006:543).

I thickly-described all observed participant interactions and their relationship to both the setting and to all persons present (Ponterotto, 2006). At the conclusion of each dyad's thickly-described set of music interventions, I added personal reflections from my fieldnotes regarding how I had felt at the time of these interventions, and also reflected on how I felt as I re-observed the video-footage.

Upon completing these thick-descriptions, I reread and created a condensed version of each dyad's interventions (Fetterman, 1998). These consisted primarily of participant responses and interactions, while minimalizing my extraneous chatter. This process provided me a second pass of my primary data source, now in a written form.

c. Thematic coding

Using the qualitative software Nvivo (8-10), I thematically coded the condensed thick-descriptions, transcribed interviews, and fieldnotes generated during this study. Thematic coding is another recognised analytical method common to ethnographic and other qualitative research that begins by searching for and consolidating key words or strings of words into one document in order to review

for similarities and contexts (Fetterman, 1998). 'Computer-assisted qualitative data analysis software' (CAQDAS) packages such as Nvivo can help organise and categorise these words by making:

> "...explicit what ethnographers do in their heads all the time: sorting, comparing, searching for patterns, and building models"(Fetterman, 1998:98).

Some researchers express concern that using CAQDAS hinders the qualitative researcher's creative process (Bringer et al., 2004; Hutchinson et al., 2010), but CAQDAS can also aid researchers in efficiently sorting large amounts of qualitative data; creating themes and making sense of the data still remains squarely in the hands of the researcher (Hutchinson et al., 2009).

The next stage in thematic coding is to develop categories for observed actions through an iterative process, during which the researcher is constantly torn between:

> "...the need to narrow down analysis through category construction and to allow some possibility of reinterpretation of the same data" (Silverman, 1993:39).

I completed two rounds of thematic coding using Nvivo (8-10): the first round involved 'open-coding' or creating a new theme (or node) for each emergent topic; the second round entailed reviewing, re-ordering, and consolidating the open-codes into larger themes. These themes provided a structure within which to further analyse the data, which I did through revisiting the data using a self-modified version of a video observation assessment instrument – 'PIECE-dem', as discussed below. A table showing specific nodes and themes that emerged during each cycle of coding can be found in Appendix 11.

d. Video observation assessment instruments

Although the wish to include more 'tangible' (e.g. quantitative) analysis within a qualitative ethnographical study can be tempting, "it is usually mistaken to count simply for the sake of counting" (Silverman, 2000:184). Yet there are circumstances when adding a quantitative component to a predominantly qualitative study may provide the researcher with a fresh perspective; perhaps the illusive 'forest for the trees', which is so easily lost when a researcher becomes too deeply immersed in, "...intensive, qualitative research" (Silverman, 1993:163).

Before choosing to modify a version of the observation tool; 'PIECE-dem', I reviewed many of a growing number of observation assessment tools; all had something to offer, but none were truly suited for the analysis I felt was needed in this study. Below I provide a brief assessment of some of the better-known extant observation instruments in order to contextualise my choice of PIECE-dem:

- 'Dementia Care Mapping (DCM)' (Bradford Dementia Group, 1997) has a venerable place as an observational tool for evaluating dementia care (Beavis et al., 2002; Thornton et al., 2004; Ballard & Aarsland, 2009). DCM aims to: "...evaluate the quality of care and wellbeing of people with dementia in formal care settings" (Beevis et al., 2002:726). However, DCM requires lengthy in-depth training (Thornton et al., 2004; Coaten et al., 2013), and is based on six-hour observation intervals (Fossey et al., 2002).

- 'Continuous Time Sampling (CTS)' involves purchasing and training in the use of a 'Psion Workabout' computer (Sherratt et al., 2004a).

- 'Facial Action Coding System (FACS)' focuses exclusively on measuring facial expressions as a means of measuring pain, and is considered to be complex and time consuming to use (Ragneskog et al., 2001; Herk et al., 2007). There are also questions regarding its usefulness when observing people with advanced dementia, because of their possible loss of facial expression muscle control (Herk et al., 2007), and possible difficulties of FACS to interpret vague cues (Asplund et al., 1995).

- 'DOLOPLUS2' requires long observation periods in a variety of situational settings, so it was not appropriate for this current study (Zwakhalen et al., 2006; Herk et al., 2007).

- The 'Checklist of Nonverbal Pain Indicators (CNPI)' and The 'Pain Assessment in Advanced Dementia Scale (PAINAD)' are more effective for observations of people engaging in physical activity (Zwakhalen et al., 2006, Van Herk et al., 2007; Ersek et al., 2010).

- The 'Cohen-Mansfield Agitation Inventory (CMAI)' focuses on 'negative' behaviours and is designed for observation intervals spanning several weeks (Cohen-Mansfield, 1997).

e. 'Person Interaction Environment Care Experience in Dementia' (PIECE-dem)

Ultimately I decided to use a self-modified version of a live-observation tool: '(PIECE-dem)' (Brooker et al., 2011) for my second review of the raw video data. Focusing on a resident's interactions and engagement, PIECE-dem was originally designed for real-time assessment of the treatment and the consequent wellbeing

of people with advanced dementia living in care homes (Brooker et al., 2011). Following an extensive period of testing and evaluating various modifications, (culminating in comparing my observations of several segments of video-footage with those of one of my supervisors), I devised an effective observation instrument. Final modifications included:

- Expanding one-minute observation timeframes to five-minutes: I determined that a five-minute timespan was more effective for capturing observed participant engagement with the music and also their interactions. As I had the luxury of stopping and starting the video-footage to ascertain that I did not miss subtle communications, these longer timeframes were considerably easier to observe.

- Considerably expanding on the original 'engagement types' (Brooker et al., 2011:112). My primary intention was capturing music's effects on individual responses and on interactions: a study by Hubbard et al. (2003:103) refers to using "...an act of social interactions between residents...[as their]...unit of study..." Thus I added tick-boxes to reflect individual responses and interactions during each five-minute observation timeframe.

- The original 'Pre-Observation Summary Questions' (Brooker et al., 2011:121) were altered to reflect the focus of this study.

- The original 'Summary of Observation Block' (Brooker et al., 2011:123) was left relatively unchanged, with only minor changes to the order of questions and elimination of questions irrelevant to this study.

Copies of the modified versions of 'PIECE-dem' used for this study can be found in appendix 9.A-C).

Though the process of making these modifications, and re-reviewing the raw video data was quite time consuming, it was well worth the effort, as it provided me a fresh perspective and new understandings of the original data. This process also afforded me the opportunity to 'hear' my participants in a new way, and thus to avoid muddying the waters with what I *thought* I 'already knew' (Mauthner & Doucet, 1998). Although this method of revisiting and re-reviewing the raw video-

footage was valuable, the modified version proved to generally lack enough sensitive to pick-up in a demonstrable way the significant changes in participant interactions and responses to the music. Examples of tables and figures derived from this modified version of PIECE-dem can be found in appendix 9.D.

Every qualitative sociological study will be different; in its intentions, scope, participants, and so on. So there will never be a 'one-size-fits-all' approach towards analysis of studies such as this. For this study, using the two major analytic approaches of thematic coding and tabulated observation proved both useful and complimentary. Qualitative analysis is time consuming and often begins with a long (and painful) phase of facing the unknown (Mauthner & Doucet, 1998). This is a key reason that qualitative research generally incorporates much smaller cohorts of participants compared with quantitative research (Braun and Clarke, 2006). Despite the small number of participants involved in this study, I feel that these two analytical approaches allowed me to go very deeply into the experiences of what are considered difficult to reach populations, and to provide reliable and useful answers to my original research questions; thereby offering much needed knowledge towards future related practice and research.

iii. VAS and biomedical analysis

I entered all blood pressure, pulse, and VAS data into Excel spread sheets in order to discern if there were any noticeable trends. Participant marks made on VAS were measured in millimetres from the anchor at one end of each scale (McDowell et al., 2006). Researchers report that the sensitivity of VAS makes it an effective measurement even within small samples (McDowell et al., 2006). Despite prior

research showing VAS to have been successfully employed with people who have dementia (Pautex et al., 2006; Kertzman et al., 2004), I found that for many residents, the abstract task of making a mark on a horizontal line to indicate their current self-evaluation of a perhaps even more abstract concept; their current level of feelings of 'apathy, depression, wellbeing, anxiety', was not particularly successful. I also found myself questioning the relevance of participant answers to the VAS; wondering if their responses could accurately reflect their current mood-state and how these were possibly affected by music.

5. Conclusion

Because this study encompassed several complex topics, creating a suitable research design required substantial investigation, leading to the utilisation of an aggregate of methodologies and methods, primarily influenced by the methodological frameworks of ethnography, RE, and the MRC guidelines for complex interventions. Having contextualised the need for this study, located this study within related research, and described the methods I chose for conducting and analysing this research, the following four chapters are as follows:

- Chapter 5 presents my findings regarding the effects that these receptive music interventions had on interactions.

- Chapter 6 presents my findings regarding the effects that these receptive music interventions had on participants' level of engagement with the music; and ultimately with their ability to experience their interventions as a 'haven'.

- Chapter 7 discusses these findings and implications for future research and practise.

- Chapter 8 reflects on the previous three chapters and on what knowledge has been added via this thesis in its entirety.

CHAPTER 5. INTERACTION

1. Participant and care home backgrounds

This first of two findings chapters discusses the effects that these music interventions had on participant interactions. This chapter begins with Table 5.1 followed by brief synopses of background information on all participating dyads and care homes where fieldwork for this study took place.

Table 5.1: Background: care homes and dyads

Care Home	Type of Ownership	Number of beds	Type of service	Resident	Resident's Age	# Music interventions	Carer	Carer's Age	Relationship	# Music interventions
RiverView	Council	33		Heather	92	1 recorded	Donna	65	Daughter	1 recorded
GreenPastures	Private	40	Nursing and palliative and respite	Iona	89	3 recorded/3 live	Calum	66	Son	3 recorded/3 live
SunnyDale	Council	39	Palliative and respite	Aileen	93	3 recorded/3 live	Tommy	61	3rd Cousin	3 recorded/3 live
SunnyDale	Council	39	Palliative and respite	Bonnie	89	3 recorded/3 live	Nessa	61	Daughter	3 recorded/3 live
SeaView	Private	40	Palliative and respite	Betsie	88	3 live/3 recorded	Gavin/ Morven	83/Early thirties	Nephew/Staff	2 live/l live & 3 recorded

SeaView	Private	40	Palliative and respite		Elspeth	80	2 recorded/2 live		Morven	Early thirties	Staff	2 recorded/2 live
SeaView	Private	40	Nursing - Disabilities		Greer	69	2 live		Brenda /Kirsty	Mid-thirties/mid-fourties	Daughter/Friend	1 live/l live
SunnyBrook	Council	32	Palliative and respite		Hazel	mid-eighties	3 live/3 recorded		Sheena	39	Staff	3 live/3 recorded
SunnyBrook	Council	32	Palliative and respite		Robert	74	2 live/3 recorded/1 live/1 emergency intervention		Mairi	46	Daughter	2 live/3 recorded/1 live

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SunnyBrook	Council	32	Palliative and respite	Edine	92	3 live/3 recorded	Cait/Bethia	68/mid-thirties	Daughter-in-law/staff	3 live & 2 recorded/1 recorded
SunnyBrook	Council	32	Palliative and respite	Edward	88	3 live/3 recorded	Isla	59	Daughter	3 live/3 recorded
SunnyBrook	Council	32	Palliative and respite	Maggie	89	3 recorded/3 live	Jean	63	Daughter	3 recorded/3 live

RiverView

Although this was a new and spacious care home with lots of light, it had a rather impersonal atmosphere. I frequently found the communal room populated by residents sitting in front of a huge blaring television that no one was watching. There were no signs of activities or interaction between either residents, or between residents and staff.

Heather and Donna

The sole resident from this care home who met this study's inclusion criteria was Heather. She was very frail, gentle, and soft-spoken, used two hearing aids, and was nearly blind. Although she moved about with a Zimmer, the majority of her time was spent in her relatively large light-filled room, sitting in a comfy chair. Heather could communicate verbally, but she chose not to speak much. I sometimes found Heather lying unresponsive and facing the wall.

Heather's daughter, Donna participated as carer. Heather's son Grant was struggling to accept his mother's declining health. Donna spoke of Heather and her late father singing together around the house. My attempt at conducting a pilot-intervention was unsuccessful due to my CD-player failing. Heather and Donna's first recorded-music intervention was unfortunately to be their last: from the beginning, both the care home manager and Donna warned me that Grant disapproved of his mother participating in this study. Prior to what was to be their second intervention, Grant left a hostile phone-message on my answering machine to inform me that he was not allowing Heather to continue in the study. It later emerged that he felt that these interventions were

impinging on precious time he could be spending with Heather. Thus, despite Heather and Donna having clearly enjoyed their first (recorded-music) intervention, I had no option but to discontinue.

GreenPastures

GreenPastures had a friendly though distant manager and predominantly young and impersonal staff – excepting for the hard-working and dedicated senior nurses who were very helpful. The cloyingly hot communal room with a blaring TV was always teeming with a diverse population of residents (i.e. differing states of health and cognition).

Iona and Calum

The only resident who met this study's inclusion criteria at GreenPastures was Iona. She had moved in relatively recently, and frequently expressed her deep unhappiness about residing there. Iona often told me how much she used to love singing.

Her son Calum lived nearby, though their relationship was apparently quite distant or awkward. According to Calum, Iona's favourite hobby had previously been reading. When asked about his expectations for this study Calum replied:

> " … I'll be interested to hear how she [Iona] gets on cuz...she's not a very sociable person. She tends...you know not to... particularly like meeting new people...so...we'll see [chuckled]" (Calum).

SunnyDale

Despite my several presentations for staff, families, and some residents at this relatively large care home, and numerous families expressing interest in having their family member participate, Aileen and Bonnie were the only two residents who met this study's inclusion criteria.

Aileen and Tommy

Alert and verbally articulate, Aileen was wheelchair-bound and highly educated. She never married, and had been happily living in this care home for over ten-years. Aileen enjoyed music, had played a bit of piano, and had enjoyed singing particularly in church choirs.

Her closest relative (a 2nd cousin), Tommy lived fairly nearby. Prior to this study, he had made only occasional brief visits to Aileen.

Bonnie and Nessa

Bonnie was a spirited wheelchair-bound woman with little short-term memory and little verbal ability. During WWII she had joined the 'Auxiliary Territorial Service (ATS)' with her older sister, had worked in the Jute mills, was a part-time cleaner, and sold newspapers at the local railroad station.

Bonny's daughter Nessa spoke of her late father playing the accordion, and of Bonnie being an enthusiastic singer and dancer who had loved singing the hymns at church. Judging from the photos on the walls, family was quite important to both Nessa and Bonnie.

SeaView

SeaView was a spacious care home. The upstairs floor was exclusively for residents with cognitive impairments, and was appropriately furnished with bygone era furniture and a small old-fashioned television that was rarely turned-on. Having both a full-time and a part-time activities director meant that there were frequent group activities including 'sing-songs'. Three residents participated in this study; I was unable to successfully obtain direct consent from a fourth resident.

Betsie and Gavin/Morven

Betsie could usually be found in the communal room, deeply absorbed in a word-puzzle book (which in reality she was scribbling in). She had little short-term memory and thus did not recognise me from one visit to the next. Betsie's energetic personality included frequent swearing and affectionate slaps. Betsie's late husband had played the 'mouthy' (harmonica). Bingo had apparently been her primary social event, as she habitually asked about when she was being picked-up for Bingo. Music did not figure much in Betsie's life although she enjoyed Scottish country dancing, and singing around the house.

Betsie's elderly nephew Gavin lived nearby and participated as carer for her first two recorded-music sessions. He had his own physical ailments however, and from the start expressed reticence about participating in this study. In his initial interview, he mentioned that he generally only came to see Betsie once every three weeks or so, and only stayed for about ten-minutes as, "...she just keeps repeating herself so there doesn't seem to be any real reason to visit."

Gavin referred to the care home residents as 'inmates' and 'patients'. He ended his participation after two interventions, citing the terrible long drive and road conditions; luckily, the care home's enthusiastic activities director, Morven, was happy to participate as Betsie's dyad partner for her remaining four interventions.

Elspeth and Morven

Elspeth was an elegant, soft-spoken woman with advanced Parkinson's. Generally quiet and a bit vague, she became considerably animated when we spoke about dancing, the wireless, and the navy. Elspeth's daughter told me that Elspeth was prone to pessimism, and thus was curious how Elspeth might respond to these interventions.

Greer and Brenda/Kirsty

Greer was an elegant former professional musician with advanced Parkinson's, who had virtually no speech or motor control. During one of my early visits with Greer, she insisted on being helped to sit (and be held-up) at the upright piano in her bedroom, and with much effort, she played some chords for me.

Greer's daughter Brenda was a busy career woman who shared a close relationship with her mother, visiting as often as she could, for a week at a time. During one of my many telephone calls with Brenda, she supplied names of specific music to play for Greer. The only time I actually met Brenda, I spontaneously seized the moment, and with their consent conducted a live-music intervention for them. Despite their clearly intense engagement with each

other during this intervention, Brenda decided against participating in future interventions, as she did not want her visits to be interrupted.

Fortunately, the daughter of a fellow resident; Kirsty, had become close friends with Greer and Brenda, and was happy to step-in as Greer's dyad partner. Kirsty was a very outgoing, chatty, enthusiastic woman who promptly kicked-off her shoes and laid-down on Greer's bed (Greer was seated in her huge comfy chair) at the start of what was to be their only shared live-music intervention.

SunnyBrook

SunnyBrook was a comfortably run-down smallish care home run by an exceptionally involved and caring manager (Evelyn), and a mostly established staff. Many of the residents came from nearby towns and villages, with some having lived there for a long time. Evelyn initially identified seven potential residents for my study; sadly one died before I could begin the interventions, and another resident was unable to provide direct consent.

Hazel and Sheena

Hazel was a handsome, quiet, and verbally capable woman with a lovely smile. A long-time resident, I was informed that Hazel did not see herself as similar to her fellow residents, and that she rarely participated in care home activities. All her children lived far away and did not often visit. Hazel and I got on well from the start as I enjoyed her dry humour and frank demeanour. Sheena, who was Hazel's keyworker, participated as her dyad partner. During her initial interview, she said of Hazel:

"...she is depressed really and the you know, doesnae [doesn't] want to go outside, doesna really care if she gets to go on a bus trip or anything because all she's gonna look at is the tree and the sky and what use is that to her...and that's kinda...how she is... so it is quite hard to please her.... I'm not sure whether Hazel will enjoy it [the music interventions] or no... because...sometimes music does annoy her even if we go downstairs to...entertainment or that, we'll come back up and she'll' say, '... that was just a bloody din'...So she'll either love it or hate it..." (Sheena).

Sheena was quiet, and had worked at SunnyBrook for about five-years. When I enquired about her own quality of life, she replied:

"I don't have a very good quality of life I don't think. I suffer a really bad back... and hip pain and...the GPs...aren't prepared to do anything about it... They're saying there's nothing wrong and basically, a lot of people have pain in their life and I just have to put up with it. So, in that way I'm no happy. Because I just have to struggle on. But I love my job..." (Sheena).

Sheena had a strong background in traditional Scottish music.

Robert and Mairi

Robert was a gentle man with an avid passion for traditional Scottish music; occasionally still playing his mouthy (harmonica) and accordion. He also had a beautiful tenor voice, and there was often traditional Scottish music playing on the CD-player in his bedroom. Robert left school at fifteen to work as a gardener. Evelyn cautioned me that he was prone to progressively intense paranoid outbursts.

Robert's daughter Mairi worked full-time and lived quite far away, so we met whenever she had a day-off. Mairi and Robert seemed to share a fond and comfortably close relationship. Mairi expressed hope that the music interventions might improve Robert's wellbeing, and perhaps help with his

ability to communicate. She also pondered whether parts of the brain could still remember music when other parts seemed unable to remember anything.

Edward and Isla

Handsome and always immaculately dressed in a dapper waistcoat and tie, Edward, who had very little verbal ability, always greeted me with a big smile and chuckle. He had a distinguished professional career and was a passionate ballroom dancer up until a few years previous.

Edward's only child, Isla lived nearby and visited often. Isla sang in several local choirs, and spoke of music having always being important for her mother and herself, but not so much for Edward. Recently widowed, Isla frequently referred to her own grief and depression. Isla regularly commented that her father had not always been the affable man he appeared to presently be, and there was a tangible feeling of distance in their rapport.

Edine and Cait /Bethia

Edine was a tiny woman who always dressed very elegantly – including a long strand of beads. She had an infectious smile and was very social; I usually found her sitting with other residents in the communal area. Our conversations generally involved her warmly greeting me and asking me where I was from and where I was going, and her telling me the name of the small nearby town she was from. Edine left school at fifteen to go into 'service' as a maid. She maintained a strong connection with the church. A mother and ever the proficient hostess, Edine frequently offered me tea. Edine was also especially frail, and had managed to rebound from a severe chest infection at the time of

her music interventions. She was visited daily by one of her nearby close-knit family.

Cait was Edine's daughter-in-law, and they shared a very close and caring relationship. Cait also left school at the age of fifteen to begin working in various shops, and also was a devout church member. When I asked Cait how she thought Edine might respond to their upcoming music interventions, she replied:

> "I actually think she will enjoy the actual contact with you because she has seemed to have a great connection with you yesterday, so I think you know, she does like company, someone coming in to see her, and I think she'll find, I think you'll discover she'll like it, I'm sure she'll like it..." (Cait).

Due to a breakdown in communications, Edine's keyworker Bethia participated as Edine's carer for one recorded-music intervention. Bethia was in her early thirties, and was a long-time staff member at SunnyBrook. She was very quiet and clearly fond of Edine.

Maggie and Jean

Maggie was the youngest of a large coal-mining family. She had very little remaining sight, although she always complimented any brightly coloured clothes I was wearing. Due to a lifetime of smoking, she had a chronic cough and frequent chest infections. Maggie left school at fifteen to go into 'service' as a maid. Her daughter Jean described Maggie as a very hard worker, and an 'emotionally distant' mother. Jean also reported that Maggie had never been very interested in music, but that her late father (who was the 'gentle emotional one') had been an accomplished folk musician.

Jean lived very nearby and visited frequently, though their rapport was markedly emotionally distant.

2. Findings - music and interaction

The significance that social interaction has for human wellbeing (Killick & Allan, 2001; Allan, 2006; Ward et al., 2008), and music's largely untapped potential as a conduit for communication (Gallagher et al., 2006; Sorrell, 2008; Gerdner & Schoenfelder, 2010) were discussed within previous chapters. To summarise, music may be able to reach and facilitate communication between people even when other avenues for communication may have diminished or shutdown entirely due to cognitive impairments.

This chapter presents findings regarding the effects that these music interventions had on interaction. The first section focuses on music's effects on dyadic interactions between participants and also with me. The second section focuses on music's effects on interactions within each triad - resident, carer, and me.

3. Dyad rapport

The primary inclusion criterion for participating as a carer was that he or she be closely connected with a participating resident. While it was not difficult to locate someone meeting this criterion, this was not as straightforward an issue as I had originally assumed, because I had not taken into consideration the *rapport* shared between each carer and resident. Dyads who shared a good

rapport (generally conveyed through affectionate exchanges of smiles and interactions) enjoyed sharing these interventions together, and generally interacted with each other throughout their interventions. Dyads whose rapport was less affable (generally conveyed through awkward silences) were more reserved in their individual responses and at least initially interacted significantly less.

The carers in this present study echoed comments made by those in previous studies (Clair, 2002; Hughes, 2013), regarding how difficult it can be to connect with someone with dementia living in a care home:

> "I think just connecting with him [Edward] is good because I find it very difficult to connect with him now. I mean he's obviously pleased to see me when I come in, but because he's been here nearly five years now...it's difficult to know how to connect with him, and I would like to be able to do something with him which is more meaningful and has some purpose and which would benefit him...but I'm not sure what to do with him" (Isla).

> "...when [I] just come to visit him [Robert]...he doesn't say very much..." (Mairi).

> " ...a visit to Aileen is fairly...well I won't say it's fairly structured but it's about the family and what I've been doing and what she's been doing and what she's been eating and what's been happening and everything's fine and then I smile and I go away..." (Tommy).

As illustrated presently, sharing the activity of listening to music provided enjoyment and generally encouraged interaction within all dyads - including those dyads that were initially less connected.

Table 5.2 below provides a brief overview of generally agreed upon forms of interaction (Clair, 2002; McAdams 1984; Astell et al., 2009; Astell et al., 2010).

Table 5.2: Types of interaction

'Positive' interactions	Verbal: (speaking to each other -singing together – chuckling - laughing together	Visual: looking towards each other – shared smiles – nods - gestures	Physical: touch
'Negative' interactions	Non-communication	Ignoring the other dyad member	

A. Dyads whose rapport remained consistent

Every dyad experienced varying extents of enjoyment while sharing the activity of listening to music. This first subsection focuses on the five dyads that maintained a similar level of interaction throughout their music interventions.

When I told Edine that Cait would be joining her to listen to the music, Edine exclaimed:

> "Oh I would love that... Cait'll love it if she wants to come, she'll love it...I hope she is, because I would love that" (Edine).

From the start, Edine and Cait enjoyed sharing their interventions together, as demonstrated by their chatting and smiling at each other throughout.

Robert and Mairi shared a comfortable and fond rapport conveyed via smiles, chuckles and brief comments to one another throughout their interventions.

Betsie and Morven were constantly singing, laughing, joking, sharing affectionate physical pats and general banter throughout the four interventions they shared.

Hazel and Sheena's interactions were fairly subdued, with Sheena frequently looking towards Hazel, smiling, and occasionally making small comments. Hazel mostly focused on me during all her interventions, later remarking that she would have been just as content listening to the music on her own.

Nessa remained completely fixated on Bonnie's responses throughout their interventions. Although they exchanged brief comments about the music and other random topics, Nessa's interactions with Bonnie mostly involved her urging Bonnie to sing; and expressing disappointment when this did not occur (see chapter 6.3.C).

B. Dyad rapport that changed

There were various reasons that dyadic interactions noticeably changed between five of the residents and their dyad partner, or with me. The most dramatic changes in dyad interactions usually occurred within dyads that initially seemed fairly disconnected. This subsection illustrates the nature of these changed interactions, and highlights specific characteristics of the played music or of the intervention format that likely contributed to these changes.

i. Live-music

I was interested to learn more about how live-music compared with recorded-music affected interaction. I found that listening to live-music particularly enhanced interaction within one participant dyad, and also prompted a significant increase in interactions between three residents and me.

Maggie and Jean

There was little doubt regarding the initial disconnect Jean felt towards her mother Maggie; describing her mother as:

> "...anti-social...never relaxed in company...very strict and cold... severe" (Jean).

Later adding:

> "I've got a lot of issues with Mum, which I've come to terms with" (Jean).

Throughout their first three recorded-music interventions, Jean's body language reflected her disconnection, as she sat on the furthest edge of her chair, tightly crossing her arms and legs away from Maggie. Meanwhile, Maggie engaged with the recorded-music, and frequently named the played tunes to Jean – who generally made no reply.

Conversely, the tone of their interactions took a dramatic upturn from the start of their live-music interventions (4-6). This was primarily because they received my playing the cello live as an extra-special occasion. Maggie spontaneously clapped her hands as most tunes ended, and repeatedly exclaimed; "This is like a dream!" Meanwhile, Jean became very animated and began interacting with Maggie. Over the course of their three live-music interventions, the ostensibly disaffected tone of their connection metamorphosed into one of a unified unit. They greatly enjoying their shared experience of my playing the cello live for them. They expressed their enjoyment through lengthy exchanges about the music; shared reminisces;

shared physical affection; and by copiously showering compliments and appreciation towards me.

Below is a representative sample of what was almost constant interaction during their three live-music interventions:

After the final tune of their first live-music intervention:

> Maggie: It was lovely [Maggie looked over at me smiling broadly, and Jean reached out her hand and fondly patted Maggie's head]

During their second live-music intervention:

> Maggie: Well this is lovely! [Laughing and looking at Jean who looked at her, smiling broadly].
>   ...
> Jean to Maggie: [reaching-out and again putting her hand on Maggie's arm] It's worth getting out of bed for isn't it.
> Maggie: Oh, I would, I would say so! [Maggie and Jean are looking at each other]

> Maggie to Jean: It's wonderful isn't it! [Maggie smiled broadly and Jean laughed]
>   ...
> Maggie to Jean: This is a dream Jean!
> Jean: [smiled and reached over to pat Maggie's arm] Well it's real.

At their final live-music intervention, Maggie and Jean's interactions began even before the music started:

> Maggie to Jean: [gesturing around the room] I can't believe this is all happening!
> Jean: I know [Jean reaching over and stroking Maggie's hair]. ... [Jean looking at Maggie who is looking towards her] And you, you absolutely adored Claire's music...[Jean patting Maggie's hand]

> Maggie: I can't believe this is happening!
> Jean: Well this is special.
> Claire: Thank you.

> Jean to Maggie: [smiling and gently rubbing Maggie's arm] This is special, isn't it.
> Maggie to Jean: [grinning broadly] Oh! Special! Very very special!

...I departed their final two live-music interventions feeling that I had been given an opportunity to contribute to, and to witness a truly magical transformation in the connection - whether fleeting or long lasting, between a previously estranged mother and daughter.

Elspeth and I

Elspeth said very little to either Morven or I during her recorded-music interventions (1&2); except to declare that she was 'not interested' after hearing the third tune during her second of these interventions.

However, from the beginning of her live-music interventions (4&5), Elspeth interacted quite a bit - not so much with her dyad partner Morven, but with *me*. During her first significantly extended live-music intervention, Elspeth expressed considerable curiosity about me playing the cello:

> Elspeth to Morven: You never think about the cello really as an instrument like that.
> Morven to Elspeth: I know, we're used to hearing the fiddle eh? [Elspeth: Ay]
> ...
> Claire: Had you heard a cello before?
> Elspeth: No as a solo instrument.
> ...

Partway through this intervention, a staff-member interrupted and called Morven away temporarily:

> Claire to Elspeth: ...Would you like another tune Elspeth?
> Elspeth: ___What made you take up the cello?
> Claire: Well that's a good question Elspeth...[I briefly answer her and Elspeth tells me at length about her grandchildren playing trumpet and piano]

> Claire: Do you want me to play another tune for ya?
> Elspeth: Ay, might as well.

I played several Scottish tunes, which were interspersed with several lengthy conversations about ceilidhs (traditional Scottish dances). After one fast Scottish tune, Elspeth commented:

> Elspeth: That's a good, toe, toe [sic] tapper.

After I played what I presumed was be the final tune for this intervention, ('Auld lang syne'):

> Claire: Elspeth thank you. I really enjoyed playing the music for you today...
> Elspeth: Well I've enjoyed listening to it...It's a funny thing, because I never would have thought anything about the...cello being musical...Just think it's just a...get a few squeaks out of it...
> Claire: [I chuckled] Oh no no, it's no squeaky!
> Elspeth: It's no squeaky no...You never think about it though.
>   ...
> Claire: You wanna stay in here?
> Elspeth: I want another sing song.
> Claire: [laughing] You want another song?
> Elspeth: Well I don't expect you to get up and sing! [slightly smiled]
> Claire: No...you want some more music is that what you're saying?
> Elspeth: Well we might as well just sit and sing and play a song.
>   ...

When Morven eventually returned:

> Morven to Elspeth: Have you been enjoying it Elspeth?
> Elspeth: Yes...I liked them all...I like the music...I used to think it was pretty dim on the event. But I've turned and changed my mind.

These excerpts suggest that Elspeth took an interest in me as a person and also in the cello as a novel musical instrument during her live-music interventions. They also show Elspeth expressing enjoyment for the music and wishing to hear still more music each time I suggested ending these interventions. Elspeth's continual initiations of interactions with me are particularly notable, because

Elspeth purportedly was not a very conversational person. It is also significant that Elspeth reported to Morven upon her return that, although she had initially not been enthused by these (recorded) music interventions, she had changed her point of view.

Bonnie and I

Bonnie was easily distracted during her recorded-music interventions (1-3), and interacted very little with either her daughter Nessa or me. However, during her live-music interventions (4-6), Bonnie started asking me about my family and about playing music:

> Bonnie to me: Does your daughter play?
>
> Bonnie: Is your laddie playing that?
>
> Bonnie: But you're never oot [out].
> Claire: I'm oot sometimes.
> Bonnie: yeah?
>   …
> Bonnie: With your Mum?
>
> Bonnie: Do you play a lot with that?
>
> Bonnie: You've got some lovely berns [children] though.
>
> Bonnie: I always like hearing em [the tunes] played eh.
>
> Bonnie: You're playing braw [wonderfully]!
>
> Bonnie: You like that eh, you like that playin [the cello].
>   …
> Claire: I do like playing. Do you like it all right?
> Bonnie: Oh it's great!

Although there may have been other mitigating factors that contributed to Bonnie's notably changed level of interaction during her recorded and live-

music interventions, her newfound interest in me as a person clearly had to do with my playing the cello live for her.

Edward and I

Edward focused almost entirely on the music and on my playing the cello, during his live-music interventions (1-3), rarely looking towards or speaking to his daughter Isla. Isla's occasional attempts to spark reminisces with him about her late Mum generally were met with polite disregard. Despite their on-going polite discordance regarding which music genres Edward truly preferred, there were some glimmers of shared affection, when Isla patted or rubbed Edward's arm, or when they occasionally shared a smile or chuckle with one another. However, Edward's primary focus was on me playing the cello and on listening intently to the music throughout his live-music interventions. He frequently responded enthusiastically after tunes with comments such as: "Yeah! - Good! - Yes! - That's very good! - Lovely, lovely!" Edward also readily responded affirmatively whenever I asked if he wanted to hear more music: "Yes I do, uh huh! - Oh yes!" Despite his very limited ability to speak, he also initiated several conversations with me:

> Edward: You should maybe go down to the music centre…
>
> Edward: Do you ever play at the…[he nods] music…
> Claire: At the music halls?
> Edward: Yeah.

When I later asked Isla if she had noticed any changes in their interactions during their live and recorded-music interventions, Isla replied:

> Isla: Well I don't think he [Edward] reacted, interacted [with me] at all when it was you playing. He was, he was more absorbed.
> Claire: ...He was just connected with me.
> Isla: Yes.

What was apparent was Edward's interest in me as a person when I played the cello live for him.

ii. Recorded-music: inter-dependence

Edward and Isla

Isla's frequent references to Edward not having always been the affable gentleman he was during the time of this study indicated the undercurrent of distance and tension underneath their polite facade. Another indication of their strained rapport occurred after a month-long break between the end of their live-music interventions and their recorded-music interventions, when Edward indicated that he had missed *me*, but *not* Isla. It is difficult to know how much Edward's deteriorating health might have contributed to his marked lack of engagement with the music during their recorded-music interventions (4-6) (sadly, he died shortly after these interventions ended). Nonetheless, Edward's communications were also considerably more difficult to understand during these latter interventions, and Isla's ability to interpret his distinctive gestures gave her an unexpected means of reconnecting with her father.

During one recorded-music intervention, Edward began waving his arms soon after the music started:

> Claire to Edward: ...Wasn't sure with that little, gesture you made! [Edward smiled broadly and Isla laughed]

Isla: I think it was probably because you were watching him. [They both chuckled]
Claire: Oh, OK. [To Edward] would you rather I didn't watch you?
Edward: Na!
Isla: Dad doesn't like that.
Claire: OK. I won't look at you directly. Sorry. [Isla laughed]

Another time, Edward lifted his arms above, and then behind his head. I stopped the music, and we shared a lengthy exchange with most of his communications directed towards Isla:

   ...
Isla to Edward: ... would you like Claire to stop?
Edward to Isla: Yeah. [I stop the music]
Isla to Edward: Yes?
Edward to Isla: Yup!
   ...
Claire to Edward: ... is it because it's too many slow ones, or are you just tired or...
Edward: [smiling at me while Isla is looking towards Edward] No.
Isla: Are you tired?
Edward: [looking at me] Yeah.
   ...
Isla to Edward: Too long. Is it too long a time for you?
Edward to Isla: Yeah.

At the end of their final recorded-music intervention Isla said to me:

"He knows his own mind. He just finds it difficult t express it... He's got very clear ideas of what he, wants to do and doesn't want to do... likes and dislikes, he just can't..." (Isla).

For whatever reasons, Edward showed little patience for the recorded-music. At the same time, his deteriorating health made it more difficult for me to understand his efforts to communicate his wishes and frustrations. Isla's 'expertise' proved invaluable to both Edward and I as she correctly interpreted his efforts to communicate his wishes. Their newfound inter-dependence brought about an unexpected reconnection between them, as Edward gratefully

relied on Isla to help express his wishes, and Isla found a way to meaningfully connect with her father.

iii. Printed song-sheets: artefacts

RE highlights the importance of uncovering the real origin of changes in behaviour. So whilst the played music was the core motivator for changes in dyadic interactions, for Iona and Calum, the addition of requested printed song-sheets seemed to really galvanise their rapport.

Iona and Calum

The tone of Iona and Calum's rapport was one of awkward detachment, which was not helped by Iona regularly expressing her deep unhappiness at living at GreenPastures. In his initial interview, Calum referred to Iona as"...not a very sociable person", later adding that "...she can be pretty grumpy and, negative..." He arrived over fifteen-minutes late to their first music intervention and barely addressed Iona. While Iona was engaged with and enjoyed her recorded-music interventions (1-3), Calum remained fairly aloof, with the extent of their interactions consisting of occasional brief chats, chuckles, glances and smiles, and culminating in a somewhat lengthy discussion about the proper name of the tune, 'Bluebells of Scotland'. They also spontaneously sang together to, 'My bonnie lies over the ocean' later in this intervention.

During their three live-music interventions (4-6), their rapport decidedly increased. This was not necessarily related to my playing the cello live for them, but instead was mainly the result of my preparing and supplying the printed

song-sheets they had requested. Iona had previously expressed considerable frustration at not being able to remember every word of the familiar tunes she was listening to. Now, equipped with the printed song-sheets, Iona immediately became completely immersed in following the words to each tune. Meanwhile, Calum meanwhile gradually became more interested in these song-sheets, so that the endings of most tunes found them engaged in animated discussions with one another regarding the 'correct' number of verses or sharing memories, and frequently exchanging smiles and chuckles. Eventually Calum became a 'master of ceremonies'; introducing each tune while passing the next song-sheet to Iona. By their fifth intervention, Calum greeted Iona with an affectionate kiss on the cheek and some grapes.

Additional illustrations of the tone of their interactions during these three interventions (4-6) are presented below:

From my thickly-described observations:

> Iona is carefully following the words with her finger, while Calum is looking over at the words as well, and they are both mouthing the words for the first verse. Iona continues mouthing the words and pointing to the words on the sheet while Calum is just looking over. At the end, she is still focused on the sheet and mouthing words.
> Calum to Iona: There we are...got to the end this time! [Calum chuckles and Iona beams at him]

> Iona scrutinises a song-sheet and Calum is also looking over at the words. Iona begins audibly singing and mouthing all the words while following along with her finger. She makes a sound and gets confused, and Calum starts pointing to the words with her and singing a bit. Then Iona shrugs and is back mouthing the words while Calum is looking over at the sheet and singing along to the final refrain.

> Calum to Iona: There we are. [Iona looks intently at the song-sheet for some time]
> Calum: [passes Iona the next song-sheet] There you go; 'When Irish Eyes are Smiling'.
> Iona: Oh ay! [They both chuckle]

This dyad provides an excellent example of the importance of remaining flexible and accommodating the individual needs and requests of participants whenever possible.

iv. Repeated interventions

For Aileen and Tommy, the repeating format of their interventions seemed to have had a particularly positive impact on the tone of their interactions.

Aileen and Tommy

Aileen and Tommy exhibited an affable if somewhat detached rapport from the start of their interventions, expressed by their occasional exchanges of brief comments after tunes ended. During their first intervention I noted that although Tommy was listening, his demeanour suggested that he was somewhat disengaged, as he sat with folded arms, looking down or around the room, and sporadically looking towards Aileen. Verbally articulate, Aileen was attentive and clearly indicated her likes and dislikes of the music that she listened to. Tommy appeared to become more relaxed and engaged with the music during each successive intervention. By their second (recorded-music) intervention, he and Aileen were already settling into a pleasant camaraderie:

> Aileen to Tommy: I'm enjoying it more than the last time!…What changed?
> Tommy to Aileen: *We're* getting jigs and things now; getting faster stuff.

-The important word here being, '*we*', which suggests a shared experience.

When I played a familiar hymn during their third (recorded-music) intervention, Aileen gave a nod of recognition before singing along, while Tommy looked over at Aileen and then at me before humming along as well - when this hymn ended, Tommy said to Aileen:

"You probably learned this at [Sunday] school about ninety-years ago."

By their fourth (live-music) intervention, Tommy and Aileen were regularly sharing brief exchanges and reminiscences after nearly every tune. When I played, 'My bonnie lies over the ocean' they sang along together in full voice.

Near the start of their fifth (live-music) intervention, Aileen named the tune, 'Scotland the brave' as I started playing, and Tommy smiled, saying, "Spot that tune!" And later in this same intervention, after I played the hymn, 'All things bright and beautiful':

> Aileen to Tommy: Do you know that one Tommy – 'All things bright and beautiful'.
> Tommy to Aileen: Oh yes yes yes, yes, 'All things bright and beautiful'. Yes."
> Aileen: [pause] 'All things bright and beautiful'.

Still later in this same intervention when I played, 'My bonnie lies over the ocean', Tommy said to Aileen: "You like this one" Aileen nodded, smiled and replied; "Yes!" – from the first refrain through two entire verses they both sang and waved their arms and hands along with the music.

Although Aileen was especially tired during their final (live-music) intervention, she and Tommy sang together for part of the hymn, 'All things bright and

beautiful'. This intervention ended with them singing together and looking towards one another while I played, 'Auld lang syne'.

Aileen and Tommy's interactions increased gradually over the course of their successive interventions. When I asked Tommy if he had noticed any changes in their interactions, he replied:

> "...at times I think we almost played a game of 'Spot that tune' (an old UK television show)!...we had other things to talk about..." (Tommy).

Aileen's keyworker also substantiated what I had witnessed:

> "Well what I did see was it has given...families an opportunity to come together a little bit more. ...[Tommy] has been quite a bit more involved since meeting with you; in a few different aspects of her [Aileen's] care... Because it's a nice wee relationship she's [Aileen] got with [Tommy] as well and that's something that they can share..." (Pat).

This dyad's experience suggests that the repeated format of a familiar pleasurable shared event can create a comfortable and safe environment in which interactions may increase.

Betsie and Gavin: new perceptions

Gavin only participated as Betsie's carer during her first two (live-music) interventions, but there was a substantive change in his perceptions of Betsie during these interventions. During his initial interview, Gavin stated that he had no expectations about this study because he believed that Betsie was "too far gone" to be "helped." However, during the two interventions he shared with Betsie he frequently conveyed pleasant surprise at seeing Betsie's ability to

immediately recognise and sing nearly all the words to practically every tune

played. At the end of their first intervention:

> "Well it's eh...amazed at the memory she's got for the songs...It seems
> eh...it seems odd...but eh, it's, the memory is a queer thing isn't it...it's
> been years since she's ever heard these tunes anyway...well for the first
> two three notes or strokes of the fiddle she's joining in..." (Gavin).

Betsie and Gavin also shared various exchanges about the music during these

interventions:

> Gavin to Betsie: You ken [know] what that was?
> Betsie: Umhmm!
> Claire: Ah she knows her tunes.
>
>   ...
> Gavin to me: Has she had a session already? [Indicating that he assumed
> she must have already learned these tunes at prior interventions]

During their second intervention, Gavin enjoyed routinely asking Betsie the

names of tunes as they ended - and seeing that she nearly always knew the

correct answer. When I played, 'Run rabbit run', Betsie immediately recognised

it and began tapping the arm of her chair and singing quite strongly while

looking towards Gavin who looked back at her nodding and smiling. When this

tune ended:

> Gavin: Run rabbit.
> Betsie: Run rabbit.

Later during this session when I asked Betsie if she would like to hear some

more music, she answered:

> "Ay, it's all right, I've got Gavin here [they looked towards each other]"
> (Betsie).

During Gavin's exit-interview, he reiterated his surprise at Betsie's ability to follow along with the music and sing most of the words. But he also commented that she seemed to have no recollection of the music once it had ended, prompting him to continue to question the merits of conducting interventions for people with dementia. Nonetheless, I would suggest that sharing these interventions with Betsie afforded Gavin a rare opportunity, however briefly, to attain a fresh perspective of Betsie as a *person*; rather than merely as 'Betsie who has dementia'.

It is important to emphasise that interactions within participating dyads never declined during these interventions; rather, interactions generally increased.

The following series of subsections considers the effects that the played music and the intervention format had on the triadic configuration of the resident, carer, and me.

4. Triadic dynamics

Connecting with others is a basic human need that never goes away. What changes during the aging process, is that cognitive and physical obstacles often materialise that make connecting with others more difficult (Froggatt et al., 2009). Studies show that when visiting family and friends share in an activity with a care home resident, their interactions are enhanced (Nolan et al., 2003; Froggatt et al., 2009). Within residential settings it is commonplace for a professional to be present during family visits with a resident who has dementia

(Adams & Gardiner, 2005). Relationship dynamics amidst three people are especially changeable (Adams, 2003; Adelman, 1987; Quinn et al., 2012). Hence, although it has heretofore garnered very little attention, looking at the possible effects that these music interventions had on triadic interactions is both very interesting, and also particularly relevant. Referring back to the social theories, SI and DA (see chapter 2.5.A-B), and the care model, RCC (see chapter 2.5.E) to help contextualise the impact that these interventions had on triadic interactions, the next series of subsections illustrate ways in which the played music wove in-between our shifting interactions; sometimes becoming the centre of attention, and at other times providing a sonic backdrop.

A. Triadic interactions

The passages below depict relatively equal triadic interactions between a resident, carer, and me. They also illustrate how the played music provided the 'glue' that connected the three of us:

> Morven to Betsie: That is, an awfully nice one. Did you dance wi [with] a handsome man to that one?
> Betsie: I might do.
> Morven: Ay! (We all laugh]
> Betsie: If ya find im first.
> Morven: That's true. [laughing]
> Claire: Are they a little skimp in here maybe? [all laughing]
>
> Iona: I can't remember the words.
> Claire: I don't know if many people know the words to this one. [to Calum] do you?
> Calum: [shakes his head] No, I don't think so.
>   …
> Iona: [moving her pointed finger as she speaks] …'Oh where, tell me where [Calum joins her] has my highland laddie gone.'
> Calum: That's right! [Looks at me chuckling]
> Claire: Is that what this is called?
> Iona: Yes.

The above excerpts are representative of triadic conversations shared during these interventions. While it is possible that similar interactions might have happened without music, the played music provided a vibrant impetus for equalised shared interactions amongst the three of us.

B. Triad dynamics within dementia care

A person with dementia is more susceptible to being excluded from interactions within a triad (Martin & Younger, 2000; Adams, 2003). Therefore it is crucial that other triad members take extra care not to do so (Adams & Gardiner, 2005). During these interventions, there were numerous instances when a resident felt able to express their wishes, and that their wishes were acknowledged and responded to by the carer and I. Regrettably, there were also occasions when a carer or I inadvertently impeded a resident endeavouring to have an equal voice or to express his or her wishes.

Tables 5.3a and 5.3b below summarise the primary forms of 'enabling' and 'disabling' interactions occurring during this present study:

Table 5.3a: Enabling types of triad interactions (Adams & Gardiner, 2005:191-194).

'Enabling'	This study
"Remove unwanted stimuli" (p191)	Could not remove alarms etc., but music could at least mask these extraneous sounds.
"Getting in the right position" (p191)	Whenever possible, positioning residents and carers so that they could easily see and interact with each other.
Empowerment	Residents were given continual encouragement to, "...express their views and opinions about what is happening or what they want to happen... (p191).
Providing opportunities to talk (p192)	Asking residents and carers questions throughout interventions and during exit-interviews.
Sensitivity to non-verbal cues (p192-193)	In the role of the 'professional', I strove to closely monitor all nonverbal communications.
"Valuing and respecting contributions" (p193)	Clearly expressing my appreciation of requests expressed by residents.
"Promoting joint decision making" (p193)	Standing back and letting dyads dictate the progression of the music (e.g. repeating, skipping, or stopping a tune).

Table 5.3b: Disabling types of triad interactions (Adams & Gardiner, 2005:194-198).

'Disabling'	This study
"Speaking on behalf of" (p195)	Carers sometimes spoke on behalf of their resident partner. In some cases, the carer was actually expressing his or her own wants (p195).
"Reinterpreting" (p195)	Ibid. "...this form of disabling dementia communication allows the carer to take on the role of 'expert'..." (p195).
Talking over	Though not listed in the referenced article, it sometimes occurred during this present study.

These tables encapsulate all forms of resident empowerment and impediments to resident empowerment that occurred during this study. Of course, the very term, 'empowerment' is problematic, as it connotes that those who do not have dementia are in a position to 'grant' or 'authorise' a person with dementia to have his or her equal say. Whilst this is not a message I espouse, this study illustrates the care that must be taken, and the ease with which even people who 'know better' can still thwart a person with dementia's efforts to interact equally; particularly within the triadic dynamic. The following subsections provide examples of the resident member of a triad being empowered in their interactions, as well as examples of how either a carer or I sometimes unintentionally impeded a resident's efforts to effectively communicate.

C. Resident empowerment

People with dementia and people who are very frail rarely have control over most aspects of their lives. During these interventions, I encouraged each resident to indicate his or her wishes concerning the music (e.g. volume, repeating or skipping a tune, or entirely stopping music). This form of empowerment is recognised as an effective method for equalising interactions within triads that have a substantial power differential (Astell et al., 2010). While some residents responded easily to my encouragements, it took more time for other residents to begin to feel comfortable enough to indicate their wishes. Ultimately each resident experienced and expressed a measure of empowerment during their interventions. Below are representative examples of the resident member of a triad manifesting empowerment:

During, 'My bonnie lies over the ocean', Bonnie swayed her head and sang the words. As the first verse ended, she started speaking loudly so I stopped the music:

> Bonnie: I always like hearing em played eh.
> ...
> Claire: Yeah. ... Do you want that one again?
> ...
> Bonnie: I like that one.
> Claire: You like that one? [Bonnie nodded] Want it again?
> Bonnie: Ay.
> Claire: Yes ma'am.

Bonnie recognised the tune, 'Anything goes' at once and started moving her head to the music. As this tune finished:

> Bonnie to me: What's that you've been playin?
> Claire: Anything Goes. [Bonnie makes a face] Want me to play that one again?
> [Bonnie smiles and nods]: I think so. Anything Goes.

When I replayed this tune Bonnie nodded her head and sang the words during each refrain; perhaps enjoying this tune all the more for having had her wishes heard and acted upon.

During Iona's latter three music interventions (when she was closely following her printed song-sheets), she grew increasingly confident with her directives towards me. At the end of the, 'Anniversary waltz', we shared this exchange:

> Iona: [looking at the song-sheet] Why did I not, recognise...[pointed to the words]...
> ...
> Iona: It seems to me that the last, verse, was different, from the others!
> ...
> Claire: Could be...would you like another tune? Would you like that one again?
> ...
> Iona: I can't...join the words to the music.

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> ...
> Iona: ...Start at the beginning again please, just...
> Claire: All right. I can do that...

This excerpt demonstrates the level of comfort Iona experienced during her latter interventions when she had no trouble requesting that I repeat tunes so she could sort-out the words.

Assuming we had concluded Elspeth's extended fourth (live-music) intervention, I asked her if she wanted to be taken back into the communal area. She replied:

> Elspeth: I don't think so...I want another sing-song.
> Claire: [laughing] You want another song?
> ...
> Elspeth: Well we might as well just sit and sing and play a song.

Apparently, Elspeth was feeling rejuvenated, and also comfortable enough to request more music; which I promptly delivered.

Elspeth refused her third recorded-music and sixth live-music interventions. My (albeit reluctant) acknowledgment and respect of her refusals supported the importance of respecting the empowerment of participants' (particularly those with dementia) freedom to refuse an offered activity (Martin & Younger, 2000; Hogan, 2003; Bartlett & O'Connor, 2007).

While no other residents refused an intervention, some residents indicated their desire for an intervention to end early:

Noting that Maggie was somewhat sleepy and confused during her third intervention, we shared this exchange after a few tunes:

> Claire: Would you like more music, or would you like me to stop?
> Maggie: [pause] Well if you stop now, that's it [gestures] isn't it?
> Claire: Just for today.
> Jean: Just for today. Well we've got…[to me] three sessions haven't we Claire…
> Claire: So I can either play a few more tunes for you now, or we can stop for now. It's up to you. We can stop and play some another day.
> Maggie: [looking at Jean and nodding] Well, I think, stop now.
> Jean: OK.
> Claire: OK then, that's enough for today. That's absolutely fine Maggie…

Towards the end of Aileen's first intervention, we shared this exchange:

> Claire to Aileen: Are you getting tired of the music?
>   …
> Aileen: [nodded and said quietly] A bit, yes.
> Claire: I could stop now, that's fine. There's a couple more on here but I don't have to play them, so if you'd rather take a break now that's okay.
> Aileen: If you don't mind.
> Claire: That's absolutely fine. Aileen I appreciate that you tell me…
>
> At another intervention, after smiling and singing along with the tune, 'Auld Lang Sine', Aileen said: "We'll make that the last." [I promptly thanked her and began to pack-up]

These excerpts illustrate two forms of 'enabling' triadic interactions: 'valuing' and 'respecting contributions' (Adams & Gardiner, 2005:93).

This series of excerpts illustrate residents feeling empowered to express their wishes, and my acknowledging and acting upon their wishes. However minimal these examples might seem, feeling empowered is often a rare experience for people with dementia, and can greatly enhance their wellbeing.

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i. Carer as interpreter

One of the reasons I chose to invite a person well-acquainted with each resident to share their interventions, was that I anticipated that s/he might be able to interpret idiosyncratic nonverbal cues expressed by their resident dyad partner:

After listening to just a few tunes during her second intervention, Elspeth and I shared this conversation:

> Claire: Do you like that tune?
> Elspeth: Not that interested __
> Claire: You're not interested in it? [Morven looks at me and shakes her head] Are you feeling like you're not real interested in the music today?
> Elspeth: Well I wouldn't say that, I'm just not interested…
> Morven to me: That's something that Elspeth says if she's no wanting to go to a activity. She'll say that she's not interested. But it doesnae (doesn't) mean in general, it just means at the moment…
> Claire: No no, absolutely…Elspeth, this is totally your decision. So if you're not interested in it today, and you might want to try it another day maybe?…
> Elspeth: Yes all right.

Morven's familiarity with Elspeth meant that she was able to immediately pick-up on what Elspeth was communicating by saying, 'not interested'. This enabled me to immediately and appropriately respond to Elspeth, and to end that intervention.

Examples of Isla interpreting Edwards increasingly difficult to understand communications were presented earlier in this chapter. Again, Isla's familiarity with Edward made it much easier for me to respond quickly and appropriately to Edward's wishes.

These examples underscore the advantages of including a person closely connected to a person with dementia during interventions. The person with dementia benefits from an increased possibility that distinctive communications will be correctly interpreted, and the carer benefits from knowing that his or her unique knowledge of their resident partner has been helpful at a time when opportunities to help may have diminished significantly. This inter-dependent dynamic may also invite greater connection and interaction between the carer and the person with dementia.

ii. Impediments to resident empowerment

Resident empowerment was sometimes compromised; either because of a resident's own embodied habits of deflection, or as the unintentional result of missteps by a carer or me. Examples of both forms of impediments are illustrated in the following subsections.

a. Embodied habits: deflecting empowerment

Despite repeated encouragements, some residents were reluctant to express their wishes, as evidenced by a tendency to deflect their power back onto either their carer or me:

When I asked Iona in one of her earlier interventions if she wanted me to repeat a tune she had clearly enjoyed, we shared this exchange:

> Claire to Iona: Would you like this one again then? [Iona looks at me with a big smile]…Yes ma'am! I told you, I'm your, you're the boss so…
> Iona: No, you're the boss!
> Claire: No, I'm afraid not!
> Iona: Oh, oh yes, I'm not…

> Claire: You are the boss of this. This is your time and you can boss me around all you want so...

This example shows Iona's resistance to the idea that she is in charge, and her efforts to put the power back in my court.

Generally when I asked Aileen if she would like more music or to have a tune repeated, she looked towards Tommy to provide the answer, saying: "It's your choice Tommy." Or: "Whatever you want Tommy."

Though Bonnie usually expressed her wishes, she was sometimes more reluctant:

> Claire to Bonnie: Are you fed-up or do you want some more music?
> Bonnie turning to Nessa: I don't know.
> Claire to Bonnie: Well Bonnie what do you think? Are you tired of the music?
> Bonnie to Nessa: Whatever. It's up to you!
> Claire to Bonnie: It's completely up to you.
> Bonnie: It's completely up to me.
> Nessa: Yeah, another one.
> Bonnie: Another one.

This example shows Bonnie turning to Nessa to answer for her. This could simply be a moment of confusion, or a relegating of power.

When asked if she would like to hear more music, Edine and Cait shared this exchange:

> Edine: Well [looking at Cait] I have plenty of time, it's up to Cait.
> Cait: Oh yeah, well I have plenty of time!
> Edine: You've plenty time.
> Cait: I have plenty time, plenty time.

This example appears to be an embodied habit, as Edine so clearly enjoyed the music, but also likely spent most of her life deferring her wishes to the requests of others.

Tendencies to deflect control back to either a carer or to me may have been due to individual personalities, cultural customs, or embodied habits. Regardless, they also underscore the internalised barriers to empowerment that people within these and similar populations and settings are likely to be especially prone to.

b. Resident empowerment impeded by carers

The excerpts below illustrate instances when a resident's attempt to communicate his or her wishes were unintentionally suppressed, contested, or simply missed by a carer during these interventions.

The issue of preferred music genre sometimes became a source of misunderstanding, with a carer seemingly confusing his or her personal preferences for those of their resident dyad partner:

Partway through Greer and Kirsty's intervention, Kirsty commented:

> "...with the ones [tunes] that she's [Greer] recognising very well [e.g. popular show tunes of the 1940s], she's looking over at you - far more observant...and the ones that *I* wasn't familiar with [e.g. classical music]...she started looking out the window..." (Kirsty).

...I then asked Greer what she thought about the classical [Bach] music, and she answered with a definitive:

"I think it's very good" (Greer).

An accomplished classical musician herself, Greer would have been very familiar with the show tunes *and* the classical music I played for her. Kirsty had no prior experience of classical music, thus it is more likely that Kirsty was projecting her *own* lack of connection with the classical music onto Greer. Directly asking Greer how *she* felt about the music returned Greer's empowerment back to her.

Having previously been a keen ballroom dancer meant that Edward favoured (fast *or* slow) popular dance tunes from the 1940s. He regularly confirmed his music preferences by smiling, tapping his foot, and exclaiming, "yeah!" and "that's it!" whenever he heard tunes from this genre. Isla meanwhile preferred hymns, classical, and lively Scottish tunes, which she repeatedly endeavoured to infer were really what Edward preferred as well:

> Isla to me: It's interesting when the [Edward's] foot starts, it's always the lively ones…that's obviously where the…pleasure is I think in the, that's why he likes…Scottish dance music, you know it's got a good lilt and beat I think…
>
>   …
> Claire to Edward: You want…more of the 40s tunes is what I understood from you? Is that right?…Scottish tunes are the…reels and jigs from the céilidhs?
> Edward: No, I…
> Claire: And then 40s tunes are…ballroom, [Edward: Yeah] 'Begin the beguine' [Edward: yeah], and…Cole Porter [Edward: yeah, yeah]…so…would you like me to play you some of the Scottish…
> Edward: [raising his eyebrows] No, no, just…
> Claire: …or the 40's tunes?
> Edward: Yeah. Um hmm.
> Claire to Isla: … he seems, to be very clear around that so…
>
>   …
> Isla: Fast ones! Fast ones with a good beat!
> Claire to Edward: I'm still going to play you a few of the slow ones I know you like. Like, 'I'm getting sentimental over you'…

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Edward: [smiled and nodded] Yes, that's right!

During the next intervention, Isla was tapping her foot along with the lively hymn, 'All things bright and beautiful' (which I played in deference to the above conversation, while Edward remained fairly impassive, simply commenting as it ended, "...it's some...hymn." After this hymn I played several upbeat Scottish tunes, and again Edward remained fairly impassive. But as soon as I began playing (slower) 1940s tunes, Edward smiled broadly, nodded, and exclaimed, "That's more like it!"

These excerpts show how easy it can be to compromise the fragile empowerment of a person with dementia.

c. Resident empowerment impeded by me

Upon reviewing the video-footage of these music interventions, I was dismayed to realise that there were several instances when I missed signs of a resident tiring, and consequentially missed the opportunity to respond appropriately:

Partway through Maggie's first (recorded-music) intervention:

> Maggie to Jean: [long pause] Well that's been very pleasant! [Smiling broadly]
> Claire to Maggie: Do you want me to stop now?...
> Maggie to Jean: Well got other ones will maybe want to hear him [sic]?
> Jean: No, this is for you!
>   ...
> Claire: Just play a few more. See if you like these couple...
> Maggie: Well play them then: *if you wish.*

This exchange shows Maggie politely but clearly indicating that she is growing tired. It also shows that despite my best intentions – or perhaps *because* of my

best intentions, I continued to play music, with the well-intentioned optimism that she would enjoy the rest of the selections I had chosen for her. Maggie's remark; "If you wish" suggests a capitulation rather than an actual desire to listen to more music. In a telephone conversation later that evening, Jean confirmed that Maggie's comments such as; 'that was pleasant' or; 'thank you very much', were indications that she was tiring. This is both another example of the helpfulness of a carer's input, and also of how easy it is to miss the possibly deeper connotations of apparent pleasantries.

During another of Maggie's recorded-music interventions, Maggie asked:

> Maggie to me: Now sir [sic], what was this all about?
> Claire: [engrossed with the CD player] Hold on a second, we're on…[I look at my tune sheet]…

This excerpt illustrates my being so focused on getting the CD-player to work properly, that I entirely ignored and failed to respond to Maggie's query.

Iona and Aileen's occasional glances at their watches, and the single time that Edine glanced at her wristwatch while stretching-out her severely swollen (oedema) leg were not immediately acknowledged by me. Instead, I was again propelled by my well-intentioned belief that the next tune would be particularly enjoyed by a (flagging) resident. Often, it was not until after several more tunes were played (possibly eliciting additional watch glances by a resident) that I realised and acknowledged that a resident was tiring.

Betsie was particularly tired from the outset of one of her last interventions, and after several tunes (all of which she had sang along with) we shared this exchange:

> Betsie to Morven: I'm wanting my bed if I tell you the truth!
> Morven: You tired?
> Betsie: No, I'm just, can't be bothered sittin.
> Claire: You gettin tired of sittin?
> Betsie: No, I just, can't be bothered.
> Claire: You can't be bothered.
> Betsie: No. So I'm wanting to go…
> Morven: You wanting another tune?
> Betsie: What time is it?...
> Claire: Do you want another tune Betsie?
> Betsie: Please yourself!

I played the next tune:

> Betsie to Morven: My bed is waiting for me.
> Morven: You tired?
> Betsie: No
> Claire: Do you want more music Betsie, or would you rather I stopped?
> Betsie: No! I like music!
> Claire: OK. [Morven and I chuckled]

I did play more tunes, and Betsie continued to sing along with every one of them, but in retrospect Betsie seemed to be trying to indicate that despite enjoying the music, she really was very tired.

After Heather responded emotionally to several tunes partway through her lone music intervention, I asked her if she would like to hear more music, to which she clearly replied; "No, that's enough." Regrettably, I responded to her clear statement by assuring her that the following tunes would be 'happier' (in fact they turned-out to be slow tunes). Heather agreed to hear more music and a number of tunes later when I again asked if she wanted me to stop playing the music, she replied, "yes" while nodding - and I did stop. When asked if the music

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had gone on for too long, Heather answered, "Yes, very long." Equally, when I asked her if there were some tunes she would rather not hear, she answered: "No, I liked them all". Her daughter Donna later told me that Heather had said how much she had enjoyed the music and had wondered if she could have a CD of the music I had played. This is the most egregious example of my enthusiastic belief in the possible benefits of the music ironically preventing me from being fully attentive and responsive to the wishes of a resident. And even so, Heather enjoyed the music and clearly expressed the desire that I come play music for her again.

Though Elspeth's lack of connection with the recorded-music has been noted earlier in this chapter, the following exchange shows my inadvertent missing of what retrospectively appears to be obvious signals that she was done:

Less than twenty-minutes into her first recorded-music intervention:

> Claire to Elspeth: ...Do you want some more music?
> Elspeth: I don't think we've got much time left.
> Claire: You've got some time...if you'd like some. See what you think. You can tell me to stop.
> Elspeth: Right.
> Claire: Do you want some more?
> Elspeth to Morven: What time is it?
> Morven: It's, just after half past eleven.
> Elspeth to Morven: I've not much time to get to lunch.
> Morven: Oh, lunch isn't until half past twelve.
> Claire: You've got some time, so it's all right that way.
> Elspeth: [pause] well maybe a half-hour or so.

This excerpt demonstrates another example of a resident somewhat cryptically expressing her wish to end an intervention, followed by her capitulating to those she perceives to be in power; in this case her carer and me.

As uncomfortable as these examples are to disclose, it is important that I do so, as they corroborate what prior research has found, regarding the ease with which this dynamic can occur during interactions with people who have dementia (Hubbard et al., 2002).

D. Shifting triad interactions

The following series of subsections draw on the conceptual frameworks of SI and DA to help demonstrate how each triad member's discrete 'roles' and alliances shifted during these interventions, and what affect the played music had on these shifting alliances and roles.

i. Resident and Carer: me as the 'outsider'

The excerpts below show how the interactions between dyad participants sometimes caused me to assume the role of the 'outsider', described by Goffman (1959) as:

> "... neither a member of the 'team' or the 'audience', nor a 'performer '"(Goffman, 1959:135).

Equipped with the requested printed song-sheets during their live-music interventions (4-6), Iona and Calum became completely immersed in following along with the words to each tune, while I became their live jukebox. At the time I felt somewhat frustrated with what I viewed as Iona no longer really listening and engaging with the music like she had during her first three (recorded-music) interventions. Indeed, I repeatedly (and ineffectively) suggested to Iona that she might enjoy the music more if she simply closed her eyes and *listened* to the music. Iona and Calum unanimously overruled me by basically ignoring my

promptings; indeed my promptings only served to increase their allegiance to the song-sheets:

While Calum passed Iona a printed song-sheet I initiated this conversation:

> Claire to Iona: Well I don't know if I'll bring the texts again. I think that they're, they're...they cause more trouble than good, don't you think?
> Iona: Uh...
> Claire: What do you think?
> Calum to Iona: Quite nice to have the words. Do you like to look at the words?
> Iona: Uh huh.
> Calum: Uh huh.
> Iona: Oh yes.
> Calum: Oh yes, OK. [Smiling at me]

Later, when Iona began repeatedly rubbing her eyes and speaking about having difficulty reading her song-sheets, I initiated this conversation:

> Claire to Iona: You know you could just listen if you don't want to be looking, and if your eyes are tired...
> Iona: Well I would like to listen...
> Calum to Iona: [handing her the next song-sheet] There you are...see how you get on.

These two excerpts show Calum quietly but steadfastly supporting their collective desire to continue using the printed song-sheets. I meanwhile felt very much the third-wheel or 'outsider' during these interventions.

During each of Greer's two (live-music) interventions, the connection within the dyad was very intense, and I felt clearly relegated to the 'role' of the 'outsider' who was only there to play music for them, but not to authentically interact with them.

My recognisably foreign (North American) accent also instantly positioned me as an 'outsider':

Betsie needed Morven to repeat nearly everything I said. I initially attributed this to hearing difficulties, but it quickly became apparent that it was my accent that she could not understand:

> Betsie to Morven:...donnae [don't] ken a fecking word she [I] says! [Morven and I laughed and Betsie made a funny head gesture]
> Claire to Betsie: That's fine Betsie, I'm not saying anything important. Nothing important.
> Betsie to me: That's fine, as long as you're no speaking about me.

Maggie and Edine regularly asked me where I was from:

> Edine to me: Where are you from lass?

> Maggie: I thought you were just fresh across!
> Maggie: [smiling wide and mocking me] interesting eh? You're an American!

Maggie also delighted in mocking my American accent:

> Maggie: [smiling broadly] You're, you're an American anyhow.
> Claire: Well, yeah, anyhow I am. 'Yeah'!
> Maggie: [smiling wide] Yeah!

My American accent automatically positioned me as an 'outsider' amongst dyads consisting purely of British and predominantly Scottish people. Further discussion of how this aspect of my being an 'outsider' might have impacted on this study can be found in the final chapters of this thesis.

ii. Carer and I as 'observers': resident as 'performer'

Sometimes a carer and I inadvertently became the 'observers', and the resident became positioned as the 'performer' or the 'outsider'. These situations generally consisted of fleeting exchanges of facial expressions (e.g. smiles,

winks, quizzical expressions) between a carer and me. However, there were instances when this dynamic was somewhat more pronounced:

After I played the tune, 'The dashing white sergeant', Aileen, Tommy, and I began a spirited chat during which I mentioned that I had recently danced to this tune at a céilidh in a town called Pitlochry. Aileen replied:

> Aileen: I haven't been to Pitlochry in a long time...we used to__Pitlochry…

…Regrettably at this point Tommy interrupted Aileen, and I too made no further effort to find-out what she was trying to communicate.

Another time, Aileen, Tommy, and I shared a lengthy conversation after the tune, 'By the bonnie banks O'Loch Lomond':

> Aileen to Tommy: Do you know that one Tommy?
> Tommy to Aileen: Bonnie Bonnie Banks of Loch Lomond...you take the high road and I'll take the low road.
> Aileen: [__]
> Tommy to me: it's not a jolly song, actually it's a funeral song... Claire to Tommy: You Scots, you like your dour [depressing] songs! [Laughs]
> Tommy: When your...
> Aileen to Tommy: What's the traffic like on the roads today at this time?
> Tommy to Aileen: Not too bad today, not too bad.
> Tommy to me: When you died your spirit returned underground... Claire to Tommy: Yes, because I heard it as a kid…[while Tommy and I continue discussing this tune, Aileen is sitting impassively, frequently glancing at her watch]

This excerpt depicts another thankfully rare example of a carer and I excluding a resident member of the triad from interaction. In her role as the 'outsider', Aileen disengaged from us by looking around the room; yawning; and gazing at her watch.

At the beginning of one of Bonnie and Nessa's interventions we shared this

conversation:

> Nessa to Bonnie: It's [her great granddaughter's] birthday tomorrow.
> Bonnie to Nessa: Huh?
> Nessa to Bonnie: [pointing to a photo on the wall] She'll be three tomorrow. [No response from Bonnie]
> Nessa to me: She would have normally went 'oh well, hope we're having a party', but...she's definitely, in the past few weeks has totally changed. Totally. In fact, had she been like this, I probably would have said to you it's no worthwhile bothering...had this been like this at the time, then I would think, nah.
> Claire to Nessa: Yeah, I know, and I understand why you would have said that, but, let's just see what happens.
> Claire to Bonnie: Okay I'm going to play some music for you Bonnie.

This excerpt illustrates a carer speaking to me about her resident dyad partner

as if she is not present, thus positioning her as the 'outsider'. Though this

thankfully did not happen often during this study, this example shows how

easily this can occur when three people are interacting.

In a related situation, there were also instances when a carer's behaviour

signified that they saw themselves in the 'role' of a fellow 'observer' of their

resident partner:

> Jean to Maggie: You love Claire's music.
> Maggie: [smiling] Yes.
> Jean: That's good. That makes it all worthwhile.
>
> Maggie to Jean: And you planned all this!
> Jean: No, this ___ Claire.
>   ...
> Maggie: Oh my goodness!
> Jean to Maggie: Some people might not be willing to, allow Claire to do it in, for the relative or their mum or dad or whatever, so this is good because Claire's getting a good feedback from us.
> Maggie: Oh Absolutely!
> Jean: And that makes it all better. That makes it all worthwhile.

This subsection demonstrates the ease with which alliances can form between a carer and a 'professional' within a triad that includes a person with dementia; despite awareness and efforts to avoid such alliances.

iii. Resident and I as 'performers': carer as 'outsider'

There was usually some amount of interaction (e.g. identifying a tune; expressing appreciation; asking questions; telling stories; asking for repeats of tunes or to stop a tune etc.) between a resident and me during every music intervention. However, sometimes our interactions took 'centre stage', and the carer was positioned as the 'outsider'. Section 3.i in this chapter presents clear examples of this dynamic. It appears that for some residents, playing the cello live prompted greater awareness of me as a person of interest, and created a more compelling medium of interaction between us. This topic is considered in greater depth in chapter 7.2.B.iii.

The only resident whose (albeit understated) interactions were almost exclusively directed towards me throughout *all* of her music interventions was Hazel: she named most tunes as they started, and said, 'very good' with a smiled at me as they ended - and rarely acknowledged her dyad partner Sheena.

5. Conclusion

Given that these interventions included three people, interactions were destined to be changeable. Because one member of each triad had dementia, and the same or similar music was played (either live or via a recording) during each of our encounters, this study afforded an unusual opportunity to learn

more about the potential effects of music on dyad *and* triad interactions involving a person with dementia. These findings are important because this triad dynamic is quite common within dementia care settings. My findings suggest that receptive music interventions can be utilised as an effective shared activity towards promoting connections and enhancing interactions between people. Listeners, regardless of their cognitive or physical status, or their historical rapport, can experience these benefits. These findings also suggest that although live-music may instigate greater interaction within some dyads, other factors can also have considerable positive impact on dyadic interactions (e.g. inter-dependence; printed song-sheets; and repeated interventions). These findings also underscore just how fragile a person with dementia's empowerment can be; and how easy it is for the other triad members (i.e. a carer or professional) to inadvertently impede on his or her empowerment.

The next finding chapter situates these dyad and triad interactions within a larger context wherein elements of the intervention structure and the music played created a 'haven' for participants.

CHAPTER 6. 'HAVEN'

1. Introduction

DeNora's (2013) concept of 'asylum' comes closest to describing the extraordinary atmosphere experienced to varying degrees by all participants during these interventions:

> "If...wellbeing takes shape in relation to environment, then asylum can be defined as a space, either physical or conceptual, that either offers protection from hostility (a refuge) or...a space within which to play...with one's environment, whether alone or...with others...an asylum is...a space for self but also a space one can, in part 'own' and share" (DeNora, 2013:47).

Although DeNora labels this experience as 'asylum', 'haven' - "A place of refuge or security" (Oxford University Press, 2014), feels a more apt term for this present study.

According to DeNora, this 'place of refuge' is created through 'removal' from, and 'refurnishing' of, one's surroundings (DeNora, 2013). During this study's music interventions, elements associated with two main factors combined to facilitate participants' experiencing their sessions as a 'haven': the format of these interventions 'removed' participants from their everyday lives; while the music sonically 'refurnished' their present reality.

Kitwood (1997) states that there are five essential human 'needs': 'comfort-attachment-inclusion-occupation-identity', which in total fulfils our core 'need' for 'love'. Kitwood defines 'need' as:

> "...that without which a human being cannot function, even minimally, as a person" (Kitwood, 1997:19).

This study's findings suggest that when participants felt that these basic human needs were fulfilled during their interventions, a sense of 'haven' was experienced.

A key objective of this thesis was to explore the effects that receptive *music* had on people from the specific populations of people with dementia nearing end of life, and their carers. My findings suggest that although music was the central motivator for changed responses, elements of the intervention format also directly or indirectly contributed to these changes. This chapter is divided into three main sections: the first section presents findings regarding the effects that elements of the intervention format had on participants' experience of 'haven'. The second presents findings regarding characteristics of the music that contributed to an experience of their interventions as a 'haven'. The third describes an extraordinarily high-charged 'emergency-intervention' I was asked to provide for one participant. This intervention illustrates the potential of music to reach, captivate, and maintain the attention of a listener in a highly dissociative and agitated state, and to provide him the opportunity to experience 'haven'.

2. Intervention format and 'haven'

This section presents findings regarding how specific elements related to the format of these music interventions influenced participants' ability to experience their interventions as a 'haven'.

A. Repeated interventions

Each intervention began in the same manner: both dyad members settled into their pre-arranged chairs, I greeted them, reintroduced myself and the study, and asked if they were both happy to listen to music (i.e. 'on-going consent': Hubbard et al., 2003b; Cameron & Murphy, 2006; Allbutt & Masters, 2010; Astell et al., 2010). I re-invited the resident participant to indicate in any way he or she felt comfortable if s/he wished the music to be stopped, replayed, skipped, or if s/he was growing tired. This ritualised format seemingly helped set a familiar tone, which encouraged participants to become more comfortable and perhaps more available to experiencing their interventions as a 'haven'. The following subsections highlight the particular benefits that participating in a succession of interventions had for some residents and carers.

i. Residents and special attention

Carers and staff conjectured that receiving a series of visits and focused attention from someone with whom s/he was familiar and comfortable was likely of significant benefit in and of itself for their resident dyad partner.

Prior to taking part in this study, Tommy rarely visited his distant cousin Aileen. During his exit-interview, he observed:

> "...whether it was the music or whether it was [Aileen] seeing me on a more regular basis...yes, I think possibly she seemed a little...at times I think she even joked, she smiled a little bit more than usual. Whether that had anything to do with the music or just my more frequent visits and she saw more of me...I have seen more her, she's seen more of me...I think she's a bit more relaxed and bit chattier to me over the last few weeks... but I think she might even miss the weekly or fort-nightly musical interludes because it's been something different" (Tommy).

Aileen's keyworker later informed me that Tommy had continued visiting Aileen more often, and had taken more interest in her wellbeing since the end of their interventions.

During Cait's exit-interview, she speculated on the benefit that these repeated interventions had for Edine:

> "...I think that it [the music interventions] certainly, most certainly did add quite a bit to Edine's...life and day as it were. Because obviously days in a home are probably like days in a hospital up to a point, where there is the long sort of days with sometimes not very much to look forward to...and I think it's a personal thing because you were actually doing this specially for her, and it makes them feel special, which is again, a lovely thing because, ya know, we all like to feel special at some point. That alone is a lovely part of it. You know just someone coming specially just to do this for you. And that's lovely" (Cait).

Although the above quote reflects Cait's perceptions, it resonates with what I witnessed during Edine's interventions, as she was clearly delighted each time she saw that Cait was joining her in listening to the music.

During Jean's exit-interview, she observed:

> "...she [Maggie] has thoroughly enjoyed it...Mum likes to be special...likes to be number one...and when you were...it was one-to-one" (Jean).

Again, though this is Jean's perception, it resonates with what I witnessed during their shared interventions.

ii. Transformed of dyad rapport

The recurring nature of these interventions also allowed those dyads whose initial rapport appeared to be somewhat strained or awkward to improve (see chapter 5.3.B). This reflects Goffman's (1959) observation that when repeated visits take place between people in the same location, a social relationship is likely to arise even when there has not previously been one.

iii. Relaxation for some carers...

Some carers accepted their repeated interventions as a pleasant break from otherwise busy and sometimes stressful lives:

> Donna: The music sessions gave me a break and a chance to make conversation because otherwise it's hard work with her [Heather]...

> Kirsty: ...it gave me an hour's worth of just relaxing...I liked lying on her bed...taking my very hectic life, it gave me an hour's worth of just relaxing.

> Tommy: ...it was...quite an enjoyable...um...quiet half hour or so: a brief oasis of calm in a normally busy day. And, yes, I mean it was...it was fine...I quite enjoyed it.

Some carers spoke of the joy they derived from seeing their resident dyad partner enjoying his or herself:

> Jean: I like to see Mum [Maggie] enjoying it...it's brilliant. It's nice to see her getting involved in it really.

> Sheena: You know and as I say Hazel's enjoyed it and that's good to watch and you know, her facial expressions and seeing that she is enjoying it.

The above excerpts illustrate that as some carers became more familiar and comfortable throughout successive interventions, they were better able to relax, and thus were more fully able to enjoy their own experience, while taking

pleasure in seeing the enjoyment that their dyad partner was experiencing.

B. Setting

The reasons for choosing to conduct these interventions in the private bedroom of each resident are detailed in chapter 4.4.D.iii. The intimate familiarity, and relative quiet of this setting, helped foster a sense of 'haven' for residents. Many of these residents did not attend public entertainments offered within their care homes, either due to physical frailty, or because they no longer derived pleasure from public or group forms of entertainment. The excerpts below illustrate the contribution that the setting chosen for these interventions made for some residents.

During her initial-interview, Sheena said of Hazel:

> "...I'm not sure whether Hazel will enjoy it [the music interventions] or no...sometimes music does annoy her...you know even if we go downstairs to you know entertainment ...we'll come back up and [she'll] say ken, 'that was just a bloody din' sort of thing you know and that's... and that's just how she is you know. So she'll either love it or hate it..." (Sheena)

...Much to both Sheena's and my surprise, Hazel *did* enjoy listening to music in her own bedroom.

The importance of setting was later verified when I played the cello in the communal room where Hazel, Edine, and Maggie lived a few months after completing my fieldwork. Seated in the front row, I was certain that they would take extra pleasure in hearing me play the cello for them again; I was surprised that all three of them appeared wholly disconnected with my playing in this much more public setting.

3. Intervention format: hindrances to 'haven'

Aspects of the intervention format also sometimes hindered a participants' experience of 'haven', as is demonstrated in the subsections below.

A. Individuals sharing interventions

People sharing an activity (such as listening to music) have influence on one another's experience of that activity (Goffman 1959). Those dyads sharing a comfortable relationship, rapidly relaxed and enjoyed listening to the music, and derived pleasure from witnessing their dyad partner's enjoyment as well. Conversely, those dyads initially sharing an awkward or distant relationship usually were also more restrained in their individual responses to the music, as well as with each other.

During this study, there were three unintended occasions when a different carer participated during one or more interventions. Though not ideal, these substitutions helped demonstrate the potential impact that the attitudes of those sharing an activity can have:

i. Edine-Cait: Edine-Bethia

Due to several communication mishaps, Edine's keyworker Bethia shared Edine's second (recorded-music) intervention. Bethia sat impassively, looking distractedly around the room, and occasionally glancing towards Edine throughout this intervention. Edine barely interacted with Bethia or I during this intervention, and her responses to the music were also notably subdued;

especially when compared with the level of her engagement during the five other interventions she shared with Cait.

ii. Greer-Brenda: Greer-Kirsty

Greer shared her first (live-music) intervention with her daughter Brenda, and her second (live-music) intervention with a contemporary friend, Kirsty.

When I started playing the cello during Greer's first intervention, which she shared with Brenda, her face lit-up, she listened attentively to the music, looking towards Brenda throughout, and squeezing Brenda's hand whenever she particularly enjoyed a tune. At the conclusion of this intervention, Greer communicated how much she had enjoyed the music and her wish that I would come play for her again. Each of the several pieces of music that had been hand-selected by Brenda elicited verbal reminiscences from her about special moments she had shared with Greer when she was a little girl, and the deep connection between this mother and daughter.

Greer and Kirsty also maintained a strong physical and visual connection during Greer's second (live-music) intervention; mostly as a result of Kirsty's solicitous attitude towards Greer. During this second intervention, Greer conveyed her enjoyment after tunes via brief verbal responses, occasional smiles, and brightening eyes. But when I began playing one of the pieces hand-chosen by Brenda that had previously elicited such fond memories from Brenda during Greer's prior intervention, Greer sat bolt upright, her respirations markedly increased, and her facial expression transformed into a grimace. I immediately

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stopped playing, and asked Greer if she was all right; to which she responded: "Nothing is right."

Eventually Greer was able to communicate to me that she wished me to go back to playing the perhaps less personalised music I had been playing previously. After several more tunes she became visibly more relaxed, and was again verbally complimenting the music, even tapping her foot a tiny bit.

Greer's very contrasting responses when listening to the same piece of music seems to directly result from the personal significance that this particular piece of music had for her. Hearing this piece with her daughter elicited shared experiences and consequently shared meaning from them both. Listening to this same piece with someone more recently involved in her life seemingly caused Greer to keenly feel her daughter's absence. These divergent responses suggest the potentially powerful impact that the presence of different people sharing a receptive music interventions can have.

iii. Betsie-Gavin: Betsie-Morven

During the two (live-music) interventions that Betsie shared with Gavin, Gavin predominantly maintained the 'role' of an 'observer' rather than as a fellow participant joining Betsie as an 'audience' member. Although Betsie and Gavin shared a pleasant rapport, Gavin's engagement with the music and his interactions with Betsie were minimal. Conversely, from the moment that Morven joined Betsie at the start of her third (live-music) intervention, they were constantly singing, laughing, joking, exchanging banter, and exchanging affectionate physical thumps.

These three presented cases suggest that the attitudes and responses of whoever shares receptive music interventions with a person living with dementia has the potential to significantly influence the quality of his or her experience.

iv. Edward and Isla

Although Edward and Isla's rapport improved during their latter recorded-music interventions (see chapter 5.3.B.ii), Edward's care home manager, Evelyn was certain that Edward would more freely have expressed his engagement with and enjoyment of the music had he been sharing his interventions with his keyworker instead of Isla:

> "…what would have been interesting, it's a pity it couldn't have happened, was for his daughter to be there, but then do another one with…[his keyworker]…I think you would have got much more [response] because…it's a different relationship…the carers are working with people who, perhaps are in palliative care…They're developing a different type of relationship with a person. These are the people who are washing, who are dressing, who are attending to very personal care, so it's very important that a relationship is developed…So, when the carer sits with them, it's okay: because they've seen them at their most vulnerable. So, it's okay to let themselves go in front of that carer" (Evelyn).

Evelyn's viewpoint reflects what I had suspected to be the main cause for Edwards' somewhat guarded responses to the music. I knew he loved listening to 1940s popular dance music, yet the evident strain in his relationship with Isla (see chapter 5.3.B.ii) was quite likely holding him back from complete enjoyment of the music.

Possible implications of these findings for future practice and research are discussed within the final chapters of this thesis.

B. Staff interruptions

Despite my placing a large cautionary sign complete with orange highlighting on the outside of each resident's bedroom door during every intervention, often unnecessary staff interruptions were an unwelcomed encroachment on participants' experience of their interventions as a 'haven'. These interruptions involved a staff member knocking (or not) and opening the door – often very nearly toppling expensive video-equipment and disrupting the flow of the intervention in progress. The reasons given for these interruptions included offering tea to a resident; summoning Morven (who was a member of staff) to try a cake; or cleaning a bathroom. While I am not in a position to fully understand why these interruptions occurred, suggestions towards possibly averting future similar interruptions are offered in the final chapter of this thesis.

C. Repeated interventions...not so relaxing for some carers...

Just as some carers experienced these interventions as an opportunity to relax, others felt compelled to maintain a watchful eye over their dyad partner, and therefore had difficulty relaxing during their interventions:

Nessa was highly vigilant over her mother Bonnie and routinely expressed disappointment when Bonnie did not respond in ways that Nessa had expected or hoped. Nessa often tried to nudge Bonnie into action:

> Nessa to Bonnie: That was a jig; you would be jigging at that.

Or:

> Nessa to Bonnie: I thought you would have been singing by now...no singing...Not singing, not speaking.

During her exit-interview Nessa spoke of her experience:

> "To be honest I was more focused on my Mum than on me...em because I kept looking at her to see if she was reacting. And I think you realise that I was worried about the fact that she's gone downhill so rapidly... so I was more focused on what she was doing then me..." (Nessa).

Kirsty expressed a similar sentiment during her exit-interview:

> " I must admit...more my caring side was very aware of looking at Greer...and reactions. Where if it had been just me lying back I would definitely have relaxed a lot more. But because I felt I had to be aware...maybe I could have relaxed more, but she was the primary..." (Kirsty).

During her pilot intervention, Brenda grew increasingly concerned about Greer being at the low-ebb of her Parkinson's medication cycle:

> "...this is not the best time of day to play for Mum when she is due medication..." (Brenda).

For these carers, their tendency to closely monitor their dyad partner resulted in their having difficulty relating and thus fully experiencing their interventions. Carers of people with dementia often feel they must work hard to keep interactions going (Astell et al., 2010), so a carer's response to sharing an activity with someone with dementia will ultimately reflect his or hers individual proclivities.

D. Biological measurements

As discussed previously (see chapter 4.4.B.v), because measuring pulse and blood pressure proved too disruptive for some residents, I quickly began only taking these measurements from carers. I found that introducing even these simple, quick, and painless medicalised procedures into these interventions felt intrusive and introduced a clinical atmosphere, which may have impeded on participant's experience of their interventions as a 'haven'.

E. Intervention duration

Whereas thirty-minutes as a targeted intervention duration (see chapter 4.4.C.iv), worked well for the majority of participants most of the time this study's findings suggest that fifteen-minutes may have been sufficiently beneficial for most residents, perhaps because of their considerable frailty. The excepts below illustrate residents beginning to tire sometimes as early as five-minutes into an intervention, but usually just about fifteen-minutes after their intervention began:

About fifteen-minutes into his fifth (recorded-music) intervention, Edward indicated that he was growing tired and wanted to end this intervention by waving his arms in the air.

About ten-minutes into Maggie's first (recorded-music) intervention, Maggie said, "that's lovely". After another five-minutes, Maggie yawned. Fifteen-minutes later, Maggie remarked; "Well that's been very pleasant!"

Aileen glanced at her watch about fifteen-minutes into her first (recorded-music) intervention, and did so again five-minutes later. She did the same about fifteen-minutes into her third (recorded-music) intervention. Especially tired from the start of her sixth (live-music) intervention, Aileen glanced at her watch several times, with this intervention concluding after about twenty-minutes.

Although Betsie engaged with the music throughout her interventions, she often sighed and quickly glanced towards her bed at around the fifteen-minute mark of most of her interventions.

Most of Hazel's interventions occurred on sunny late afternoons, and about fifteen to twenty-minutes into each of her first four interventions (three recorded-music and one live-music) she mentioned she was feeling sleepy.

Between fifteen to twenty-minutes into her first (recorded-music) intervention, Elspeth expressed concern that lunch would be coming soon. During her second (recorded-music) intervention she proclaimed she was: "not interested" after only five-minutes of music.

Iona yawned after about fifteen-minutes into her first two (recorded-music) interventions, and again about ten-minutes into her fourth (live-music) intervention.

Bonnie usually became notably more distracted during the latter half of her interventions.

Heather said she had heard enough music around fifteen-minutes into her (recorded-music) intervention.

These examples illustrate that many residents grew tired well before the targeted interval of thirty-minutes. Some of the likely reasons for a resident growing tired earlier than anticipated are detailed in the subsequent sections, and include: the pace of the music not matching a listeners' current mood; slower paced music; the time of day; individual medication cycles; the present health of each resident; and that for some residents, the recorded versions of the music may have proved less stimulating.

F. Time of day

The scheduling of these music interventions was based solely on the availability of each carer, which did not necessarily correlate with the optimal time of day for their resident partner:

Maggie appeared confused at the start of her third intervention because she was coming directly from her morning bath. She mentioned to Jean that she was feeling 'overwhelmed' towards the end of this shortened intervention.

Most of Hazel's interventions took place in the late afternoon, and it is possible that the warm late afternoon light contributed to a shared feeling of lethargy in all three of us during some of these interventions.

The medications that Greer and Elspeth took for Parkinson's disease meant that their energy levels and responsiveness were largely predicated on where they were in their medication cycle. Unfortunately Greer's pilot intervention coincided with a low-point in this cycle, prompting her daughter Brenda to remark:

> "This is not the best time of day to play for Mum when she is due medication..." (Brenda).

G. Intervention-related concerns

Some of the (female) residents felt that they should be sharing their interventions with other residents:

> Heather:...there's a lot of people that's living here they would like to hear that music.
>
> Aileen to me: Is there no one else to [   ]?
>
> Maggie: I don't know why you're not in the sitting room?
>
> Aileen: Are you playing for any others at SunnyDale House?

Iona was often concerned that the music might be disturbing her neighbours:
> Iona to Calum: Probably __ wondering what's going on today!... All my neighbours will wonder...
>
> Iona: [pointing towards the door] Did the people roundabout there not object, to your...

A loud call-alarm incessantly blaring during one intervention again prompted

Iona to be worried about disturbing her fellow residents:

> Iona: [pointing at something] That __ keeps__
>   ...
> Iona:...are we interrupting?
>   ...
> Claire: No no. We're not interrupting anybody. That's interrupting us but [Calum chuckled] we're not interrupting them.
> Iona: Oh, I see. Well that's not so bad...As long as there's nobody outside the door, because they would...

Aileen regularly voiced concern during her live-music interventions that *I* might

be growing tired:

> Aileen: We're not taking up your time?

> Aileen to me: Am I taking up your time though?

> Aileen asked me: Do you tire yourself out?

These concerns may have interfered with experiencing an intervention as a

'haven'.

This series of subsections draws attention to elements related to the structure

of these interventions that may have hindered a participant's experiencing a

sense of 'haven' during an intervention. The next section presents findings

regarding characteristics of the played music that both facilitated and perhaps

hindered participants' experiencing their interventions as a 'haven'.

4. Music in the 'here-and-now'

Before presenting this study's findings regarding the impact that various

characteristics of the played music had on participants in relation to their ability

to experience a sense of 'haven' during these interventions, I will first provide a brief overview of the categories of participant responses applied in this study:

Categories of responses to music

Participant responses to the music are grouped within three categories: 'positive'; 'negative'; and 'neutral'. Although not definitive, these response categories are based on communication assessment criteria recognised within psychological and sociological studies (Cohen-Mansfield, 1997), and are not intended as inclusive or conclusive descriptors.

- **'Positive' embodied responses:**

  Physical responses: swaying, tapping, nodding, 'dancing', gesturing, facial expressions (grinning), eye-gaze (towards the source of the music)

  Vocal responses: talking about the music, reminiscing, singing, humming, whistling

  Emotional responses (crying - laughing)

  'Negative' embodied responses:

  Distraction (looking around the room)

  Boredom (yawning, looking at watch)

  Verbal interruptions (unrelated to the music)

  'Neutral' embodied responses:

  No perceptible response to the music.

A. Individualised music

The following subsections demonstrate how playing each resident's preferred familiar music promoted a sense of 'haven' during his or her interventions.

i. Embodied tune recognition and identification

Although previous research highlights the value of playing familiar music for people with dementia, I had not anticipated the impact that correctly *identifying* familiar music could have on his or her experience. Though I aimed to play favourite familiar music to each resident, sometimes he or she either did not recognise, or was unable to correctly identify the music that was playing. Some residents seemingly viewed correctly identifying familiar tunes a fun challenge; listening intently with a furrowed brow, until they suddenly burst into a broad smile upon successfully identifying the tune. When listening to a familiar tune that they were unable to correctly identify, some residents simply shrugged, chuckled, and commented that they recognised the tune but could not remember the name or the words, before proceed to engage with the music anyway. Other residents did not connect with tunes they were unable to identify; sometimes expressing boredom or low-level frustration during these unidentified tunes. The excerpts below illustrate various resident reactions related to being able or not to correctly identify familiar tunes, and how this affected their experiencing their interventions as a 'haven':

Betsie usually began moving and singing along with each played tune after hearing only a note or two, and she derived great pleasure and pride from not only correctly identifying each tune, but in remembering all the words of virtually every tune as well. She would beam proudly whenever this particular talent of hers was acknowledged. At the end of their first music intervention, her nephew Gavin noted:

> " She's [Betsie] enjoyed it...amazed at the memory she's got for the ...it seems odd...but eh, it's, the memory is a queer thing isn't it...it's been years since she's ever heard these tunes anyway...well for the first two three notes or strokes of the fiddle she's joining in..." (Gavin).

On the rare occasions when Betsie did not remember the words to a tune, she would laughingly comment, "I ken the tune, but donnae ken the words!" – before going right back to fully engaging with the music anyway. Betsie also occasionally remarked; "...I like music...if it's something that I ken!"

Aileen's ability to recognise and correctly identify the tune she was listening to corresponded directly to her level of engagement with the music. At the start of each tune, Aileen sat attentively listening; if she recognised and was able to correctly identify the tune, she began smiling and singing along. Every time she heard, 'My bonnie lies over the ocean' Aileen immediately made comments such as:

> "This is a favourite song of mine in the student songbook!"

Or:

> "Lovely...that's my favourite. Bring back."

Or:

> "Oh this is my favourite...with all the actions! [While moving her thumbs in rhythm with the music]."

When she heard, 'The roads and the miles to Dundee' during an intervention, Aileen smiled, named it, and when it ended, remarked:

> "That's a change that one, 'The roads and miles to Dundee', I thought I recognised it!"

Edine clearly appreciated everything about her music interventions, but upon correctly identifying a familiar tune, she would raise her eyebrows, widen her eyes, burst into a broad grin, nod her head, and begin swaying or tapping along with the music with unbridled delight. One especially lovely illustration of this transpired at the start of her sixth (recorded-music) session when, as soon as she heard, 'You are my sunshine', Edine shook her head, grinned broadly, and exclaimed; "That's it!"

Iona was prone to theatrical expressions of satisfaction upon identifying a familiar tune: once she waved her hand while uttering a sound of recognition; another time she sat looking blankly towards me for a moment before swinging her head back and forth and mouthing the words. During the introduction of, 'Anniversary waltz', Iona sat with a furrowed brow until the melody began, whereupon she immediately made an exclamation of recognition and 'conducted' the music whilst grinning from ear to ear. At the start of another tune, Iona looked puzzled until I told her its name,, whereupon she waved her arm, smiled broadly at Calum, and visibly relaxed. Upon hearing another tune, Iona exclaimed, "Oh, I know this one!" and began moving her hand along with the music. When, she heard, 'You are my sunshine', Iona smiled, shook her head

in recognition and exclaimed, "of course!" while mouthing the words and moving her hand along with the music.

Bonnie usually looked towards Nessa to supply the names of tunes as they began playing. At the start of one tune Bonnie said to Nessa; "I don't know what this is she's playing"; when I supplied the name, Bonnie responded, "Oh ay [yes]." At the start of another familiar tune, Bonnie gave a nod of recognition and continued nodding her head along with the music. After singing along with, 'The bonnie banks O'Loch Lomond", Bonnie said to Nessa; "I ken that one." Later, when asked if she had recognised a tune that had just ended, Bonnie replied, "Oh, I know them all!"

During her exit-interview, Nessa commented:

> "…I think it's the sort of thing that obviously works because you saw how suddenly she [Bonnie] would perk-up and go, 'ooh'! And realise, recognise the tunes from years ago, and so it does definitely stimulate…and you see sometimes when her foot would go or her arms would go, that she understood what was going on. Em, and that she was enjoying it because it jogged her memory for…I think it definitely worked…she would have just sat probably most of the morning sleeping…so it definitely stimulates a bit (Nessa).

Elspeth frequently made comments such as; "I don't remember the title of that one" or; "I knew the music but I couldn't think what the name of that was." While she didn't seem particularly troubled about being unable to identify a tune, she was usually more engaged with the tunes she was able to correctly identify, as indicated by her singing along and then naming these tunes when they ended.

Hazel correctly named with a satisfied smile nearly every tune soon after it started.

These excerpts depict the positive impact that correctly identifying a familiar tune had for most residents, and thus how this aspect of listening to favourite familiar music likely contributed to an experience of 'haven'.

ii. Embodied memories: familiar music and time travel

Music's ability to 'transport' listeners back into pivotal life-events is well documented (Gallagher et al., 2006; Janata et al., 2007; Gerdner & Schoenfelder, 2010). But music is also steadily gaining recognition for its ability to tap into our embodied or stored memories (DeNora, 2013). The excerpts below illustrate examples of (mainly resident) participants being 'transported' back in time by music:

After Jean left at the end of their second (recorded-music) intervention, Maggie launched into an extended reminiscence about growing-up the youngest in a large coal-mining family and losing her closest brother during WWII: I quickly pulled–up a chair and listened. Throughout Maggie's live-music (4-6) interventions, various played tunes evoked memories or emotions associated with her late husband, 'Colm'; whom Jean had previously told me Maggie never spoke of:

Upon hearing, 'The dashing white sergeant', Maggie smiled broadly, began moving with the music and exclaimed; "this is like a dream!" before putting her hands to her eyes and crying during the rest of this tune:

> Jean to Maggie [looking over at Maggie] You okay? [Maggie nodding and smiling slightly]
> Claire: What are you thinking about Maggie?
> Jean: Are you sad? ... Emotional?
> Maggie: [nodded] emotional dear.
>   ...
> Maggie: Just thinking about my husband, and...things we did...

Upon hearing, 'somewhere over the rainbow', Maggie again became emotional -

closing her eyes and shaking her head:

> Maggie: Lovely. [She sits for a moment and then shakes her head] memories, memories.
> Claire: What are your memories? What memories?
> Maggie: All lost memories dear....Like my husband, and...Lived parts of our life together, and...
> Jean: That's good memories.
> Maggie: All good memories.
>   ...
> Jean: Not everybody has such good memories really... What's your feelings?
> Maggie: My feelings?...Well, the music brings back a lot of...
> Jean: Memories and whatever.
> Maggie: Memories. Yeah. Reminiscent...But just wonderful.

With Nessa's help, I was able to appreciate that some of Bonnie's verbal and

physical responses to the music were likely indications of her being,

'transported' back into distant memories:

Upon hearing 'the roads and the miles to Dundee', Bonnie began talking, and I

immediately turned-down the music:

> Bonnie to me:___berns (children)___...___see all the chairs. ___to come and sing yeah___
> Nessa to me: All her family used to sing. [to Bonnie]They all used to come and sing didn't they?
> Bonnie: Ay [yes].
> Claire to Bonnie: Big singing family.
> Bonnie: [nods]
> Claire to Bonnie: Do you remember singing this one with the family?
> Bonnie: [nods]

When Bonnie first heard, 'the white cliffs of Dover', she started rhythmically kicking-up her legs:

> Nessa to Bonnie: Marching, yeah. That's when you were marching.

Upon hearing, 'Scotland the brave', she began making what looked-like highland-dance gestures:

> Claire to Bonnie: Were you doing a little dancing to that one?
> Bonnie: Ay!
> Claire: Did you do that when you were little...?
> Bonnie: Oh yes! Yes!

These last two excerpts illustrate the music's ability to rouse long dormant embodied memories: Bonnie had been a member of the Auxiliary Territorial Service (ATS) during WWII, so although the tune, 'The white cliffs of Dover' does not have a march-like rhythm, she may have associated it hearing it with embodied memories of marching during WWII. Likewise, listening to the popular Scottish tune, 'Scotland the brave' seemed to have evoked embodied memories of her highland dancing as a little girl.

The traditional Scottish tune, 'My bonnie lies over the ocean' was Aileen's favourite, and each time she heard it she sang along. During one intervention she added hand-gestures; during another she said, "...with all the actions" before moving her thumbs in rhythm to the music. During another intervention she moved her clasped hands in time to the music during each refrain, and after singing-along to three verses, we shared this conversation:

> Aileen: Awe! [a satisfied sound]
> Tommy: [turning towards Aileen and smiling] You liked that one didn't you?

Aileen: Yes! It's in the student songbook...I used to take a lot of different songs out of this...That was always my favourite.

When 'Anniversary waltz' began to play at Iona's third intervention, she smiled before putting her hand to her face and crying throughout the rest of the tune:

Calum to Iona:... you back to your days of dancing!
Claire: [pausing] Does that bring back some memories Iona?
Iona: Yeah... [looking down]...come and go...[looking at me] and once they go, [gestures] they're gone...Just carry on.

During his exit-interview, Calum observed:

Calum:...she [Iona] seemed, she seemed to enjoy it [the music]...to get quite involved in it....probably brought back memories, some of the old tunes ___ the old tunes relating, you know, going back to, her younger days.

Traditional Scottish dance tunes were so ingrained in Robert's being, that he often tapped or 'danced' complex rhythms along with these tunes – even when by all appearances he was sleeping!

The played music also triggered 'time travel' in carers:

Cait verbalised two evoked memories during her sixth (live-music) intervention:

At the end of the hymn, 'By cool Siloam's shady rill':

Cait to Edine: That was always the baptismal thing at one time...It's all changed now.... It's just lovely. You just visualise them all comin-in, carrying the babies to be christened...Lovely.

After hearing, 'The bluebell polka', Cait shared this memory:

Cait: That used to be a highland dance, but I can't think of what it was...The Bluebell Polka?... It's also one that I used to highland dance...obviously years ago. And that was, we did something to that.

After listening to, 'Salute d'amour' (a piece specifically identified as one of Greer's favourites by Brenda), Brenda confessed to having suggested this piece because of its special significance for *herself as* she had played it on the violin with her mother Greer accompanying her on the piano when as a little girl:

> Brenda to Greer: You did the most beautiful accompaniment for it, you sort of covered up a lot of it, you tried to make me try harder didn't you?

The above excerpts illustrate familiar music's ability to 'transport' listeners back into long forgotten embodied memories; thereby holding the attention of listeners and facilitating an experience of 'haven'.

B. Music genre

The success with which the music 'removed' a participant from their present reality was also mediated by his or her affinity to the genre of the music, as is illustrated in the following subsections.

i. Residents

When I was unable to determine a residents' specific favourite music, I aimed to play their favourite music genres (e.g. traditional Scottish, hymns, popular 1940s tunes etc.). Some residents enjoyed listening to a variety of music genres, while others were more selective:

Whenever Aileen heard Celtic tunes, or lively hymns she nodded her head and sang along.

Edward had a clear preference for 1940s ballroom dance music, and nearly always whistled along, tapped his foot, and was attentive whenever he heard this genre.

Robert especially enjoyed Scottish music – as conveyed through his nodding head, tapping feet or hands, brief comments, and whistling along with all the music from this genre.

ii. Carers

The music played during these interventions did not necessarily coincide with each carer's personal music preferences, as my primary focus in choosing the playlist for each dyad was the preferences of each resident (see chapter 4.4.C.i). Happily, most carers had little trouble adjusting to whatever genre of music they were listening to. Better still were the occasions when a carer's preferred music genre(s) coincided with those of their resident partner:

Cait enjoyed all of the played music, but particularly brightened whenever she heard Scottish tunes and hymns. After hearing 'By the bonnie banks O'Loch Lomond', she laughingly exclaimed:

> " Something rousing about Scottish music!" (Cait).

Jean became very animated when I spontaneously played some classical music (Bach) during her final two interventions; bursting-out into a smile, sitting upright, clapping effusively, and exclaiming, "brilliant!" at the end of one piece, exclaiming, "that's beautiful...well done Claire!" at the end of another. During her exit-interview, Jean remarked:

> "... when you played the classical, I know you're a professional musician, but you play music that suits Mum's [Maggie's] generation from the war...but when you played the couple of [classical], I had this beautiful, 'now look there's the window with the trees, the leaves moving' I just thought it was special" (Jean).

Jean (carer) had mentioned her fondness for classical music during her initial interview; Maggie and Jean's enthusiasm was at such a high pitch during their final two live-music interventions, that I spontaneously played some J.S.Bach - Maggie clearly also enjoyed these pieces, though she was not at all familiar with this music genre.

C. Music tempi and temperament

Determining the effects of quickly-paced compared with slower-paced music is difficult, because livelier tunes tend to evoke more obvious external responses, whilst slower-paced tunes generally evoke more subtle internalised emotions and greater relaxation; sometimes even inducing sleep. Moreover, the *tempo* (pace) of music (i.e. slow or fast) does not necessarily coincide with the *temperament* (mood) of music (Black & Penrose-Thompson, 2012). So music can be slow and happy (i.e. in a major key), slow and angry or sad (i.e. in a minor key), fast and angry or sad, or fast and happy. As discussed in chapter 3.3, it is music's tempo and rhythm that triggers 'entrainment' (e.g. tapping; moving; and breathing with the music's rhythmic pace), whilst the temperament of the music triggers the 'iso-principle' (i.e. either altering or amplifying the current mood of listeners). Below are examples of 'entrainment' and the 'iso-principle' in action during these interventions, and how they impacted upon participant experiences of their interventions:

After just a few moments of listening to a slow-paced and sad (minor-key) tune, Aileen interrupted by saying:

> Aileen: I like more cheerful music – that's sad, that.

I promptly skipped to a 'happier' (major-key), but still somewhat slow tune, and Aileen remarked, "I like that better" before singing along. Later in this same intervention I played another slow and 'sad' tune, and Aileen glanced at her watch. During her next intervention I played music that was predominantly fast-paced and 'upbeat'. Partway through, Aileen and Tommy shared this exchange:

> Aileen to Tommy: Oh what a wonderful selection Tommy! I think they're better than the last time! I'm enjoying it more than the last time!...What changed?
> Tommy: We're getting jigs and things now. Getting faster stuff.

At another intervention when asked if she wanted to hear calmer or lively tunes, Aileen promptly replied, "lively." I offered to play some gentler and slower-paced music during a later intervention, to which Aileen responded, "yes, slower tunes" - during which she dozed; when I began playing the upbeat tune, 'You are my sunshine', Aileen immediately woke-up and sang along.

These excerpts suggest that though Aileen generally engaged more with 'happier' tunes, her mood and energy levels at any given time during her interventions dictated what sorts of music she connected better with.

Edward tapped his foot along with most of the quicker-paced tunes, but it was the slower-paced tunes that evoked exclamations such as, "yeah!" or, "that's it!" In my fieldnotes I later wrote that:

"...Edward seemed to really be transported somewhere during the slower more suave tunes" (my fieldnotes).

For example, Edward smiled and 'whistled' along throughout the entirety of the comparatively lengthy and slower-paced tune, 'Begin the Beguine' and spontaneously clapped as it ended.

Whilst Edine moved her legs and hands, and nodded along with the faster-paced music, she often sat with a blissful expression, and her eyes closed while gently swaying along with the slower-paced tunes.

Hazel identified several slower-paced tunes as special favourites, while also telling me she did not like listening to 'sad' tunes. Late in one of her interventions, when Hazel commented that she was getting sleepy, I offered to play her one last lively tune, and she responded:

Hazel: Ay! Give me some life!

During her exit-interview, Hazel's carer Sheena commented:

" Well I felt...when it was a slower song and that I felt that Hazel would sit with her eyes shut, but when it was a cheerier song then...she'd pep up a wee bit" (Sheena).

Sheena's observation is representative of one expressed by several carers, and demonstrates the subjectivity that observers (including myself) are prone to. That Hazel showed less external response to the 'slower songs' doesn't necessarily mean she was not engaging with these tunes just as much as she did during the faster-paced ones.

The above examples illustrate that the pace and mood of played music evokes different responses in listeners, and that how well the music matches the current mood state and energy levels of listeners generally determines how successful it will be at capturing and holding their attention, and to thus 'transport' them into an experience of 'haven'.

D. Musicianship

I was somewhat surprised by Consultant 8's suggestion that the more advanced a person's dementia is, the more crucial it is that the music played be of a high standard. But over the course of these interventions, the importance of this issue became clearer:

I quickly recognised that Hazel had exceptionally keen ears, when we shared this conversation after I finished playing (not terribly well) one tune at one of her early (live-music) interventions:

> Hazel: That was flat! [I promptly replayed this tune]
> Claire: Is that better?
> Hazel: Um hmmm.
> Claire: Ah, I can see that you probably have some problems when you go downstairs [to the general live care home entertainment] if they're no good [Hazel usually refused to attend].
> Hazel: Ay.
> Claire: Ay.
> Hazel: Cuz that's a load of shite!

Aileen often commented during her live-music interventions that I was 'a wonderful player'.

While there are few clear examples as to what effect the level of my musicianship perhaps had on participants during this study, this issue warrants closer scrutiny in future research and practise as will be discussed in later chapters (see chapter 7.3.C.iv).

E. Recorded and live-music

A central objective of this study was to explore the comparative effects of live and recorded-music on populations represented by these residents and carers. This subsection presents excerpts from these interventions illustrating the potential of *both* versions of the played music to encourage an experience of 'haven' in participants.

i. Live-music: a special occasion

Expecting that the unusual event of hearing a relatively large cello within the confines of a private care home bedroom might initially astonish participants, I was surprised to note this was not generally the case. However, my playing the cello live did elicit particular excitement from some participants:

At the beginning of their first live-music intervention, Isla looked expectantly towards my cello and I:

> Isla to Edward: I feel like a film star! Do you feel like a film star?...A celebrity. I think we are dad!...Celebs. [laughing] I think we're celebs!

Though Edine enjoyed all of her interventions she was especially taken with my cello. At the start of their second live-music intervention:

> Claire to Edine: I'm going to turn on my 'machine' in just a moment [Edine had just referred to my cello as a 'machine']

Edine: I want the machine, to listen again...
Cait: The music.
Edine: Yes, music.
Cait to Edine: You liked it didn't you?
Edine: Oh, I loved it! [Smiling broadly at Cait]...Yes, oh I love that music...Carried away right enough.
... [Edine's face lit up as I tune the cello]

At the start of their third live-music intervention:

Edine: It's [the cello] a lovely...
Cait: Beautiful colour isn't it, the wood's...
Edine: I remember last time, I was here, I admired it.
... And I like the music [chuckles].
Claire: Yes.
Cait: You liked the music [chuckles].
Edine: And the player [chuckles].

These two excepts show not only Edine's clear pleasure at seeing and hearing the live cello, but also her remembering having heard the live cello at her intervention the previous week.

Because Maggie and especially Jean's tangible excitement during their live-music interventions is detailed in previous chapters (see chapter 5.3.B.i), I will simply list excerpts of Jean's comments illustrating her enthusiastic reception of my playing the cello live for her as a special event:

- "Do you feel like you're at the opera?..."

- "It's not often you get somebody to play music to ya is it?"

- "...It doesn't happen to everybody..."

- "It's not often you...some professional musician...come to play ya music is it?"

- "This is a once in a lifetime occasion...."

- "We're privileged; we're very privileged..."

- "This is special...it's like having a private...music class..."

- "...It is like you're...going out to listen to somebody play professional music, and you're gettin it in your own little bedroom!"

Near the end of Maggie's pilot-intervention she remarked:

> Maggie: [leaning back, smiling and chuckling] This is like a dream!
> Claire: I hope it's a good dream.
>   ...
> Maggie: Well it's a strange dream.
> Claire: Is it a strange dream? Hearing somebody playing the cello for you in your room like this.
> Maggie: [looking around her room] In my bedroom!...I've sat for ages you know downstairs, and nothing, nothing doing, and I come up to my bedroom, and I musician comes in my back!

ii. Residents: live and recorded-music

a. Residents who engaged similarly to live and recorded-music

Six of the ten residents who listened to both versions of the music engaged similarly to both:

Hazel appeared to be equally content listening to both versions of the music - listening attentively, smiling, and naming most tunes as they ended. She later confirmed that she had equally enjoyed both versions of the music.

Robert's degree of engagement with the music depended on the amount of sleep (or lack thereof) he had the previous night, his present emotional state, and the genre of the music played. Both versions of the music similarly impacted on Robert's level of attention, physical responses to the music (e.g. nodding his

head; tapping his feet or hands - sometimes in complex rhythms; whistling or humming along with the music), and verbal interactions with his daughter Mairi and me. Robert sometimes slept during some of the slower tunes, and often resumed tapping his feet during the faster tunes. He also frequently smiled, chuckled, made satisfied sounds, or exclaimed, 'that's it!' as tunes ended. Occasionally Robert expressed agitation - pulling at his shirt or rapidly rubbing his hands together (Cohen-Mansfield, 1997); but never while either version of the music was playing.

Ever gracious and always pleased to have company, Edine expressed great pleasure with all of the music she listened to - nearly always smiling or grinning, swaying, or nodding along with most tunes, and chuckling as tunes ended. Edine's development of a life-threatening chest infection (which she thankfully survived) meant that she more easily tired during her recorded-music (4-6) interventions, but did not dampen her enjoyment of the music.

Aileen broke into song almost immediately upon hearing the first tune played at her first recorded-music intervention, and continued sporadically singing along with the tunes she was able to identify throughout her interventions. Early into her first recorded-music intervention Aileen remarked:

> Aileen: I would just be sitting and watching the television.
> Claire: You'd rather be watching the television?
> Aileen: No! I've rather have music!

Although Aileen's energy levels vacillated (resulting in two recorded-music and one live-music intervention ending early), she was attentive and engaged with the music during all her interventions. She frequently sang along with and named the tunes she knew, complimented my choice of music, and occasionally reminisced.

Betsie sang, tapped her feet or hands, nodded, and swayed along with virtually every tune as they started. She also routinely expressed her delight after a tune ended via small idiosyncratic gestures or exclamations. Shortly before her recorded-music interventions (4-6), Betsie experienced several falls, which resulted in some bad facial bruising, a broken arm, and her more quickly tiring. This meant that she frequently dozed between tunes during these interventions, but was immediately singing, tapping, and nodding along just as soon as the next tune began.

Although Iona engaged differently with the music during her live (4-6) and recorded-music (1-3) interventions, it was during her recorded-music interventions that she engaged more directly with the music: looking towards me; drumming her fingers; smiling broadly; tapping her hands and feet; and nodding her head along with most tunes. Whilst she was indeed at least as fully occupied during her latter live-music interventions, her focus shifted almost entirely to following along with the printed word-sheets I had provided, and her engagement with the music shifted to mouthing words; tapping her feet;

smiling; 'conducting' some of the tunes; and interacting with Calum (see chapter 5.3.B.iii).

The above examples indicate that both the live and recorded versions of the same or similar music captivated and held the attention of six of the ten participating residents. This suggests that recorded as well as live-music can evoke an experience of 'haven' for many listeners who have dementia.

b. Residents for whom live-music was more effective

Meanwhile, four of the ten residents engaged significantly more with the live compared with the recorded-music:

Edward engaged quite a lot with the live-music (1-3): he was attentive; 'whistled'; tapped his feet along with most tunes; smiled; chuckled; and clapped as many tunes ended. Despite his difficulty with speech, Edward frequently exclaimed, "good!" or, "yeah!" or, "lovely, lovely!" at the conclusion of tunes, and he also initiated a number of brief conversations with me (see chapter 5.3.B.i).

Edward showed markedly less engagement with the recorded-music (4-6): he was more distracted, and grew impatient - frequently making large gestures to indicate he was tiring of the same tunes he had previously enjoyed during his live-music interventions. He ultimately requested that several of his recorded-music interventions end early. When I asked how he felt about the recorded-music, he cryptically answered that it had felt 'slower'.

During her two recorded-music interventions (1-2), Elspeth expressed minimal engagement with the music she was listening to; and the little she said was fairly terse. Despite her occasionally humming or singing along with some of the tunes and remarking that all the tunes were good, she indicated she was finished with the first of her recorded-music interventions after less than twenty-minutes, and her second recorded-music intervention concluded after just three songs.

Conversely, Elspeth became very animated after listening to just a few tunes during her first live-music intervention; humming and singing along, and also occasionally tapping her foot along with most of the tunes I played. She also struck-up a number of lengthy conversations with me (see chapter 5.3.B.i). Her first live-music intervention lasted for nearly an hour. Elspeth also sang, verbally interacted, and frequently asked me to replay tunes throughout her second extended live-music intervention. During her exit-interview, Morven observed:

> "She [Elspeth] was a lot more animated during and after the live ones...once she kind of got the swing of it and she said about, 'Oh I didn't know you could play so many different types of music on the cello'. And she was really interested, and she spoke about that for a while after the session...I think she was quicker to come to the next session as well because she knew what she was coming to" (Morven).

Although Maggie sang, tapped her feet, nodded, and named most tunes during her first three recorded-music interventions, she also indicated she was tiring of the music earlier than the targeted thirty-minutes during each of these interventions.

From the start of her live-music (4-6) interventions, Maggie became 'enthralled' (Jean's word) with the music. Maggie alternately sang, cried, reminisced, clapped, interacted with Jean, complimented and thanked me, and repeatedly exclaimed, "This is like a dream!" (something she never said during her recorded-music interventions) during her live-music interventions.

Below is a representative sample of excerpts illustrating Maggie's responses during the live-music:

At the end of her first live-music intervention:
> Maggie: It was lovely [Maggie looked over at me smiling broadly]... [Wiping her eyes] Well I enjoyed that very much, dear, thank you VERY much!

...I wrote in my fieldnotes that Maggie had clutched my arm as I was leaving, while profusely thanking me again.

At the end of her next live-music intervention (which was full of enthusiastic responses to the music and also of dyad interactions):

> Maggie to Jean: This is like a dream!
> Jean: Yeah.
> Claire to Maggie: So is it okay if I come play again for you sometime?
> Maggie: Oh, wonderful!
> Claire: Thank you Maggie.
> Maggie: Thank me! It's for me to thank you dear!

I found Maggie still lying in her bed and seemingly quite unwell when I arrived for her final live-music intervention (I later learned she had a chest-infection). But she was up, fully dressed, and sitting in her comfy chair not ten-minutes later when, persuaded by Jean, we went back upstairs to Maggie's room! Before I started playing the cello:

> Maggie to Jean: [gesturing towards the room] I can't believe this is all happening!
>
> ...
>
> Claire to Maggie: I wasn't gonna come play music for you today Maggie.
>
> ...
>
> Maggie: Oh, just, just you play your music dear. Lovely.
>
> ...
>
> Claire: So, Maggie, the rules are...you can fall asleep, you can sing, dance...
> Maggie: We'll not going to fall asleep, we could enjoy your music! [Gestured]...I'm gobsmacked!

As I picked-up my cello, Maggie clasped her hands in eager anticipation. When Jean asked Maggie if she was enjoying the music, Maggie exclaimed, "Oh I love the music, I love it."

The above excerpts suggest that for these four residents, the live versions of the same or similar music were significantly more effective at capturing and holding their attention; and thus of transporting them into an experience of 'haven'.

iii. Carers: live and recorded-music

During their exit-interviews, all but one carer professed a preference for listening to the live compared with the recorded-music. Reasons cited included finding it more interesting to watch me playing the cello compared with watching me operate a CD-player:

> Calum: ...well I think that the live versions were more interesting. It's always more interesting to actually see someone playing, then just, to listen to a recording...
>
> Isla: I preferred the live much more to the recorded-music...I think it gave a focal point as well, where you could watch. And it's interesting to watch a musician playing as well...So for me, that was far better than listening to the recorded-music.
>
> Nessa: well, obviously when it's live you realise the amount of work that you're putting into it, and how good you are. Whereas when you hear a

piece of music on a tape or a CD, it's totally ____. Whereas when you see you...oh that's really good and suppose that is more stimulating.

Sheena: It's better watching you playing than just listening to it. Doesn't kind of mean the same you know. I think you've got to see ya actually doing it is better.

Cait found the live-music more 'personal' than the recorded-music:

Cait: Yes, I preferred the live...I think it's just more personal probably. You know, it's like, when you're playing a recording, well you can do that any day, or any time generally...I found that the live much more, em...as I said just much more personal, much more...it was just lovely. Probably just lovely to be, to actually see you play it...just to...ya know just to watch which was lovely.

Jean felt like she was being played a private concert when I played the cello live

for her:

Jean: ... I especially loved when you played the...it was like being in a concert hall when you played the cello, and you were playing live to Mum and I. And we just had a completely different feel from the CD. And you're so talented as well...you're a professional musician.

Tommy was the only carer who did not state any preference for the live or

recorded versions of the music:

Tommy: ...Ok when it's live it's more of a spectator's sport. But em, from the point of view of the calm, the appreciation of the music, the relaxation, really no not much change, not much difference.

In reality, few carers engaged significantly more with the live-music compared

with the recorded-music: excepting Jean, (see above section 2.A.ii, and chapter

5.3.B.i).

During her exit-interview, Jean commented:

Jean: Oh I loved the live-music...your live-music was lovely...you were getting a special performance...

F. Music-related barriers to 'haven'

Just as I previously drew attention to elements of the intervention format that may have hindered participants' ability to experience their interventions as a 'haven', the following subsections highlight characteristics of the played music that may have impeded on participants' ability to experience their interventions as a 'haven'.

i. Inability to identify familiar music

Whereas correctly identifying a familiar tune provided extra pleasure for some residents, *not* being able to correctly identify a familiar tune caused some resident's to disengage:

Aileen sat impassively during tunes that she was unable to identify, usually requesting the tune's name as it ended. Perhaps due to her especially low energy levels during her latter interventions, Aileen had more difficulty correctly identifying even familiar tunes which she had previously identified, which likely contributed to her diminished level of engagement during her three live-music (4-6) interventions – each of which concluded prematurely.

When Iona did not recognise or correctly identify a familiar tune, she stared blankly or furrowed her brow. During her first three interventions her on-going frustration at not being able to recall every word of the familiar tunes she was listening to prompted me to create and supply her with printed song-sheets.

Maggie tended to look distractedly around the room during tunes she was unable to identify; generally asking for its name when it ended.

As for most of us, being unable to correctly identify a familiar piece of music can be distracting or even irritating. Thus it is not difficult to surmise that being unable to correctly identify the familiar tunes they were listening to during their interventions might impede on a residents' ability to experience a sense of 'haven'.

ii. Familiar tunes: traveling back to sad times

Heather sat inexpressively staring at me throughout most of her single (recorded-music) intervention. However when she heard, 'The old rugged cross', she clenched her jaw. Tears were welling-up in her eyes by the start of the following hymn, 'Amazing Grace', and were falling by the second verse. Her daughter Donna and I frequently checked-in with Heather, who assured us that she was okay and was enjoying the music. Like most nonverbal responses, tears can have many meanings. I assessed these to be tears of emotion rather than of distress. Music's ability to release emotions in listeners is not necessarily a 'negative' outcome. This makes it a matter of debate as to whether or not Heather's tearful response should be considered a possible barrier to her experiencing her intervention as a 'haven'. As previously discussed, music also took Iona and Maggie back into some tearful memories. Again, these were fleeting emotional moments rather than distressing 'negative' events.

iii. Music genre

When participants heard music genres they disliked, they sometimes responded

critically:

Hazel firmly declared her disdain for all Scottish music and hymns, so when I

mistakenly started playing a Scottish tune during her pilot-intervention, Hazel

responded:

> Hazel: Is that a hymn?
> Claire: It's a, no, you're on the right track, 'Ae Fond Kiss'.
> Hazel: Oh, right.
> Claire: Scottish.
> Hazel: Ay.
> Claire: Not your cup of tea.
> Hazel: No really.

...Needless to say, I did not play any Scottish tunes or hymns during her ensuing

six music interventions.

Robert loved all music, but as an accomplished traditional Scottish musician

himself, he preferred traditional Scottish and Celtic music. So during one of his

latter interventions (during which he was more brittle due to severe

deficiencies in sleep), Robert sat impassively listening to a popular 1940s tune

(one he had enjoyed during previous interventions), and at the end commented:

> Robert: Is that it?
> Claire: Do you that to be it? Are you done?
> Robert: [expressionless] Um hmmm.
> Claire: You don't want to hear any more?
> Robert: No.
> Claire: The next one's 'Oh Danny boy' [an Irish tune]. Do you want to hear 'Oh Danny Boy'?
> Robert: Oh ay!

This example shows how a listener's present disposition can determine how tolerant (or not) they are of hearing music that is not from one's favourite genre. Robert had enjoyed this popular 1940's tune during previous interventions, but was too raw on this particular day to engage with *any* music that was not from his preferred music genre.

Sheena remained virtually devoid of emotion during all of her interventions; during which I was playing Hazel's preferred music genre - popular 1940s tunes. Sheena liked traditional Scottish music, and later professed:

> " As far as the music's concerned...it doesn't do anything for me...it's not really my cup of tea...it's...no I have to be honest it's no, it's no my cup of tea..." (Sheena).

Isla was particularly unresponsive whenever I played one of Edward's preferred 1940s popular tunes, and really only engaged with traditional Scottish tunes and hymns. During her exit-interview, she commented:

> "...They're [the tunes] not my choice obviously...it's more dad's [Edward's] era than my era really... it's nice music...I'm more of a classical person, then light music... the kind of music that you were playing as well, is not really my choice...so for me, it's...I was really just, for me it was a case of supporting dad, rather than me getting anything out of it..." (Isla).

Jean did not enjoy either the popular 1940s or the traditional Scottish tunes that Maggie so enjoyed:

> "It's not my sort of music really...It is Mum's generation...I'm not into Scottish music ___basically. Never have been" (Jean).

The above excerpts illustrate how a listener's aversion to the genre of the music being played can impede on their experiencing a sense of 'haven'.

iv. Tempo and temperament

The complexities of teasing-apart the effects of music related to its tempo, and temperament are discussed previously in this chapter (see 4.C). Sometimes either the pace, or the mood of the music did not match a listener's present disposition, thus causing him or her to disconnect or even feel some discordance with the music. The example below presents a somewhat related issue of a familiar piece of music being played at an unfamiliar pace, and how this caused some discordance for a listener:

Being from the USA, I was not as familiar with traditional Scottish tunes as one might have hoped given the demographic of most of these participants. So my first pre-recorded version of the well-loved traditional Scottish tune, 'By the bonnie banks O'Loch Lomond' was significantly too fast. Bonnie was the first resident to hear this pre-recorded version, and she immediately started moving her head and singing along with words at full voice; but she was unable to fit the words in with this quickly-paced version:

> Bonnie to Nessa: I'm singing too loud aren't I?
> Nessa: No, you were singing right, keep going.
> Bonnie: ＿＿? [Bonnie started singing again through to the end of the tune, but seemed somewhat frustrated] Miss it.
> Nessa: Doesnae [doesn't] matter if you miss it.
> Claire to Bonnie: I think it's too fast on the record. I think it needs to go a little slower to get all the…there's a lot of words in that one isn't there?
> Bonnie: Yeah

…At Bonnie's next intervention, when I played a suitably slowed-down re-recorded version of this tune, she fully enjoyed it and contentedly sang along.

v. Tune duration

I found that a tune's duration could also cause a listener to lose interest in the music. Despite my considerable training and prior experience playing music in similar situations, I still found it difficult to correctly interpret residents' signalling that their attention was flagging. So a resident might be quite engaged during the first several verses of a tune, but could quickly lose interest or become distracted during successive verses:

In one intervention, Aileen was so engaged during the first several verses of her favourite tune, 'My bonnie lies over the ocean' (gesturing and singing along), that I decided to play an additional verse; during which she quickly became disconnected. Aileen also glanced at her wristwatch when I played a third verse of another favourite tune of hers.

Equally, playing extra verses of a tune sometimes afforded a resident enough time to experience the gratification of correctly identifying a familiar tune: Edine often needed a few verses before she would burst into a big smile, indicating her successful identification of a familiar tune.

vi. Residents' concerns during recorded-music

Aiming to replicate the setting for both the live and recorded-music interventions as closely as possible, I sat in the same place during both versions of the music: either playing the cello, or holding a CD-player and a speaker. Questions asked by residents during their recorded-music interventions suggest

that (quite understandably) they felt they were being observed and that they were expected to *do* something:

Partway-through Elspeth's first recorded-music intervention, she asked:

> Elspeth:…What do you want me to say about that?

Near the end of Bonnie's third recorded-music intervention, Bonnie asked Nessa:

> Bonnie: What are we learning through this*?*

On a number of occasions during her recorded-interventions Maggie asked me what these interventions were all about:

> Maggie: … I'm a bit nosey, I'm ___of course wondering what's this all about?

While not all residents expressed this line of questioning, it is possible that other residents felt similarly during their recorded-music interventions, but perhaps did not speak-up due to verbal difficulties, or embodied manners. These types of questions never materialised during live-music interventions. It is easy to understand how feeling that one is being observed could hinder one's experience of listening to the music as a 'haven'.

vii. Residents' concerns during live-music

Similarly to the examples previously given regarding general resident concerns about their interventions (see 3.G), this subsection illustrates resident concerns that only surfaced during their live-music interventions:

When I began playing the cello at Iona's first live-music intervention she

frowned and said to Calum:

> Iona: __that's loud for a place like this!

During her next live-music intervention:

> Iona: All my neighbours will wonder…

And a bit later:

> Iona: … I'm worried about the…[to me] Are you sure you got [pointing
> towards the door] permission?...

Bonnie only expressed concern about the 'neighbours' during her final live-

music intervention:

> Bonnie to me: She likes it playing down the stairs there that woman.
> 　　　…
> Nessa to me:… She's sayin about your, the woman down the stairs for the
> noise.

> Claire to Bonnie: Oh no, they're all right. They don't mind. I checked with
> everybody…
> Bonnie to me: [nodding her head] Tell him I'm listening for the music.

Later during this same intervention Bonnie spoke while I was playing:

> Bonnie to me: Do you get on better with your neighbours?
> Claire: Ah, the neighbours are all right.
> Nessa to me: Worried about the noise again.

Residents also occasionally wondered aloud if fellow care home residents

should be invited to hear the live-music:

During Edine's pilot intervention she asked: Will all the ladies [residents] not be
coming?

Iona said: As long as there's nobody outside the door, because they would...

During all three of Maggie's live-music interventions (4-6), she voiced concern that someone might be standing outside her door listening to the music (which in fact there was during one intervention). She never expressed similar concerns during her recorded-music interventions, and was perhaps communicating her feeling that the live-music should be shared with other care home residents:

> Maggie: [pointing towards the door] There's no anybody listening is there?
>   ...
> Jean: Why?
> Maggie: [to Jean while gesturing with wide eyes] Cuz...could come in!
>
> Maggie: [pointing towards the door] Hope they're not___They could come in though and...
>
> Maggie: I don't know why you're not the sitting room?
>
> Maggie: I think we should open up the door, you know to let them hear it.

These expressed concerns may have at least briefly impinged on residents' ability to fully experience their live-music interventions as a 'haven'.

5. Intervention + music = 'haven'

So far, this chapter has presented findings reflecting how elements of the intervention format and characteristics of the music played enhanced or hindered participants' ability to experience their interventions as a 'haven'. The following subsections demonstrate two key indicators that a participant was experiencing an intervention as a 'haven'.

A. The alchemy of music and temporality

During these interventions, a resident or a dyad sometimes became so completely immersed in the music, that I extended their intervention well beyond the targeted thirty-minutes. Maggie-Jean, Iona-Calum, and Elspeth-Morven participated in a number of such interventions; each of which lasted close to, or over an hour. I have no concrete evidence that these participants were experiencing 'flow', or an IME (see chapter 3.4). However, there was something special undoubtedly transpiring, because Maggie, Iona, and Elspeth; each of whom were quite frail and quite old, appeared rejuvenated at the conclusion of these intensive and lengthy interventions, after having been highly engaged and interactive throughout. This subsection summarises these interventions during which either a resident or a dyad became so absorbed or captivated with the music, that time seemingly 'evaporated':

For Iona-Calum, it was the addition of requested printed song-sheets during their last three live-music interventions that undoubtedly triggered their shared immersion. While each of their first three recorded-music interventions lasted approximately thirty-minutes, their latter three live-music interventions each lasted well over an hour; and found them both apparently happy and refreshed at the conclusions of these extended spans of focused concentration.

For Maggie-Jean, my playing the cello live was the apparent trigger for their complete enthrallment with the music during their latter three interventions.

Each of these interventions lasted over an hour; and found them both apparently happy and refreshed at their conclusions.

The live versions of the music inspired Elspeth to become very involved and inquisitive; asking me lots of questions and repeatedly requesting more music. After both of her two approximately hour-long live-music interventions, Elspeth appeared very happy and energised.

These interventions suggest that if circumstances are 'right', receptive music listening may not only capture and hold the attention of listeners, but may sometimes do this so successfully that listeners literally become 'lost' in the listening; and certainly are transported into an experience of 'haven'.

B. Mood

My findings confirm prior research regarding music's ability to affect listeners' moods (Khalfa et al., 2008). This was most clearly indicated when a participants' initial mood significantly brightened during the course of an intervention:

Iona was often very sad or in tears before the start of her interventions. But as soon as the music started, she quickly became preoccupied, as she moved to and mouthed the words along with most tunes, and chatted about the music.

During one (recorded-music) intervention, Iona's mood progressed from very tearful to chuckling. By the end of the second tune, Iona was engaged in an extended discussion with Calum and I about tune names. Slightly later Iona

cried while listening to the 'Anniversary Waltz', then was smiling; chuckling; moving her head and hands; and 'singing' along with the next eight tunes. She was crying again while listening to, 'We'll meet again', and then smiling broadly and tapping her foot along with the very next upbeat tune, 'The dashing white sergeant'; which is how she ended this intervention.

Elspeth was prone to 'good' and 'bad' days. Prior to the start of one (live-music) intervention, Morven alerted me that Elspeth had not been feeling particularly 'bright' that day. The music quickly roused Elspeth, and she stayed extremely engaged throughout what turned-out to be a very extended intervention. Morven later remarked:

> "She [Elspeth] really did have good days when that [the music interventions] was happening, and I wouldnae (wouldn't) say she... had a particularly brilliant day before the [music] session, but the good mood stayed..." (Morven).

I found Betsie in a particularly negative humour at the start of several of her later interventions; which was likely an understandable consequence of several recent falls. Nevertheless, from the moment the music started, she became completely engaged; singing, tapping, and interacting with Morven throughout the intervention. Morven later remarked:

> "I think, I think it was her [Betsie's] last session that we did... she'd been in a really bad mood beforehand, and, that lifted her mood. And, that mood stayed through the rest of the day...That is good, because there's days when she does get upset that it can be quite hard to bring her around. So I think knowing that, with the music, can help the carers, and that can help care planning for everybody" (Morven).

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In her understated manner, Hazel enjoyed all of her music interventions. She was attentive; frequently smiled; named most tunes; and engaged in brief verbal exchanges throughout. Her ostensible enjoyment of these music interventions was especially remarkable given Hazel's historically negative attitude towards care home activities, prompting staff to express doubt regarding how she might respond to these interventions.

During her exit-interview, Sheena remarked:

> "I suppose...what's happened is not what I thought it was going to be....I'm glad that Hazel's enjoyed it so I didnea know how she would be, but you [Hazel] seem to have liked it so that's good" (Sheena).

Music can uplift a listeners' mood. Equally music can evoke feelings of deep sadness. Regardless of the moods that arose during their interventions, all participants appeared to be generally brighter at the end of each intervention, suggesting that they were 'transported' out of their present realities into a different 'place'; a 'haven'.

This findings chapter regarding receptive music's ability to provide the experience of a 'haven' for listeners concludes with the presentation of an 'emergency' intervention I conducted with Robert.

C. Robert: 'emergency intervention'

Music can effectively capture and sustain the attention even of a listener in a highly disturbed or anxious state (Aragon et al., 2002; Sacks, 2007). This section describes an 'emergency intervention' that I was urgently requested to conduct with Robert, whose dementia sometimes took him into a dark dissociative

paranoia. On this particular day, Robert had not slept the previous night, and was expressing a very high-pitched state of agitation. Because no one was able to get close enough to administer medications crucial for calming him down, the care home manager (Evelyn) called on me to come play music for him. Robert was especially fond of music and had been enjoying his music interventions; Evelyn hoped that my playing music for him might possibly reach, and eventually sooth his very jangled nerves. I found Robert red-eyed, unshaven, and frenetically pacing the hallway. I greeted him and invited him to come listen to me play music for him in his bedroom, which he happily did. I quickly unpacked my cello as Robert perched himself on the edge of his bed - all the while tightly holding his 'mouthy' (harmonica). After briefly chatting with Robert, I commenced playing any fast upbeat Scottish or popular 1940s I could think of, because I knew that I would only be able to capture his attention if I matched his restless mood with fast and upbeat music (see chapter 3.3). As soon as I began playing music, Robert started robustly tapping his feet and thumb, and nodding his head. We continued in this manner for some time, only briefly stopping when his keyworker (Sharon) entered to offer Robert some juice - which he accepted and drank. Sharon also offered Robert a bowl of 'crispies' - which he also accepted and continued to take small bites from after Sharon had left, while I resumed playing music. As soon as I began playing fast and upbeat music again, Robert was again robustly tapping his feet; nodding his head; and sporadically singing along. During breaks between tunes, I gently cajoled Robert to eat some more cereal, to which he readily complied. When the faster-paced music appeared to have 'entrained' (see chapter 3.3) Robert, I began to slow-

down the music's pace, intending to gradually ease his agitation. This process was initially successful; Robert slowed-down his foot tapping, and even briefly closed his eyes. However, he resumed his vigorous foot-tapping and started rapping his cereal bowl with his spoon when I momentarily stopped playing music; prompting me to begin this entire process again.

After over an hour of fairly steady music, Robert appeared to be peaceful enough that I quietly packed-up my cello and began taking things back to my car. However, when I came back inside not three-minutes later, I found Robert pacing the hallway again. He did not raise his voice, but he had a peculiar far-off look in his eyes and said menacing things like; "I know what you're doing!" and; "I'll get you!" threatening to; "beat me" etc. It was evident that Robert was neither seeing nor speaking to *me*, but instead was addressing someone from a distant time. I was equally aware that I was standing well within striking-distance: I remained calm, and quietly invited him to re-join me in his room to hear more music. He eventually agreed to come to his room, and I again quickly unpacked my cello, and resumed playing fast upbeat Scottish and 1940s tunes, to which Robert immediately responded by tapping his feet and seemingly enjoying the music – although his jaw was visibly clenched. We continued like this for quite a while, and then Evelyn entered the room accompanied by a doctor who stood in the doorway with an astonished expression as she witnessed Robert gradually become calmer as I again played successively slower tunes. Eventually, this doctor was able to approach Robert, ask him some questions, and have him stick his tongue out; she left saying she would, "leave

him to the music". Evelyn later informed me that this doctor who was quite familiar with Robert's condition, had been extremely moved by what she had witnessed; saying that while she had read about the beneficial effects of music, she had never actually witnessed it in action. Once the doctor departed, I resumed playing fast Scottish tunes in order to recapture Robert's attention. He again immediately began tapping his feet, but he also began frenetically rubbing his hands, which is a known sign of agitation (Cohen-Mansfield, 1997). Evelyn soon returned and sat beside Robert on his bed, joining him in singing along with the fast upbeat Scottish tunes I continued playing. I again gradually played slower tunes, and this time Robert became calm enough for Sharon to come sit beside him and feed him dried fruit with his much needed medications mixed-in. After over three-hours of nearly continuous cello playing, I left to attend previously scheduled music interventions at another care home.

Evelyn later said of this intervention:

> "... a phone call that I gave you because staff were finding it very problematic to actually calm this person down... when you came in and went into his room - and it was a brave thing that you did, because not everybody could have gone into that room where that gentleman was at that precise moment in time. When you walked into that room, what he gained from the music that you gave him, and that you played, brought him back to down where he lives in here. Rather than the place that he was experiencing, which was very frightening...and one in which we couldn't bring him out of. But you managed through music..." (Evelyn).

Robert's passion for music was epitomised by his instantaneous embodied responses to the music I played for him; despite his being so very agitated, dissociated, and severely exhausted. For Robert, music was perhaps the *only* means of reaching and connecting with him. I felt extremely gratified knowing

that I had aided in affording him some respite; and perhaps at least a brief 'haven', wherein the music was able to bring him *back* to his current reality, and *away* from the apparently scary imaginary place he had gone into. This intervention provided a rare and vivid insight into the capacity of music to reach and improve the mood of a particularly agitated listener: to replenish his basic need for occupation (with the music); inclusion (with me and others involved and focused on him); identity (derived from the familiar Scottish music); comfort (from the familiar Scottish music); and attachment (the familiar Scottish music may have tethered him back into his real present life), and to call him back from the darkness he was presently lost within.

6. 'Haven': conclusion

This chapter illustrates and supports prior findings about music's ability to engage and 'transport' listeners into a sonic reality I have referred to as a 'haven'. Using examples from their interventions, and quotes from participants and staff, this chapter presented this study's findings regarding the effects that specific music characteristics and specific intervention format elements had towards either promoting, or occasionally hindering participants' experience of their interventions as a space where some or all of their basic human needs (i.e. inclusion-attachment-identity-comfort-inclusion; and love) were fulfilled; in short, a 'haven'.

I concluded this chapter with an account of an 'emergency' intervention' I carried-out with Robert. This 'emergency' intervention encapsulates music's

ability to reach even a person with severe dementia in the midst of a severe psychotic, dysphoric break; and shows that with time, patience, and appropriate knowledge and training, music can guide any listener into a peaceful place: a 'haven', which is, "...not a place of bricks and mortar...but rather a conceptual space..." (DeNora 2013:136).

CHAPTER 7. DISCUSSION

1. Introduction

RE's central query regarding 'what works for whom in what circumstances' (Pawson & Tilley, 1997) acted as a reminder to me to maintain an inquisitively detached perspective throughout my wholly unpredictable fieldwork experience. This query now provides the structure for the discussion of my findings as I set about contextualising these findings within existing research and practise, and highlight outstanding questions and gaps that have yet to be explored.

This study has achieved its initial objectives; to build upon and add to existing scientific and practical knowledge regarding the effects of receptive music on people with dementia who are nearing the end of life, and also on those who care for and about them. These findings reveal that the shared activity of listening to individualised live *or* recorded-music can enhance and encourage interactions between dyad members, and can also prompt interactions between the resident and the musician when the music is played live. These findings also show that listening to individualised live *or* recorded-music can capture and hold the attention of a resident and their carer; thereby paving the way for them to experience a state of comfort, safety, and 'removal' from present-day concerns –a 'haven'.

This chapter is divided into two sections: the first discusses findings regarding music's effect on dyadic and triadic interaction; the second section discusses findings regarding participants' experiences of their interventions as a 'haven'. Placing these findings within the context of previous research, this chapter reviews substantiations and discrepancies, and highlights newly exposed territory along with implications for future related practise and research.

2. Interaction

A key focus for this research was exploring the effects of receptive music on interactions that include a person with dementia. Because difficulties with communication can cause people with advancing dementia to feel isolated (Piechniczek-Buczek et al., 2007; Kelly, 2010), this issue is of particular importance. Therefore, I invited a person with whom each resident was closely connected to share these music interventions; an aspect rarely included in related research designs. The following sections use the frameworks of RE, SI, DA, and RCC to help contextualise this study's findings regarding interaction, relationship, and music.

RE seeks to understand *how* outcomes come about, whilst also fully accepting that in social science, no cause and no outcome is immutable. Instead RE recognises that, "...each relationship is itself forged in a wider network of social processes" (Pawson & Tilley, 1997). Likewise, SI is based on the premise that meaning is derived from interactions between people about a shared stimulus

(Blumer, 1969), and is contingent on the specific individuals, and the nature of their relationship (Manis & Meltzer, 1978). Thus, whilst each dyad took part in similar interventions, the shared activity of listening to music evoked unique interactions - and unique meanings within each dyad. Criticisms of SI regarding its lack of attention to historical context were largely irrelevant to this study, because this study was concerned with music's effects on the intimate interactions taking place in the 'here and now'. This reflects SI's belief that understanding the intricacies of interactions between people who are pushed to the edges of society is the starting-point for creating improvements for the greater society (Blumer, 1969).

SI views spoken language as just one method of interacting (Blumer, 1969), and DA suggests that completely reflexive responses do not exist (Appelrouth et al., 2008). It is not difficult to appreciate the relevance of these viewpoints for the present study, which pivots around understanding the effects of music on interactions between someone who may have little or no use of verbal language. From a DA perspective, we are all 'actors'; consciously or subconsciously acquiring various and fluctuating 'roles', depending on the given setting and who one's fellow actors are within any given 'scene' (Melzer et al., 1975; Applerouth et al., 2008).

Goffman's description of the 'roles' that are commonly enacted during any interaction (Goffman, 1959) provide an apposite theoretical model for better

understanding the interactions witnessed and experienced during this study. For example, when the shared stimulus was live-music, dyad members tended to become 'audience' members, and to interact with each other (and the musician – 'performer') accordingly (e.g. discussing the music and complimenting the performance). However, when the shared stimulus was pre-recorded-music, our collective 'roles' sometimes shifted, and residents sometimes felt that they were the 'performers' being 'observed' by an 'audience'. Carers sometimes became the 'shill' - perceiving their 'role' to be one of surreptitiously instigating responses from their resident partner. As the musician providing the live-music, I sometimes found myself relegated to the 'role' of the 'outsider'' - simply providing the music that fuelled interactions between dyad participants as their interactions became more inwardly focused.

Given these findings, Goffman's comparison of the role of the 'non-person' (e.g. a person who does not take on an actual role) to "…the very old, and the sick…" (Goffman, 1959:135) is rather ironic within the context of this study. It has been suggested that some medical personnel may still believe that people with advancing dementia are incapable of forming relationships (Li, 2002; Malloy & Hadjistavropoulos, 2004). The findings of this study refute these misperceptions by clearly demonstrating the capability of *all* resident participants to interact with myself either as the musician or as the person delivering the intervention, and to be able to gain benefit from the shared experience of receptive music listening.

A. People who care about people living with dementia

Potential discrepancies between the embodied self-perceptions retained by a person with dementia, and a carer's externalised opinion of this same person as no longer being the person he or she once was, are common sources of tension between people with dementia and those with whom they share a historically close connection (Sabat, 2001).

There has been little previous research regarding the effects of *any* stimulus on the interactions between people with dementia and a person with whom they are closely connected. There is however some research focusing on the triadic configuration (i.e. the person with dementia – an informal carer - a professional) commonly seen in dementia care (Fortinsky, 2001; Adams & Gardiner, 2005; Quinn et al., 2013). This study demonstrates that listening to music during repeated interventions held over a two to three-month period promoted greater equalized rapport within dyads. The music sometimes became a conduit for greater communication, while at other times it seemed to become another 'actor' with whom the participants were directly interacting. The music simultaneously enclosed the three of us - evoking vocal and physical responses from its listeners, whilst accompanying interactions within each triad – and always sonically providing something generally absorbing and enjoyable to listen to.

Systematic reviews of related research highlight the significant lack of research focused on the impact of music – or of any creative arts - on social interaction (Bradt & Dileo, 2010; Cohen-Mansfield, 2013). In the very few studies found during the course of this research, there is clear consensus that music can have a positive impact on interactions between people with dementia who are in their final phase of life, and those with whom they share a close bond (Krout, 2003; Magill, 2009; Black & Penrose-Thompson, 2012).

These findings also suggest that specific characteristics of the played music, together with the format of the interventions, sometimes significantly influenced interactions within each triad (e.g. resident, carer, researcher). This is a particularly important finding, as the shifting nature of triadic dynamics is recognised as being generally challenging (Adelman, 1987; Adams, 2003; Quinn et al., 2012) - especially when one triad member has dementia (Martin & Younger, 2000; Adams, 2003; Adams & Gardiner, 2005). No prior research has looked at the music's effect on interactions within the dementia care triad. This study suggests that music may be quite useful towards facilitating the sometimes awkward dynamics which can occur in this context, and that having a third 'neutral' person present during shared receptive music sessions may be useful (Adams, 2003).

B. Dyad interaction

While there has been some research into the effects of various creative arts on interactions between a person with dementia or a person who is nearing death

and a family carer (Haight et al., 2003; Rosenberg, 2009; Roush et al., 2011), only four studies were found which specifically focused on the effects of music on family members present either at interventions focused on a person nearing death, or focused on a person with dementia (Clair, 2002; Krout, 2003; Sherratt et al., 2004a; Magill, 2009). Each of these four studies concurred with the findings of this study regarding the ability of music to positively influence interaction. Considering the widespread acknowledgement that people closely connected to a person with dementia, or to a person in the final months of life are usually under exceptional stress (Bryan, 2006; Weinrich et al., 2006; Murphy et al., 2007; Astell et al., 2010), the absence of studies investigating the potentially beneficial use of music within these populations is surprising.

RE's explicit acknowledgement that situational variables effect interventions underscores the likelihood that not every potentially contributing factor involved in the interactional changes witnessed and experienced during any observational study can be identified. Indeed, even those factors amenable to detection are constantly changeable, depending on the specific people and contexts involved (Pawson & Tilley, 1997). Nonetheless, RE helped direct the focus of this study towards learning more about the specific elements involved in each specific circumstance that produced specific changes in interactions (Pawson & Tilley, 1997). This study found several discrete factors that encouraged interaction within dyads - mostly between resident and carer, but also between resident and myself as researcher/musician.

i. Familiar music and interaction

Though the music played for this study was specifically tailored towards the preferences of each resident, it was usually also familiar to each carer. The findings of this study regarding the positive effects of familiar music on interaction within dyads reinforce findings of three of the four studies cited above (Clair, 2002; Krout, 2003; Sherratt et al., 2004a;). In addition, Astell et al. (2010) looked at the effects of various reminiscence materials (e.g. photos, videos, music), and found that the shared activity of listening to familiar music had an especially positive effect on interactions between a person with dementia and a carer. The British Association for Music Therapy (BAMT) also cites the value of playing familiar music for people with dementia in order to arouse reminiscence (Music Therapy in Dementia Care n.d.).

Because familiar music is known to be able to evoke past memories for all listeners (Gallagher et al., 2006; Janata et al., 2007; Gerdner & Schoenfelder, 2010), it is likely that at least some if not all of the preferred familiar music chosen by each resident during this study evoked memories of events shared by both dyad members, which doubtless encouraged interaction (Hays & Minichiello, 2005; Astell et al., 2010). As there has been no research comparing the effects of listening to familiar and unfamiliar music on interactions between a person with dementia and their carer, this aspect of shared receptive music sessions has yet to be explored. Nonetheless, this study's findings support the potential benefits of playing familiar music as a vehicle for enhancing

interaction between people who have dementia and who are very frail, and someone with whom they have a shared history.

ii. Live-music and interactions between residents and carers

Live-music generally stimulated more interaction within participant dyads compared with pre-recorded versions of the same or similar music. As will be discussed in the following subsections, for most dyads there were a number of demonstrable elements that apparently contributed to changes in their interactions. Nonetheless, listening to the live-music clearly stimulated a considerable increase in interactions between Maggie and Jean (see chapter 5.3.B.i). Although Maggie enjoyed all of the music, Jean was completely disengaged during the recorded-music interventions (1-3). Conversely, Jean completely 'lit up' upon hearing the live-music, which spurred them *both* to a high level of engagement with the music and with each other. Psychologists refer to this phenomenon of drawing on one another's reactions to a shared stimulus as, 'transactional process of interaction' (Sameroff & MacKenzie, 2003; Kelly, 2010). In DA parlance, Maggie and Jean's 'roles' transformed from that of two discrete 'audience' members to a fully unified 'audience'. This shift in roles also evidently affected Jean's long-established disconnected attitude towards her mother Maggie, as they became equals sharing and enjoying a special experience and shared memories. At the same time, my relationship changed from that of 'non-person' during their recorded-music interventions, to that of the 'performer' situated clearly 'outside' of their intensive interactions during their live-music interventions.

Previous research suggests that live-music inspires more interaction amongst those who are listening compared with recorded-music (Magill, 2009; Tang & Vezeau, 2010; Black & Penrose-Thompson, 2012). However, because none of these cited studies compared the effects of live-music with the effects of truly analogous recorded-music (instead comparing live-music either with no music or with completely dissimilar recorded-music), the legitimacy of these findings is dubious.

iii. Live-music interaction between residents and musician

Although this study aimed to observe changes in interaction *within* dyads during live compared with recorded-music interventions, it quickly became evident that playing the cello live sometimes generated interactions from residents (Edward, Bonnie, Elspeth) towards myself as the musician. That these residents began asking questions about my personal life when I played the cello live suggests that at least some of the residents began to see me as more than yet another generic 'outsider' coming in and out of their residential lives; and more than a generic 'audience' observer expecting something of them. Rather, I began to be seen as a 'performer', and more importantly, their questions imply that I myself became 'seen' by these residents as a person in *my* own right.

This shift depicts the way in which the locus of interactions within each triad sometimes was between a resident and me as the musician, with the carer

becoming the 'outsider' (Goffman, 1959). This also highlights why criticisms of DA regarding its lack of emphasis on historical context for interactions are largely irrelevant for interactions that involve people with dementia, as relationships in the here-and-now seem to take precedence over past connections (Melzer et al., 1975).

iv. 'Expert' interpreters and inter-dependence

As in previous studies (Clair, 2002; Hughes, 2013), carers in this present study spoke of finding it difficult to meaningfully connect with the person with dementia whom they were visiting at the care home. A person who has shared years of history with a resident with dementia may be uniquely capable of interpreting his or her sometimes idiosyncratic communications, yet generally family carers remain an untapped resource in care homes and in research (Ingersoll-Dayton et al., 2003; Nolan et al., 2003a). Edward and Isla's interactions notably improved as a result of their inter-dependence: he needed an interpreter; she needed a means of connecting with her father (Ingersoll-Dayton et al., 2003). This example illustrates why the concept of inter-dependence is gaining greater traction within the disability population (Bartlett, 2000; Wendell, 2006). Though this was the most overt example of 'expert' interpretations during this study, there were other instances throughout (e.g. Nessa suggesting that Bonnie's seemingly odd movements during a WWII tune represented marching; Morven explain that Elspeth saying 'not interested' was the way she indicated she wanted to stop the intervention). These examples suggest that the untapped and unique knowledge of carers could be better

utilised towards fostering the possibility of inter-dependence, and that sharing the activity of listening to music can be a beneficial platform for this inter-dependence to thrive.

v: Repeated interventions

Aileen and Tommy's level of interaction increased during each successive intervention. Relatively few music-related studies incorporate a series of interventions, and only one study suggested that repeated music interventions may have contributed to reducing agitation in participants who had Alzheimer's (Svansdottir & Snaedal, 2006). Goffman's (1959) assertion that people sharing repeated visits within the same setting will eventually become more socially connected regardless of their initial (or historical) relationship supports this study's findings that whenever feasible, repeated sessions can be beneficial for recipients within practical and research environments.

vi. Printed song-sheets; artefacts

Supplying the requested printed song-sheets to Iona and Calum provided something tangible that they could comfortably focus on and share together. Paradoxically, at the time I felt somewhat annoyed by Iona's attention seemingly shifting almost entirely away from listening and responding to the music as she had during her previous three recorded-music interventions (1-3), to becoming utterly absorbed in the minutia of the words on the song-sheets! A report by Bamford and Clift (2006:9) quote a musician echoing similar feelings of vexation:"...everyone was very focused on the words, with little eye contact and participation."

Despite my concerns being genuine and well-meaning, my reaction represents a prime example of a potential but rarely overtly discussed danger lurking within this type of research: the risk that well-intended beliefs held by a practitioner about what is deemed to be 'beneficial' will supersede the indicated wishes of the recipient. Indeed, Iona was very engaged and happy with her printed song-sheets. Perhaps even more significantly, I witnessed a shared sense of intensity, focus and meaning between Iona and Calum due to the addition of these printed song-sheets (Blumer, 1969).

vii. Dyad rapport

I gave limited consideration to who would participate as the 'carer' within each dyad, with my primary concern simply being that he or she met the 'carer' criteria set for this study. It quickly became apparent that each carer's attitude towards the interventions, the music played, and their residential dyad partner, had potential to significantly influence not only dyad interactions, but also perhaps impacted on the level of engagement with the music expressed by each resident.

Barnes (2006) suggests the importance of recognising the relationship that the carer and person with dementia may have had prior to the onset of dementia. Evelyn, who managed the care home where Edward lived, speculated that he might have felt more comfortable sharing his music interventions with his keyworker instead of his daughter Isla, as he had a more affable relationship with his keyworker. Perhaps the same could have been said for Maggie, and also

for Iona. However, DeNora (2013) and Goffman (1959) note that when people are focused on the same stimulus, they may establish a connection with one another regardless of their differing backgrounds (or the historical nature of their relationship). Indeed, for varying reasons, these three dyads experienced notably positive turnarounds in the tone of their dyad rapport over the course of their interventions

Findings from this study suggest that greater consideration is warranted regarding who may be most beneficial for a resident to share future receptive music sessions (in practical settings) or interventions (in research settings). Nevertheless, some researchers believe that the historic nature of relationships is likely to have much less impact on a person with dementia compared with the present tone of their relationship because people with dementia tend to be predominantly aware of their present circumstances (Martin-Cook et al., 2001).

This study's findings also show that sharing the activity of receptive music listening may offer possibilities for successful and fulfilling interactions between people who perhaps have experienced difficult or strained relationships in the past, thus offering opportunities for dyad members to have a new experience of and with their dyad partner. DeNora (2013:139) observes that, "...people who come together through musical activity are people who, potentially, can be transformed."

Researchers and key consultant C6 have found that the frequency of carer visits to a care home resident with dementia is largely predicated on how well the previous visit has gone (Martin-Cook et al., 2001; Piechniczek-Buczek et al., 2007). The possibility that music can enhance these visits may result in residents with dementia receiving more frequent visitors. Indeed, Nolan et al. (2003a) found that:

> "Collaborating was associated with supportive interactions between carer and care recipient in which both demonstrated that they still cared for and valued the other...couples successful in this were subsequently able to 'evolve' and create shared meanings which in the best situations, brought them closer together and allowed a new perspective on life to emerge" (Nolan et al. 2003a: 265-266).

The possibility that receptive music interventions such as were conducted during this study may facilitate the invaluable gift of reconnecting and thus healing within historically troubled relationships deserves greater attention and investigation:

> "...given the central importance of the quality and history of dyadic relationships between the person with dementia and the caregiver, both in influencing the quality of life of the person with dementia and the 'experience of caring'...interventions that foster improved communication between the carer and the person with dementia are likely to prove very fruitful... " (Nolan et al., 2003b: 143).

viii. Dyad interaction summary

The previous subsections suggest that although music provided the primary catalyst for enhanced interactions within dyads, there were a number of other factors present that facilitated greater dyad interaction. Previous related studies suggest that live-music has the most positive effect on interaction (Götell et al.,

2002, 2004a; Sherratt et al., 2004). However, because these studies did not compare analogous versions of recorded and live-music, it is not possible to validate their findings. Although live-music may be preferable, it will not always be available due to funding issues (Cohen-Mansfield & Werner, 1997). Findings from this study suggest that recorded-music can be beneficial for enhancing interactions between dyads including a person with dementia, which implies the possibility that a greater number of people may be able to benefit from shared receptive music sessions in the future.

C. Triadic interaction

Over the past several decades, dementia research has shifted from focusing on the wellbeing of the person living with dementia, to considering the wellbeing of those who care for and about the person with dementia (Bartlett & O'Connor, 2007). More recently, the impact that improving interactions and relationships *between* these two groups of people, as well as with 'professionals' can have on their collective wellbeing has gained greater attention (Fortinsky, 2001; Nolan et al., 2002).

Although researchers suggest that one-to-one interactions are most effective for people who have dementia (Killick & Allan, 2001), there is often a third 'professional' person present – especially within residential settings (Adams & Gardiner, 2005; Quinn et al., 2013). Thus inviting a carer to join these music interventions corresponds with the ethos of ethnography (Silverman, 2000; Hammersley & Atkinson, 2007; Bryman, 2008), SI (Blumer, 1969; Meltzer et al.,

1975), DA (Goffman, 1959), and RE (Pawson & Tilley, 1997; Atkinson & Housley, 2003; Bonnell et al., 2012) by allowing for as 'natural' a setting for these interventions as possible. However, it also meant inviting the imbalance associated with triadic interactions (Adelman, 1987; Adams, 2003; Quinn et al., 2012). C8 felt that having a carer present during music interventions complicated her job as a MT, because she felt beholden to consider the carer's needs in addition to those of the person with dementia for whom the intervention was intended. Seeing myself as an actively participating triad member during each intervention, it was indeed sometimes tricky finessing the shifting dynamics within each triad.

Family carer's tendencies to project either their own personal preferences or historically attributable preferences onto their family member who has dementia, even when he or she is clearly indicating a different preference in the here-and-now, is one of the chief difficulties cited regarding family carers acting as proxies for decisions (Potkins et al., 2000). During this study, triadic imbalance most frequently occurred when a carer projected their personal musical tastes onto those of their residential dyad partner. Other difficulties resulted when a carer was overly solicitous towards their dyad partner, when a carer disregarded their dyad partner, or when either a carer or the researcher excluded a resident from interactions. Nolan et al. (2002) suggest that professionals recognise carers as the experts in their *situation*, and people with dementia as experts in their own *experience.* The findings of this study corroborate prior research suggesting that the neutralising presence of a

professional or 'outsider' can facilitate interactions between a care home resident with dementia and someone with whom they are closely connected (Adams, 2003). This may also enable reconfiguration of deep-rooted perceptions and roles shared within the dyad (Quinn et al., 2012). This study's findings further indicate that having a 'neutral' third person present during receptive music sessions may foster the reconnection of dyad members (Adams, 2003).

As the locus of interaction is fluid within triadic relationships, Adams and Gardiner (2005) caution that when a triad includes someone who has difficulty communicating (such as a person with dementia), it is essential that the other two triad members take extra care not to exclude him or her from interactions. The following subsection discusses findings regarding the success (or not) that carers and I had regarding this particular triad dynamic during these interventions.

i. Resident empowerment

Sprague and Hayes (2000) suggest that 'empowerment' is socially based:

> "Building empowering relationships with people who have developmental disabilities is likely to require interaction strategies that are flexible and multichanneled. People who are less verbal may rely more on nonverbal communication..." (Sprague & Hayes, 2000: 685).

Participating in a series of similarly structured interventions afforded residents the necessary time and space to act upon their own empowerment. Although limited to encouraging each resident to preside over his or her music

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interventions, even this degree of empowerment may have facilitated residents to experience their interventions as a 'haven' because their wishes were heard and responded to. This finding is significant because there is growing appreciation of the positive impact that experiencing empowerment can have on wellbeing (Nolan et al., 2002; Aggarwal et al., 2003; Fetherstonhaugh et al., 2013).

However, the beneficial impact that empowerment has on residents goes substantially deeper. In the 1970s, Seligman developed the psychological theory of 'learned helplessness' (Faulkner, 2001), positing that if a person's efforts to control their surroundings are repeatedly thwarted, he or she will not only cease trying, but will actually forget that having control is even a possibility, often leading to feelings of depression (Faulkner, 2001). The counterbalance to 'learned helplessness' is the theory of 'learned mastery', developed some years after, which argues that if a person is encouraged to control something in his or her surroundings, and if this encouragement is *restated* during *repeated* visits, it is likely that he or she will, "...develop an expectation that future events will also be controllable" (Faulkner 2001:380-382). Research has shown that once someone has experienced learned helplessness in one area of their lives, it often spills into other areas (Faulkner, 2001). As care homes tend to foster a sense of dependency in residents (Harmer & Orrell, 2008), the amalgamation of these two related theories, together with the theory of embodiment discussed earlier within this thesis (see chapter 2.3.A), strongly suggests the importance of offering whatever empowerment may be possible to people living with

dementia; particularly within care home settings. Thus, a resident with an *embodied* sense of 'learned helplessness' (perhaps even prior to having dementia) might, after repeated encouragement during a series of receptive music interventions, be able to unlearn his or her 'learned helplessness' by experiencing a degree of empowerment. He or she may then be able to convert their embodied 'learned helplessness' into 'learned mastery', which might consequently positive impact on other areas of his or her life. Examples of embodied 'learned helplessness' were perhaps expressed by some (interestingly only female) resident participants when they insisted that I was the 'boss' whenever I solicited their opinion.

There were times when a resident's empowerment was inadvertently impeded by either a carer or myself. For example, though residents quickly settled into their interventions, I feel that my occasional gentle coaxing of an understandably uncertain resident to leave the communal area bordered on coercion. This is because, despite my good intentions, I verged on not honouring his or hers right to say 'no', and thus for him or her to have their wishes *fully* acknowledged and respected (Hatfield & McClune, 2002). Carers and I also sometimes interrupted or spoke over a resident, further illustrating how easy it is even for people who are extra vigilant to exclude a person with dementia from the triad interactions discussed above and elsewhere in the literature (Martin & Younger, 2000; Adams, 2003; Adams & Gardiner, 2005).

Another notable way that I may have unintentionally hindered some residents' experiences of empowerment was when I missed or overlooked indications that a resident was tiring. This finding highlights the importance of paying close attention to the individual embodied communications of people with dementia (Kontos, 2012; Downs, 2013), and also underscores how difficult it sometimes is to properly interpret these often subtle cues in the moment (Coaten & Newman-Bluestein, 2013).

D. Interaction conclusion

The findings from this study corroborate those of the small number of existing studies regarding the beneficial effects that receptive music listening can have on the interactions between a person with dementia who is especially frail, and someone who closely connected with him or her. These findings also spotlight the effects that specific elements of the format of these interventions had on interactions; providing a response to DeNora's (2013) call for more research into the impact of specific elements involved in music interventions, as well as fulfilling RE's mandate to discover the effects of particular 'mechanisms' (Pawson & Tilley, 1997).

This study's findings suggest that sharing the experience of receptive music listening can promote interactions between listeners, even when their relationship has become distant or disconnected. Further research should be conducted in this area; particularly as RCC related research suggests that the presence of a 'neutral' third person can help diffuse potentially awkward

dynamics between a person with dementia and someone with whom they share a historically close relationship (Adams, 2003; Quinn et al., 2012). These findings coalesce with the core principles of PCC - that personhood is defined by one's interactions with, and the perceptions of, those who surround us (Kitwood & Bredin, 1992; Chalfont, 2009), and also with SI's view; that meaning is created through shared interactions (Blumer, 1969). Through the heightened interactions each resident experienced during these music interventions, a sense of self, of inclusion, of being cared for, and of being acknowledged and responded to, were also enriched.

This study is one of a very few that compares truly analogous versions of live and recorded-music. The potential benefits that both live *and recorded* receptive music listening was shown to have on interaction merits additional research using analogous music interventions. These findings also strongly suggest the possibility that when used thoughtfully, skilfully, and appropriately (see chapter 8.6.A), recorded-music can substantially benefit individuals and increase interactions between those who are listening. The implication that sessions can be delivered by an appropriately trained non-musician raises the possibility of far more people within similar populations having the opportunity to partake in and therefore to benefit from similar receptive listening music sessions.

3. 'Haven': 'I'd rather have music!'

A. 'Haven' introduction

A key focus of this study was exploring and comparing the effects that the same or similar live and recorded-music had on each resident and carer during a series of six receptive music interventions. Searching for a term that aptly described what each participant seemingly experienced to varying degrees during these interventions, I chose 'haven'. Findings from this study support prior research regarding the positive effects that receptive music listening can have on all listeners (Grocke & Wigram, 2006). However, the principles of RE spurred me to delve further into learning how specific aspects of the played music and the format of these interventions influenced responses from certain participants (Pawson & Tilley, 1997). What I discovered, was that although the music was undeniably the overall primary motivator of participant responses, there were distinct, sometimes subtle characteristics of the music, and also aspects of the intervention format that elicited positive responses from some participants, which aided towards these interventions fostering a sense of 'haven' for participants.

This section is divided into three subsections, and discusses findings regarding participant responses within the context of his or her ability to experience their interventions as a 'haven'. The first discusses how specific elements of the intervention format helped to 'remove' participants from their everyday realities. The second considers specific features of the played music that 'furnished' an enjoyable stimulus that he or she could engage with and also share with their dyad partner; further promoting an experience of 'haven'. The final subsection discusses the 'emergency intervention' I conducted with Robert,

and further demonstrates the possibilities of receptive music listening to 'transport' even the most agitated person living with dementia towards a changed and improved reality. Implications for future research and practice will also be discussed throughout this section.

B. Environment

Although the significance that the environment has on people living with dementia is well-recognised (Hung & Chaudhury, 2011), most related research tends to focus on changing the *physical* environment of people with dementia, generally towards reducing extraneous distractions (Kovach, 2000; Wood, 2005). Physiological research also emphasises the importance of finding a balance between too much and not enough stimulation for people with dementia, but again on the focus is on changing the *physical* environment (Kovach, 2000; Wood et al., 2005). Social Interactionists believe that people can experiences of the same physical setting very differently (Appelrouth & Edles, 2008), so it is heartening to find researchers beginning to look beyond the physical surroundings of people with dementia living in care homes, and putting greater emphasis on the impact that *interactions* have on wellbeing (Wood et al., 2005; Brooker, 2006). For example, DeNora (2013) suggests that:

> "...asylum [sic] is not a place of bricks and mortar...but rather a conceptual space, an anytime/anyplace of health promotion..." (Denora, 2013:136).

Fascinatingly, a study by Cox and Roberts (2006) cite a participant who was nearing the end of life describing his experiences of listening to music during repeated music vigils as that of being transported to a 'haven':

> "...he went to another place altogether...somewhere where he experienced love and trust. He called it 'The Haven – The Place Of No Fear'" (Cox & Roberts, 2006: 86).

Findings from this study promote the value that interaction has for people with dementia and also for those with whom they are closely allied. This study also demonstrates the capability of shared receptive music listening interventions to encourage interactions between listeners through sonically 'removing' them from their current physical reality and 'transporting' them into a sonically constructed 'haven'. Kovach (2000) refers to a special care unit in the US that recognises "...the need for both stimulation and *retreat* for people with dementia" (Kovach 2000:380): this study suggests the ability of receptive music listening to simultaneously provide listeners with just such an experience.

DeNora (2013) suggests that:

> "Music and sound can change the relationship between public and private experience, and they can change the locations available for this experience" (DeNora 2013:63).

Researchers have found that people with dementia living in care homes tend to feel more comfortable when their surroundings are 'homelike' (Cioffi et al., 2007; Fleming et al., 2008; Campo & Chaudhury, 2012). This study posits that the familiar music played during these interventions sonically created a 'homelike' environment by playing familiar music, which helped residents feel greater comfort – and perhaps a feeling of 'haven'. This finding opens-up potentially wonderful and crucial possibilities for people with dementia who are in the final phase of life, for although they may be unable to control their physical environment, music's portability offers the possibility of one's

environment being *sonically* altered; meaning that more people who are especially marginalised and overlooked in care home settings may benefit from and be able to be transported to an experience of haven; regardless of their cognitive or physical frailty.

However, situating these interventions within the private bedrooms of each resident did minimise the many general distractions intrinsic to care home settings (Powell, 2000; Heine & Browning, 2004; Bryan, 2006; Hargie & Dickson, 2006; Goldfein, 2007; Hobson, 2008). Also, various alarms and staff interruptions seemed to only temporarily impede on participants experience of their interventions as a 'haven. This is because the familiarity of each resident's bedroom also contributed to encouraging a sense of comfort (Coaten et al., 2013); further facilitating each resident to experience his or her interventions as a 'haven'.

i. Repeated interventions

Conducting a series of similarly structured interventions seemingly provided ample time for residents and carers to become familiar and thus more comfortable with this presumably unfamiliar way of listening to music. This increased comfort over successive interventions was generally conveyed thru heightened engagement with the music and increased interaction. This finding corresponds with Goffman's (1959) belief that repeated contact between people enhances interaction. Music researchers tend to schedule a 'washout' interval between different types of interventions (Kim & Buschmann, 1999; Gerdner,

2000). Per the ethos of both RE (Pawson & Tilley, 1997) and ethnography (Fetterman, 1998), I scheduled this study's interventions based in the availability of each carer. This meant that some dyads had no gap between their live-music and recorded-music interventions, while other dyads had a significant hiatus (e.g. over a month). It is impossible to gauge how much these varying hiatuses might have influenced participants' biases towards one or the other versions of the played music, if at all. What was apparent was that all participants benefited from engaging in a series of similarly structured interventions.

a. Residents and special attention

Not all of the positive reactions expressed by residents were necessarily the exclusive result of listening to music. Indeed, a systematic review of psychosocial treatments for people with dementia speaks to the powerful impact that "...personal attention of any kind..." can have on the life of people with dementia living in care homes" (O'Connor et al., 2009a:227). Some of the residents seemed to find particular delight in receiving repeated visits from their dyad partner, as well as the extra focused attention that came with the format of these interventions.

Loneliness is an oft-cited actuality for care home residents due to their loss of connection with family and friends (MacDonald, 2005; Froggatt & Payne, 2006; Garland, 2007; Choi et al., 2008; Wilson et al., 2008). Care home residents also report experiencing a high incidence of boredom (Cohen-Mansfield & Werner,

1997; Stanley, 2009). Residents with dementia are particularly prone to experiencing loneliness, isolation, and boredom due to difficulties with communication (Cohen-Mansfield & Werner, 1997; Harmer & Orrell, 2008). Even the few residents in this present study who had regular visitors would generally not have been visited as regularly or for such extended time-spans if not for these music interventions. These findings, coupled with the above-cited potential for family members to visit more often if their visits are enjoyable, imply that shared receptive music sessions hold the possibility of improving the wellbeing of care home residents with dementia, and that the by-product of increased attention can help residents to experience their music sessions as a 'haven'.

b. Carers and repeated interventions

Nolan et al. (2003) describe two types of carers: the 'ideal' carer is flexible and accepting, and does not harbour unrealistic expectations. The 'compromised' carer has unrealistic expectations and is thus often disappointed. Hennings et al. (2010) add an additional carer type - the 'disengaged' carer: an adult child of a person with dementia, who generally shares a conflicted past with this parent. The responses and interactions of each carer in this present study generally matched with one of these three carer types. The 'ideal' carers experienced their music interventions as an oasis – a time for relaxing and of enjoying a shared activity with their resident dyad partner (Tommy, Cait, Mairi, Donna). The 'compromised' carers reported experiencing the interventions as 'hard work' due to their over-vigilance of their dyad partner (Nessa, Brenda, Kirsty). The

'disengaged' carers were initially almost entirely detached from the entire experience – and also were the ones who demonstrated the greatest change over the course of their interventions (Jean, Isla, Calum). The benefits of standing back and allowing each carer space to acclimate to their interventions echoes Whyte's (1989) suggestion that PO be conducted with as little intrusion as possible by the researcher. This strategy allowed me to witness carers experiencing peace and enjoyment and a sense of 'haven' during shared receptive music sessions, regardless of which carer-type he or she was at the start of his or her series of music interventions.

These two subsections show that participating in a series of similarly structured receptive music listening interventions allowed residents and carers an opportunity to adjust to experiencing what is a decidedly an extraordinary event – and thus a greater likelihood of experiencing these interventions as a 'haven'.

ii. Optimal intervention length

Thirty-minutes appears to be the 'gold-standard' duration for most music interventions (Horne-Thompson & Grocke, 2008). However this study suggests that for most residents, fifteen-minutes is perhaps sufficient. People who have dementia and who are very frail are likely to have less stamina, and despite some researchers and music therapists classifying music listening as a 'passive' activity (Sherratt et al., 2004a; Bernardi et al., 2006; Sakamoto et al., 2013), I argue that music listening is a 'receptive' activity, requiring listener(s) to actively

listen to the played music. 'Entrainment' and the 'iso-principle' (see chapter 3.3) are further examples of the non-passivity of receptive music listening.

Receptive music listening was shown to be a very pleasurable experience for participants during this study; but too much of a good thing may leave a listener exhausted. C2 cautioned that resident participants might not only grow tired, but might even become bored or frustrated if the music interventions lasted too long. There remains need for further investigation regarding the establishment of optimal duration for receptive music listening interventions within similar populations. Irrespective of the planned duration there should always be flexibility built-in for interventions to either end earlier or to last longer, depending on the expressed wishes of listeners. Because of resource implications, the possibility that significantly shorter interventions may still provide listeners with the opportunity to experience a feeling of 'haven' during a receptive music listening session also opens-up potential opportunities for more people from similar populations to be able to benefit from similar sessions.

iii. Biological measurements

Similar to previous study findings (Lee, 2005; Freeman et al., 2006; Horne-Thompson & Grocke, 2008), carer pulse and blood pressure measurements were not significantly affected by these interventions. Even if there *had* been a noticeable change in these measurements, C2 and C3 warned of the near impossibility of pinpointing probable causes for these basic biological changes. Though there was no indication that these quick and simple measurements

negatively impacted on carers' experience, I felt that these biomedical procedures introduced an unwelcomed sense of a 'laboratory experiment' into these interventions; particularly at the end of interventions, when these measurements could easily compromise a carer's experience of their intervention as a 'haven'.

iv. Environment and 'haven' - conclusion

This study's format of repeated interventions offered participants leeway to relax into the activity of receptively listening to music. The ritualised format of reintroducing myself and the interventions, re-obtaining consent, and reminding each resident that he or she was in charge, may have helped to psychically prepare residents to more receptive to the played music. The nature of these repeated interventions also provided residents with the nurturing experience of being the centre of attention, and of having their wishes (whenever possible) acknowledged and acted-upon: which was likely unusual in their present living situations. Consequently, residents were able to experience the satisfaction of two of Kitwood's (1997) stated basic human needs; '*inclusion*', and '*comfort*', before the music even began thus allowing the played music to further fulfil Kitwood's (1997) basic human needs of '*identity – occupation – attachment'* more successfully, and create a 'haven' for listeners.

C. 'I like music!'

Live and recorded individualised music was at the heart of this study's interventions. Guided by the RE acronym: 'contexts – mechanisms - outcomes' or 'COM' (Pawson & Tilley, 1997), the following subsections discuss findings

regarding the effects that specific characteristics of the played music had on participants' experiencing their interventions as a 'haven'.

i. Individualised music

The general benefits of playing preferred familiar music for people with dementia have previously been elucidated (see Chapter 4.4.C.i). To summarise, this study concurs with prior research regarding the particular benefits of playing individualised music for people with dementia (Gerdner, 2000, 2009, 2010; Sherratt et al. 2004a; Park & Specht, 2009; Sakamoto et al., 2013). Perhaps this is because familiar music triggers more responses in the brain's pleasure centres than unfamiliar music, regardless of whether the played familiar music is liked or disliked (Pereira et al., 2011). Alternatively, perhaps hearing familiar music aids the listener with dementia to feel a sense of 'attachment' to something familiar (Brooker, 2007); a sense of "...continuity with their past life and identity" (Katz et al., 2013:57). The following subsections discuss findings regarding how specific aspects of the individualised played music especially contributed to residents experiencing their interventions as a 'haven'.

a. Identifying familiar music

Despite some neurologists questioning the capability of people with advanced Alzheimer's to retain 'explicit' music memory (Baird & Séverine, 2008), researchers generally concur that even people with quite advanced dementia *do* demonstrate the ability to recognise familiar music by singing along with

familiar tunes and frequently remembering some or even most of the words, despite having not heard a tune for many decades (Cuddy & Duffin, 2005; Vanstone et al., 2009). Indeed, I witnessed this phenomenon frequently during these interventions. Nevertheless, residents' reactions to hearing presumably preferred familiar music varied considerably, and it quickly became evident that *correctly identifying* a familiar piece of music significantly impacted on the level of engagement with the music expressed by some residents. Indeed, for some residents correctly identifying a familiar tune became a challenging game; further fulfilling Kitwood's stated basic human need of '*occupation*' (Kitwood, 1997). I was unable to locate any previous research referring to the impact that correctly identifying familiar tunes might have for listeners, let alone for listeners who have dementia. This study's findings indicate a need for greater attention to be paid to this issue, as some of the residents in this study expressed evident pleasure or angst depending on his or her ability to correctly identify the played familiar music.

b. Music and time travel

One of the most commonly cited reasons that familiar music is believed to be particularly beneficial for people with dementia is its proven ability to reach and to 'transport' even listeners with very advanced dementia back into distant memories (Gallagher et al., 2006; Janata et al., 2007; Gerdner & Schoenfelder, 2010). While I witnessed this phenomenon numerous times during these interventions it did not always happen, and it is important to emphasise that

familiar music will not always elicit such memories from listeners (Janata et al., 2007).

Sometimes I was unable to pinpoint each resident's specifically favoured music. Thus I was pleased that this study verified previous findings (Janata et al. 2007), and C1's suggestion regarding from the importance of playing music from key eras of a listener's life towards effectively engaging and thus 'transporting' him or her back in time. In the context of participants experiencing their interventions as a 'haven', the research literature and this study's findings show that when played music has historical importance to a listener's life, he or she can be 'transported' out of their present reality back into the experiences and emotions of a faraway memory; an attribute of 'haven'.

However, the emotional nature of evoked memories cannot be predicted. Crying or upset should not necessarily be construed as 'negative' as these emotions and memories are equally meaningful and can be cathartic for listeners (Grock & Wigram, 2007). Indeed, Hatfield and McClune (2001) state that increased emotions such as crying are, "…positive and valid responses to the intensely personal space shared by the therapist [sic] and the person with dementia" (Hatfield & McClune, 2001:105).

Regardless of whether the memories evoked were happy or sad, listening to familiar music generally stimulated reminiscence and also inspired shared reminiscing within dyads; again fulfilling Kitwood's (1997) basic human needs for '*attachment*', '*inclusion*', '*identity*' and '*occupation*'. Akin to the discussion above, Whyte's (1989) suggestion that PO be conducted with as little intrusion as possible helped remind me of the importance of allowing events to unfold without making value judgements or interfering.

c. Music genre

Though it was not always possible to ascertain a resident's specific favourite pieces of music, I was able to determine his or her preferred music genres (e.g. Scottish, 1940s popular, classical, hymns, etc.).Indeed, some residents indicated clear likes and dislikes for specific music genres; frowning or grimacing when a disliked genre was played; smiling and engaging with favoured genres. This finding echoes experiences reported by music therapists working with people across all settings (Grock & Wigram, 2007). Instances where music genre preferences within a dyad were diametrically opposed required special tact on my part, while maintaining a focus on the music genre preferences of each resident. That some participants expressed considerable levels of affinity or animosity towards specific music genres was a further indication that they were 'occupied' with the music and thus were likely 'removed' from their present reality. In RE parlance, the 'context' does not seem to be much of a factor when referring to the effects of specific music genres on listeners, as listeners will likely have similar responses to music genres playing, regardless of where they

are listening to it. Thus this study suggests that that more weight be placed on the beneficial effects of playing music that matches the listener with dementia's musical genre preferences, rather than getting overly concerned with striving to determine specifically preferred pieces of music.

ii. Music tempi and temperament

A study by Bernardi et al. (2006) found that the *tempo* of the played music had considerably more of a relaxing effect on (healthy) listeners then did the *genre* of the music. This makes sense because music that has a lively beat will likely 'entrain' and thus arouse listeners rather than relaxing them. There is a clear need for continued research regarding the relative effectiveness of various music genres, preferred or otherwise, particularly with listeners who have dementia.

A study by Bernardi et al. (2006) found that the *tempo* of the played music had considerably more of a relaxing effect on (healthy) listeners then did the *genre* of the music. This makes sense because music that has a lively beat will likely 'entrain' and thus arouse listeners rather than relaxing them (Glass, 2001; Clayton et al., 2005). The recurring visible signs of the played music 'entraining' listeners during these interventions provides additional proof that participants were 'occupied' with the music they were listening to - literally to the point of being 'moved' by it, and provides further evidence of their 'removal' from their present reality into a sonic 'haven'.

Participants' moods were never discernibly lower at the end of an intervention compared with at the start. Indeed, residents generally appeared cheerier at the conclusion of their interventions. Aileen let me know when she did not feel like hearing 'sad' music; Hazel commented that some of the slower tunes made her feel a bit sad; and Heather said the same. Shifriss et al. (2014) suggest that these responses may be due to the 'positivity affect', meaning that older people tend to want to be happy and so tend to want to hear happy music when they are in a low mood in order to change their mood rather than choosing to listen to music matching their low mood. The responses of each listener to the same tune played across interventions largely depended on his or her present mood-state; a tune might be too slow during one intervention, and might really suit the listener during the next. This finding demonstrates the effects of music via 'iso-principle' (see chapter 3.3).

Researchers suggest that the changes in mood that occur when listening to music may be the result either of a listener being distracted by or being especially focused on the music (Shifriss et al., 2014). At the start of the 'emergency intervention' I conducted with Robert, I chose to play quickly-paced music with the intention of capturing his attention via 'entrainment', whilst also hoping to distract him from his obsessive ruminations. I gradually slowed the pace of the music down, while keeping the temperament upbeat, hoping to

bring him into a calmer disposition via the 'iso-principle': by the end of this extended 'emergency intervention', Robert was markedly quieter and happier.

Despite a study conducted by Ragneskog et al. (2001) indicating that music has no effect on the moods of people with very advanced dementia, this current study and others suggest otherwise (Särkämö et al., 2012). Indeed, Robert's emergency intervention principally demonstrates the unique power of music to reach someone who not only had advancing dementia, but who was also in a highly agitated and altered state. This finding provides further evidence of the potential that receptive music listening can have towards guiding listeners into an experience of 'haven'.

iv. Musicianship

The proficiency of the musicians playing live-music, and the quality of the version of pre-recorded-music selected to be played for people who have dementia are rarely addressed in research. Grocke & Wigram (2006) speak to the importance of this issue, as did C8 (see chapter 6.4.D). This is a matter of increasing relevance as due to the growing number of well-meaning musicians who wish to play for care home residents (many of whom are likely to have dementia).

The absence discussion about this topic in existing research is worrying, as it infers either a lack of musical knowledge on behalf of researchers (which could

easily be remedied by soliciting advice from experts in related fields or worse, an assumption that people with dementia are not considered to be discerning listeners. A case study by Cuddy and Duffin (2005) clearly shows that people with severe dementia can immediately notice wrong or altered notes within a familiar tune; in this current study, Hazel rebuked me several times for mistakes she noticed in my cello playing.

In fact, it can be argued that it is especially crucial that both the proficiency of live-musicians and the quality of pre-recorded-music be of the highest standard when listeners have dementia, due to the greater likelihood of successfully capturing and holding their attention. Also, a person with dementia who is very frail will likely be much less able to communicate his or her dislike of the music they are listening to; to either physically turn the music off, or to physically leave. This means that there is a greater risk of people becoming recipients of unsuitable care. Ultimately, everyone in every setting should have equal access to the best quality music possible; assumptions that people with dementia won't be able to perceive the quality of music that is played are at best misinformed.

v. Receptive music listening interventions

Corresponding with RE's principle of seeing what unfolds in any given situation rather than creating artificial objectives, this study was based on receptive music listening interventions. This means that participants were free to respond (or not) as they wished, with no intended goals set. The residents who participated in this present study represent a segment of both the wider

population, and of care home populations, who are less likely to participate in more general group activities and entertainment; largely due to his or her cognitive or physical impairments.

Wood et al. (2005) described the majority of care home activities provided for care home residents as merely:

> "... activity-oriented veneer, they functioned more as containers in which residents could be safely placed and monitored, but not necessarily meaningfully engaged" (Wood et al., 2005:114).

Conversely, Grocke and Wigram (2006) suggest that receptive music interventions can create a contained rarefied atmosphere that enables "...the client [sic] [to] let go into the experience" (2006:49). These two quotes indicate the potentially vast differences in intent and hence benefit that seemingly similar interventions may have for people who have dementia, and the need for further exploration and exploitation of the latter form of music intervention.

That *all* the residents taking part in this study engaged with the played music and interacted with the people present during their receptive music interventions serves as further validation of research suggesting that *everyone* can benefit from listening to music and thus that there is *no* reason for *anyone* to be excluded (Cuddy & Duffin, 2005, Särkämö et al., 2012). 'Everyone' is the key word here, because people with advancing dementia are sometimes assumed to not be able to benefit from listening to music (Ragneskog et al., 2001), and music researchers commonly exclude people if they have less than 'normal' hearing (Ragneskog, 2001; Park & Specht, 2009; Gerdner, 2010). Several residents in this

present study had evident hearing loss, but were able to enjoy the played music regardless. Indeed, Aldridge (2000:28) suggests that even for those listeners who have very little ability to hear, the "...social contact and gesture[s]..." may be enough. Lastly, music is a medium that can be enjoyed by all people; regardless of how 'educated' they may or may not be about the music they are listening to (Götell, 2002; Cuddy & Duffin, 2005), thus making the musical background of listeners an irrelevant consideration (Renz et al., 2005; Bernardi et al., 2006).

The tendency of prior related studies tendency to favour interactive music interventions over receptive music interventions for people with dementia or for who are nearing the end of life is perhaps misleading, because these studies generally compare interactive music interventions which include the presence of a trained music therapist with receptive music interventions where the person with dementia is left listening to music *alone* (Raglio et al., 2013), or to interventions which involve *no* music (Hilliard, 2003; Sung et al., 2006; Svansdottir & Snaedal, 2006; Wlodarczyk, 2007). The findings of this present study strongly imply the need for research comparing the effects of interactive and receptive music interventions where the presence of the same person(s) remains constant throughout: leaving a room with music playing for a person who is unable to stop or change the music is not an appropriate option as this is bad practise.

The above subsection reinforces the merits of having someone present during pre-recorded receptive music interventions who has a modicum of training in nonverbal communication, palliative approaches, dementia, and knowledge of 'entrainment' and the 'iso-principle' so as to mitigate potentially negative effects resulting from listening to music that for whatever reasons does not match the mood of the listener(s). Of course, if someone wishes to listen to music on his or her own, that is fine - so long as he or she has the capability to control the music that is playing.

vi. Embodied responses

Examples presented of residents expressing 'embodied' responses to the music they were listening to earlier in this thesis (see chapter 6) serve to reinforce the importance that recognising embodied memories and communications has towards successful dementia care. DeNora (2013) describes the embodied responses that people can have when listening to music as, 'warm consciousness', wherein:

> "...bodily self-perception does not involve conscious reflection and where there is an interaction between music and perception and bodily perceptions that circumvents or has no need for language..." (DeNora, 2013:104).

Purves and Perry (2009:188) suggest that for people with 'severe cognitive impairment', embodied communication through nonverbal gestures and movements "...is the fundamental means of engaging with others". Moments such as Bonnie 'marching' upon hearing a popular 1940s tune and breaking into highland dance arm gestures during a Scottish tune, or Robert dancing and

tapping complex rhythms to Scottish tunes in his sleep, and Betsie affectionately and gleefully 'hitting' Morven during various tunes, are all illustrations of embodied communications and responses. Some proponents of SI may view these responses as 'nonsymbolic' reflexive interactions with a stimulus (Blumer, 1969). However, Goffman's (1959) contention that people never interact reflexively, and the steadily increasing recognition of the existence and influence of embodied memories, knowledge, and responses (Aggarwal et al., 2003; Kontos, 2012; DeNora, 2013) suggests otherwise. Indeed, Shustik and Thompson (2002) posit that:

> "Each person's ability to access and express feelings through the body remains until the last dying breath, no matter what physical or cognitive limitations exist" (Shustik & Thompson, 2002:49).

Leman et al. (2009) suggest that:

> "...embodied listening responses may involve implicit learning, and hence, that the shared expression among participants may be enhanced in response to repeated exposure to music" (Leman et al., 2009: 273).

Finally, residents who expressed regret at being unable to offer me tea were likely conveying a life-long embodied habit (Kontos, 2012), while also portraying a need we all share of being able to reciprocate (Katz et al., 2011; MacRae, 2011); suggesting that providing ways for residents to be able to reciprocate, and acknowledging long-held embodied habits should be given greater attention in future research and practise.

vii. Who should be present?

C8 speculated that a carer's presence during music interventions could prompt a resident to resist expressing very sad or other 'negative' feelings for fear of causing upset. This concern appears somewhat incongruous, because one of the refreshing aspects of working with people who have dementia is their general lack of inhibition. This study corroborates prior findings regarding the reciprocal impact that people sharing an experience together (such as listening to music) can have (Martin-Cook et al., 2001; Kontos, 2012; DeNora, 2013). The degree of willingness and the general attitude of carers sharing an activity such as receptive music listening can considerably influence a resident's engagement with the played music, and can also considerably impact the timbre of the shared interactions and thus the relative ease with which those who are sharing this activity will experience a feeling of 'haven'.

D. The alchemy of music and temporality: 'flow' and 'intense musical experience (IME)'.

Varying degrees of 'flow', or 'IME' were experienced by most of these participants over the course of their interventions. Regrettably, these related concepts are rather nebulous, and in-depth exploration is well beyond the scope of this research. Indeed, according to Diaz (2013) the concept of 'flow' is:

> "...an event that occurs in time, and thus summative accounts based on either interview techniques or questionnaires do not provide sufficient information relating to the temporal characteristics of the experience" (Diaz 2013:45).

Nonetheless, there were instances during these interventions when a participant or a dyad became so intensely absorbed with the played music that

time seemingly 'evaporated', causing an intervention to be considerably extended (see chapter 5.3.B.i/iii and chapter 6.4)

What is particularly striking is that Schafer et al. (2013:15) state that IME's "...enabled people to understand each other without words..." This was something I witnessed during brief and sometimes longer periods of time throughout these interventions. Schafer et al. (2013) also suggest that IMEs "...contribute to what has been called spiritual well-being" (Schafer et al., 2013:17).

For Iona-Calum, the addition of requested printed song-sheets during their latter three live-music interventions undoubtedly triggered their collective absorption. Whilst their first three recorded-music interventions each lasted approximately thirty-minutes, their latter three live-music interventions each lasted well over an hour, and at the end of each of these interventions both participants appeared to be happy and refreshed rather than somewhat tired as one might expect after such an extended span of focused concentration.

Elspeth also became very engaged and inquisitive during her latter live-music interventions, as expressed thru her asking me questions about playing the cello and also repeatedly requesting more music. She also appeared to be happy and refreshed at the end of each of these significantly extended interventions.

Maggie and Jean were completely engaged with the live-music and with each other during their latter three interventions and also appeared to be happy and refreshed at the end of each of these three lengthy interventions.

Whilst these two dyads and Elspeth represent the most dramatic examples of 'flow' or an 'IME' during this study, Betsie, Hazel, Edine and Cait, were also completely engaged with the music throughout their interventions, and other participants or dyads may also have experienced 'flow' or an 'IME' but none so overtly, or for so comprehensive a time-span. I argue that every participant experienced 'flow' each time the music captured and held their attention; thus 'removing' them from their present reality and perhaps helping them towards an experience of 'haven'.

The Piece-dem Tables in appendix 9.D illustrate the high-level of involvement that Maggie-Jean, Iona-Calum, and Elspeth experienced during these particularly extended interventions. These tables further support the conclusion that, if the circumstances are 'right', receptive music listening is not only able to capture and hold the attention of listeners but can sometimes draw listeners in so deeply that they literally do become 'lost' in the listening (Sixsmith & Gibson, 2007) and find themselves in a 'haven'.

E. 'Haven' conclusion

In this section, the more overt and relatively tangible elements that likely contributed to, or detracted from participants experiencing some measure of

'haven' during their interventions were discussed. When conditions were 'right', various aspects of the intervention format and the played music successfully combined to 'remove' a participant from his or her present reality, which was then 'refurbished' by the music; fulfilling Kitwood's (1997) basic human need for occupation, attachment, identity, inclusion, comfort; and love.

This study supports prior findings regarding the benefits of playing individualised music for people with dementia. This is because familiar music can 'transport' listeners back to significant past memories, provide the stimulating challenge (for some) of correctly identifying familiar tunes, and create a comforting, familiar sonic environment. All of which can facilitate the 'removal' of listeners from their present reality and into a sense of 'haven'.

Though this study validated prior findings regarding the effectiveness of playing live-music for people with dementia and as well as for carer, this study also suggests that pre-recorded-music can be nearly as effective and beneficial for some people with dementia and some carers. There is a need for further research into the most effective use of both versions of music within these populations.

That receptive music listening can sonically 'refurnish' a listener's current reality, and possibly conjure a feeling of 'haven', is an original way of encapsulating the myriad of basically intangible effects that the intervention

format combined with the played music characteristics can have. Two findings that particularly merit further exploration are the beneficial effects of providing a series of repeated interventions or sessions with similar formats and content; and the potential that beneficial effects can be experienced within a considerably shorter duration than the commonly employed length of thirty-minutes for receptive music interventions or sessions within similar populations.

This study validates prior research regarding the ability of music to affect the moods of listeners and refutes prior research inferring that the mood-state of people with advancing dementia cannot be affected by listening to music. Robert's emergency intervention clearly demonstrates that if the person playing the music has practical knowledge of 'entrainment', the 'iso-principle', dementia, and nonverbal communication, receptive music listening has the potential not only to reach, but to connect and hold the attention even of a person with advancing dementia who is in a highly agitated and dissociative state, and can bring him or her into a calmer temperament. Indeed, these findings indicate that people less likely to benefit from the public group activities and entertainments commonly offered in care homes (Katz et al., 2013) can receive significant benefit (including the amelioration of current agitated or otherwise 'negative' moods) via receptive music listening sessions similar to those conducted during this study.

Caring for and about a person living in a care home who has dementia and may be in the final months of life can be exceptionally stressful, particularly because of likely difficulties with communication. Equally, being that resident is also very stressful; both because of likely difficulties with communication, but also due to isolation resulting from having fewer opportunities to take part in or to benefit from care home activities. Nolan et al. (2002) postulate that:

> "Engaging in meaningful activity is now widely accepted as a 'basic human need'...and is no less important for PWD [sic]...the aim therefore is to 'enhance, enliven and enrich the present'..." (Nolan et al., 2002:202).

Taken in aggregate, this study's findings suggest that receptive music is an exceptionally effective medium for enhancing and enriching the lives even of people who, for various reasons are often excluded from, or do not benefit from generalised care homes activities. The effects of receptive music are varied and complex. Whilst tabulating external pre-set categories of responses using a modified version of PIECE-dem helped create a picture of music's effect on listeners, these tabulations can only tell part of the story. Employing analysis methods requiring repeated reviewing of video-observations, and thematic coding of all thick-descriptions, fieldnotes, and interviews with participants and staff, fieldnotes, were also required in order to derive a better understanding of the intangible yet powerful capabilities that receptive music had in not only reaching all who were listening (Schafer et al., 2013:4), but also in 'removing' them from, and then 'refurnishing' their reality – thus providing an experience of a 'haven'.

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CHAPTER 8. CONCLUSION

1. Introduction

The primary objectives of this research were twofold: firstly, to explore the effects of receptive music interventions consisting of individualised live and recorded versions of the same or similar music on persons with dementia who were in their final phase of life and for persons who care for and them; secondly, to explore the effects that both types of receptive music interventions had on interactions. These two specific populations were chosen because communication difficulties common to people living with advancing dementia cause them and those who care for them great frustration and isolation. In addition, these difficulties can lead to marginalisation and even stigmatisation within care homes and also within the wider community. Whilst there has been prior related research conducted within similar populations, this study sought to employ innovative methods towards addressing existing research gaps regarding the practical harnessing of music to improve the lives of people within these and similar populations.

People who care for someone with dementia often cite difficulties with communication and with handling outbursts of agitation as major sources of stress. Although the majority of studies involving music for people with dementia or people nearing the end of life are small in scope (an issue to be revisited presently), there is growing scientific as well anecdotal evidence

regarding the beneficial effects that music can have within both of these populations. These benefits are primarily due to the unusual ability of music to successfully reach and engage *all* listeners - regardless of one's physical frailty or cognitive impairment. Music is also particularly effective for encouraging communication and hence interactions between listeners regardless of their prior history or current rapport. This is best demonstrated by a study conducted by Clair (2002), in which the dancing or singing interventions conducted with people who had advanced dementia and their spouse resulted in considerable improvement in their interactions (see p81-82).

This concluding chapter begins with a series of subsections based on the RE query of 'what worked?' – 'for whom?' – 'in what circumstances'? These are followed by reflection on my chosen methods of analysis. The next section focuses on suggestions for future related research and practice. This final chapter culminates with contemplation on what has been learned and the way forward.

2. 'What worked, for whom, in what circumstances?'

Prior to addressing these three RE queries, the main findings of this present study are briefly reviewed. Firstly, individualised live *and* recorded receptive music generally encouraged greater interaction within participating dyads. Secondly, individualised live *and* recorded receptive music generally captured and held the attention of participants, thus assisting participants to experience

their interventions as a 'haven'. It is important to note that none of the impacts described here were global or consistent across all participants.

The chief importance of this present study derives from the innovative approaches utilised, and the elucidation of how specific aspects of the interventions and the played music elicited specific responses from specific participants. This is where closer scrutiny of the RE enquiry; 'what worked, for whom, in what circumstances' begins.

A. 'What worked?'

Because RE seeks to "...explain how things work by going beneath their surface (observable) appearance and delving into their inner (hidden) workings" (Pawson & Tilley, 1997:65), this deceptively straightforward question is actually very difficult to answer. There were many facets of the intervention format and the music played that contributed, independently or collectively, to bringing about an experience of 'haven' for participants and also to improving their interactions.

Some of these facets have received attention in prior related research; particularly around the benefits of using live and individualised music. However, most prior studies have lacked adequate evaluations of the merits of using recorded-music compared with live-music for receptive music sessions within similar populations. This is mostly due to researchers not comparing truly analogous versions of music or, in many cases, comparing live-music only

with the effects of *no* music. I had anticipated that live-music would have a markedly greater effect than recorded-music. However, this study showed that this was not necessarily the case. Indeed, although live-music did have considerably more impact on some participants and also sometimes on interactions, for many of the participants, live-music was just one of a number of variables and music characteristics that impacted on their overall experience.

Aspects of the *intervention format* that 'worked' include: conducting a repeating series of similarly formatted interventions; providing the same quiet, familiar, private setting for each intervention; generally having the same people present for each intervention; and having each intervention begin in the same almost ritualised way (e.g. reintroducing myself and the study, re-obtaining on-going consent, and reminding residents that they were in-charge). Characteristics of the music that 'worked' include: individualised familiar music – and being able to correctly identify this familiar music; live-music; preferred music genres; various tempos and temperaments of the played music; various durations of tunes; and the quality of the played music.

The potential impact that the quality of the played music might have on listeners is not addressed in related research. This will always be a subjective issue, dependent on each listener's background, hearing ability, and individual tastes. Nevertheless, people who are conducting music-related research and who are not knowledgeable about music would do well to collaborate with someone who does have this knowledge in order to ensure that the musicians

employed, and the recordings chosen, are of the highest standard possible. Details of musicians and recordings should be provided in written reports for future validation and replication. This approach would provide listeners with the best possible experience and would also likely elicit more 'positive' responses from listeners.

B. 'For whom?'

Correspondingly to the above question, this question is also not easy to answer. This is because the aforementioned aspects of the intervention format and the played music affected each individual differently, and these effects were often quite changeable. For instance, the carers who focused on the played music generally seemed to become more comfortable and relaxed during successive interventions. Meanwhile, for residents, the repeating nature of these interventions, including recurring reminders and encouragements to express their wishes about how their interventions proceed, generally resulted in each resident feeling better able to voice his or her wishes over the course of their interventions.

Another example of the complexity that the question 'for whom' present, concerns the impact that the historic relationship and the current rapport shared between dyad members had on their collective and individual experience of their interventions. It can be argued that some residents may have responded more freely to the played music, and would have interacted more, had they been sharing their interventions with someone with whom they

shared a closer and more comfortable bond. While this may well be true, some of the dyads that initially portrayed considerably strained relationships evolved over the course of their shared interventions into the most engaged collaborative dyads. It was also true that the attitude of each dyad member seemed to influence the attitude of the other dyad member, meaning that some residents may have been responding less to the music due to the more inhibited or dampened responses expressed by their dyad partner. Although interesting, these findings mostly serve to open-up more questions regarding who is most 'suitable' to share in similar receptive music interventions or sessions with a person with advancing dementia.

Playing the preferred music of each listener will understandably increase the likelihood that receptive music listening will be experienced as an enjoyable activity. However, difficulties arise when there are *two* music listeners, and their individual musical tastes do not mesh. There is no perfect answer for this conundrum. In this study, I decided to focus on fulfilling the musical preferences of each resident, with the hope that if the chosen music did not match the musical tastes of a carer, he or she would still derive enjoyment from seeing his or her dyad partner enjoying the played music. Also, whilst some of the residents were able to communicate their current musical preferences, the majority were not and thus it was necessary to rely on information provided by family and staff towards ascertaining what music to play for some residents. Basing a person with dementia's current music preferences upon those of his or

her past is a questionable approach, as the onset of dementia may alter these preferences: ultimately, as Isla observed, "It's a bit hit or miss isn't it."

Thus, precisely *who* benefited from playing each resident's preferred music is not easily adjudicated. It appeared that for the most part each resident enjoyed hearing music that was familiar. This undoubtedly added a measure of comfort to what must have felt a rather foreign event in an already confusing world. Also, playing each resident's familiar favourites meant that there was more likelihood not only of tapping into past memories, but also into the shared memories within dyads that for the most part shared long histories and thus many memories.

An aspect of playing familiar music for people with dementia that is not discussed in prior related research is how important correctly identifying the played music can be for some residents. Some residents would burst into broad smiles and let out sounds of satisfaction upon identifying the music that was playing, and some even turning this aspect into a challenging and rewarding game.

Live-music was generally more successful at capturing and holding the attention of participants, but the comparative differences in responses to the live and recorded-music ranged considerably. Given how few related studies have made useful comparisons of live and recorded-music, this study's findings provide useful and important information regarding the potential of recorded-music;

namely that if it is provided in an appropriate manner (as will be laid-out presently) it may prove to be nearly or equally as beneficial for some listeners from similar populations.

Each participant's responses to the tempo and mood of the music played varied in accordance with his or her individual personality and particular mood during each intervention. This will always be the case when people are listening to music, and suggest the importance of having someone playing the music (either live or via a recording who has an understanding of 'entrainment' and the 'iso-principle' in order to react appropriately to listeners' responses.

Participant interaction generally increased over successive interventions, and playing the cello live clearly prompted some residents to interact more with me as the musician (e.g. Maggie, Elspeth, Bonnie, Edward). Live-music also engendered greater interaction particularly within one dyad (Maggie and Jean). Interactions increased within other dyads for different reasons: Edward and Iona developed a new appreciation of their interdependency on one another; Iona and Calum bonded over printed song-sheets; other dyads connected over shared memories evoked by a played familiar tune; while in other instances the played music simply provided a needed focus for a dyad to comment on.

Though the reasons that interactions increased varied, what I observed and what participant feedback indicates is that the activity of listening to music generally increased interactions between listeners. This is important because

family and friends commonly report feeling reluctant to visit a person with dementia in a care home because of a lack of communication and thus of connection. Shared receptive music listening could remedy this recurrent problem, thereby lessoning the isolation experienced by residents, and providing visitors with a greater sense of connection and fulfilment.

C. 'In what circumstances?'

My proposition that music was able to sonically 'remove' 'refurbish' each listener's reality, implies that the actual physical environment wherein these interventions took place was not perhaps that terribly relevant. However, conducting these interventions within the same familiar, private, and reasonably quiet physical environment undoubtedly facilitated the played music to have this effect

It could be said that the structure of these interventions (i.e. repeated; in a private familiar setting; involving people who shared a close connection) provided a safe and comfortable setting that permitted the music (i.e. familiar preferred music or music genres, played live and via a recording) to create a sonic environment within which relationships were able to flourish through sharing the experience of listening to music together. The outcome was that most if not all participants experienced their interventions as a 'haven' - a time and a space wherein they were 'removed' from their everyday realities, with the music 'refurnishing' their 'here-and-now' reality.

3. What did *not* work: barriers and limitations

RE interprets elements of interventions that are not successful as equally informative since this accrued knowledge can help avert similar mistakes in future research and future practice. This section summarises aspects of this study that either did not quite go to plan or proved ineffective, and reviews the learning that resulted from these mishaps and missteps.

Corresponding to the above discussion enumerating the elements of these interventions that worked, those aspects of this study that did *not* work are not necessarily glaringly evident, and there are few elements of this study that can be considered universally unsuccessful. Interestingly, many of the elements that might be considered to have been unsuccessful are identical to those listed above as having worked, hence RE's assertion that 'who' and 'where' are equally crucial parts of the equation whenever an intervention involving people in a realistic setting is being evaluated.

What universally did not work was the use of biological measurements (e.g. pulse and blood pressure). These procedures were intrusive and netted mostly unusable and irrelevant data. Similarly, the use of VAS, though not intrusive, did not provide usable or relevant data. Unnecessary staff interruptions happened all too frequently during these music interventions, and certainly never aided participants in settling into an intervention; suggestions to help avoid or minimise staff interruptions during future research will be provided presently.

Other elements that did not 'work' were less universal in scope; meaning that they did not always 'work' for every participant. Providing a series of similarly formatted interventions was less beneficial for those carers who maintained a watchful eye over their dyad partner, because they likely felt exhausted and somewhat disappointed at the conclusion of each intervention rather than fulfilled and energised. Conducting these interventions within the private bedrooms of each resident meant that sometimes there was an understandable initial awkwardness on my part, and some reluctance on the part of a resident when I invited him or her to leave the communal area. When people have dementia this can become particularly difficult because people with dementia may not recognise the researcher or remember prior interventions. This matter was partially remedied when his or her dyad partner were present to invite them into the intervention.

The pre-recorded-music and live-music interventions evoked generally comparable responses and interactions from participants. However, several participants (Jean, Elspeth, Edward) clearly did not connect or engage with the recorded-music. This suggests that there will likely always be some recipients of receptive music for whom the medium of recorded-music simply will not 'work'. Another difficulty that occasionally surfaced during these recorded-music interventions occurred when a resident expressed confusion and discomfort regarding what they were expected to be doing while listening to a recording. Again this confusion was completely understandable, and implies that the circumstance in which recorded-music is played needs to be carefully

considered in order to prevent recipients feeling that they are under observation. It is not clear how this issue can be resolved, and thus it warrants additional enquiry.

Just as each person sharing the activity of receptive music listening together may enhance the listening experience of others who are present if s/he has an open and positive attitude, someone with a more closed and negative disposition can significantly detract from the experience of fellow listeners. Not much can be done to avoid these negative effects, other than maintaining a watchful eye for signs that a participant is flagging and responding quickly and appropriately (e.g. checking-in with the participants, changing the music, or ending the intervention early).

Playing music familiar to each resident (and consequently each carer) undoubtedly contributed to the enjoyment expressed by residents. However, sometimes listening to familiar music can evoke sad or upsetting memories. For example, Greer got visibly upset upon hearing a favourite piece of music; presumably because it caused her to feel more sharply the absence of her daughter Brenda. Similarly, Heather cried when I unwittingly played a hymn that had been played at her late husband's funeral. While these types of situations are difficult to avoid, feeling strong emotions and remembering sad times are not necessarily negative experiences or responses. Music's ability to reach and 'transport' listeners means that all manner of emotions are likely to arise. What is important is that the musician or person controlling the recorded-

music has training regarding how to gauge and appropriately respond to these expressed emotions.

While some residents took extra pleasure in correctly identifying familiar tunes, other residents disengaged if they were unable to correctly identify a familiar tune and occasionally even became a bit irritated. Upon reflection, although this matter is not mentioned in related research, these expressions of irritation are hardly surprising, as not being able to identify music playing on the radio can cause consternation in any listener. This is another issue requiring assessment by the person supplying the live or recorded-music. It may be that if a listener who has dementia is expressing disengagement with the played music, it would be best to name the music before it is played.

Most participants seemed to enjoy all the music that was played for them - regardless of its specific genre. However, some participants clearly had particular preferences for, and against, specific music genres. Again, although it is likely impossible to completely avoid playing a disliked music genre; particularly if the tastes of a listening dyad conflict, close monitoring and quick reactions to expressions of strong dislike may assuage this issue. Slower and sadder music appeared less able to capture and hold the attention of most listeners, but again this is a very subjective and difficult issue to assess. Responses to slower and sadder music tended to be more internalised, sometimes facilitated much needed rest, or evoked deep-felt emotions in residents.

During her exit-interview, Isla admitted:

> "The cello is not an instrument that I really enjoy as a solo...sorry...it's not my favourite instrument..." (Isla).

This is an excellent example of a key element of these interventions that did not work for one participant, but which was apparently agreeable for all of the other participants. Isla's comment also points to another overlooked yet important matter; that the sound of different musical instruments will either attract or detract listeners to varying degrees. This issue is a further vivid example of an individual and subjective aspect of music interventions or sessions that cannot always be easily remedied.

A somewhat related consideration is that of the quality of the recordings chosen and the proficiency of the musicians playing during receptive music interventions. Not only is it patronising to assume that a listener who has dementia may not notice if music that is played is not of a high standard, but it is also counterproductive. This is because music, especially well-known and well-loved music (either live or pre-recorded), when played badly is much less likely to captivate and hold the attention of any listener regardless of their current cognitive status.

There are many other elements that are likely to evoke a mixture of responses in recipients, such as: the duration of music interventions or sessions; the duration of individual pieces; and the tempo and temperament of the played

music. Each of these elements will evoke unique responses from listeners, and these responses will likely vary from day to day, and perhaps even within a single intervention. This is yet another reason that it is paramount that someone be present who is equipped with knowledge of how to react appropriately to observed, often subtle nonverbal responses from listeners, and who also has the capability to remain flexible and open to the event as it unfolds.

4. Conducting research in care homes: what worked, what didn't?

The degree of support received from care home staff was directly correlated with the values conveyed by each care home manager, and how effectively the information materials I supplied were disseminated to staff. If the manager was engaged with her care home's activities, I received considerable support; otherwise I received noticeably less staff support. Although I made presentations = to staff at each participating care home, due to rotating shifts and holiday schedules, not all staff attended. Thus I had to rely upon managers to disseminate the information sheets I supplied and to put up the posters that included a photo of me along with a brief explanation of the study. The posters were not put up in any of the care homes, and the information sheets rarely got to the staff. This is not surprising, as care homes are very busy universes of their own, and even within the most supportive of care homes the study was likely to be viewed as yet another matter they had to contend with. In retrospect, it is clear that greater effort needed to go into disseminating the information sheets

to staff. When I encountered staff who did not know anything about the research, they quite understandably viewed me as an annoying intruder wandering about in their already too-busy environment. The ethos of care homes or indeed any location where similar types of studies might take place (e.g. hospices, hospitals, private dwellings, etc.) is beyond the control of researchers, but researchers can, and must make every effort to connect with everyone who is even tangentially involved, and to ascertain that everyone is as informed about the study taking place as is possible.

Akin to the above issue, during this study my blatantly North American accent meant that both staff and participants positioned me unquestionably as an 'outsider'. All the participants and staff were from the UK, and predominantly from rural Scotland. It is not unusual for ethnographers to be foreigners amidst the culture they are studying, but I had not considered what the impact of my being an 'outsider' might have on my fieldwork prior to the start of this study. Generally, being accorded 'outsider' status worked favourably for me, as any inadvertent cultural blunders I made were accepted as signs of the naiveté that they indeed were. My being an 'outsider' also meant that I was perhaps perceived as less 'threatening' to participants; that I was less likely to judge them within the context of their everyday lives. Carers enjoyed teaching me bits of Scottish lore, and residents enjoyed my accent. Indeed, my accent occasionally required a carer to 'translate' what was said – which could be perceived as an additional inducement for dyad interaction!

5. Data analysis

Though the combinations of methods employed during the data collection phase of this study were perhaps uncommon, the methods of analysis I utilised will likely be familiar to qualitative and especially ethnographic researchers. This section reflects on which methods of data analysis worked, and which did not, and how this knowledge can inform future research.

A. Video analysis methods

My experience during this study validates views expressed in prior related studies regarding the high value and perhaps even essential nature of video-recording interventions such as these; particularly as I was the sole researcher (Becker & Geer, 1957; Husebo et al., 2007; Coaten & Newman-Bluestein, 2013). Methods of video analysis are continually evolving, and whilst using the two respected qualitative observation tools - thick-description and thematic coding was crucial, the information I gleaned from using a modified version of the observation tool; 'PIECE-dem' (see chapter 4.D.ii), helped to further corroborate and inform my analysis. Also, because the modified PIECE-dem instrument required that I tabulate what I observed during a revisiting of the intervention video-footage, I was able to obtain a fresh perspective of, and to go deeper into the raw data (Mauthner & Doucet, 1998, 2003, 2008). Still, my experience of analysing the raw video data during this study prompts me to agree to with Coaten et al. (2013) regarding the necessity of not relying solely on tabulated observations:

> "It is not about ticking boxes and scoring people's well-being, but observing the value of those taking part..." (Coaten et al., 2013:8).

Despite the repeated calls for researchers to standardise results emanating from smaller innovative studies (O'Connor et al., 2009), until now no one has successfully accomplished this goal. Future collaboration with fellow researchers who are employing music and other creative arts within similar studies, could help, but perhaps a more achievable aim would be to establish standards across specific stimuli when used with specific populations for specified intentions. Regardless, what is apparent is that there is need for greater debate and discussion regarding the importance of ensuring that interventions involving creative arts gain greater recognition, increased funding, and broader application.

There is an associated need for more research comparing analogous 'attention controlled' interventions (O'Connor et al., 2009a); that is to say, interventions that include a stimulus such as music, which are likely to capture the attention of participants, as opposed to interventions where no stimulus is involved. This would help to better establish how specific elements of 'attention controlled' interventions work best for whom, and in what circumstances. This knowledge could inform future practice and lead to optimally effective delivery of receptive music sessions in order to 'transport' all recipients, regardless of their physical or cognitive status, towards a peaceful and comforting experience of 'haven'.

B. Researcher bias

The literature review in chapter 2 was critical of a study by Gerdner (2000), which, much like this present study included a single researcher who conducted all of the interventions and analysed all of the data. Gerdner (2000) recognised and acknowledged that (although as a PhD it was unavoidable) this was indeed a weakness for that study, as it jeopardised its validity. Indeed, Coaten et al. (2013) state that:

> "Having an independent researcher...to capture the varying degrees of complexity, is a real necessity if the evaluation is to be as rigorous as it can be" (Coaten et al., 2013:9).

Later in chapter 2, various methods that qualitative researchers often use in order to assure their study has validity were outlined. These included: using self-reflection and maintaining transparency regarding researcher bias; including deviant findings; allotting enough time for fieldwork (Creswell, 2009); comparing cases; using tabulations; providing raw transcriptions as examples of findings (Silverman, 1993); and thickly describing researcher observations (Fetterman, 1998; Cresswell, 2009). I employed all of these methods during this study.

Another perspective of potential researcher bias that needs to be addressed in a study such as this is the impact that a researcher's very presence may have in terms of leading to biased responses and influencing the general behaviours of participants (Hammersley & Atkinson, 2007). It is equally important to keep in

mind that no matter how many times each care home was visited, and how familiar I became with each participant, "...there will always be some measure of bias" (Hammersley & Atkinson, 2007:177). My intense involvement with these music interventions coupled with my later immersion in the interpretation and analysis of the raw data meant that it was almost impossible for me to remain completely unbiased. What's more, this study necessitated that I establish long-term relationships with each participant, and that I learn about each dyad's historical relationships, so that I could better understand the effect that the music had on these relationships. Thus, it seems almost inevitable that someone with 'fresh-eyes' may have noticed different elements in the video-footage, or may have interpreted participant responses and interactions differently (Cook, 2002).

Due to the effort I made to maintain a high level of transparency and replicability throughout this research, I feel that despite the undeniable weakness that being the sole researcher introduces when striving for high levels of validity, this study does have acceptable and useable levels of validity and replicability.

6. Future practice; future research

Having reflected back on what did and did not work for whom in what circumstances during this study, this section points forward towards applying what has been learned; firstly towards informing future practise, and then towards informing future research.

A. Future practice

A key aim of this study was to provide practical information towards informing future use of music within similar populations. This subsection distils the practical knowledge accrued during this study:

i. Intervention format

This study's findings indicate that the configuration of sessions (i.e. 'context') in which receptive music is played can considerably affect its 'successful' impact on listeners. Whilst by now it should be understood that virtually no aspect of sessions aimed at benefiting individuals who have dementia will be universally beneficial, the following suggestions garnered from this study's findings can inform future receptive music listening sessions.

Firstly, it is important that an 'appropriately trained' person be present and attentive throughout receptive music interventions whenever a recipient is unable to operate and thus control the music being listened to. This is because it is unethical to leave a person listening to music alone if they are unable to operate the device that is playing the music (DeNora, 2013). As discussed earlier, 'appropriately trained' refers to having a basic understanding of nonverbal communication and cues, of dementia and empowerment, and of the potential effects of various characteristics of music (e.g. tempo, temperament, and familiar music). Also, for a majority of people, sharing receptive music sessions with someone with whom they are comfortable is preferable, as the

music can spur social interactions that may be quite rare in a person with dementia's current everyday life.

The level of training I am proposing is relatively minimal, and could feasibly be imparted to formal and informal carers within an intensive weekend or two. In a paper discussing a similar lack of oversight and appropriate training during dance interventions for people with dementia, Coaten et al. (2013) suggest that experienced practitioners could serve as mentors:

> "...mentoring for those involved can be regarded as an important form of over-sight and governance with opportunities to share learning..." (Coeten et al. 2013:12-13).

Repeated receptive music sessions that start and end in a similar manner, are held in the same familiar and comfortable surroundings with a minimum of distractions, and that involve the same person who shares a comfortable and close relationship with the recipient who has dementia, will provide a situation in which the played music can be of greatest benefit. Though the setting of this study's interventions was care homes, there is no discernible reason why lessons accrued from this study could not be applied to any other setting; including private homes.

This study illustrates the potential benefits of including a person who shares a close relationship with the recipient who has dementia during receptive music sessions. Unless a person with dementia indicates that he or she would prefer to listen to music by themselves (or only in the presence of a formal and

appropriately trained carer), asking who he or she might like to share the activity of listening to music with is the first avenue towards seeking the most suitable person. If no preference is expressed, then seeking the opinions of care home staff and family can help to determine whom best to invite to join the recipient with dementia. It is also important that the person who is managing the receptive music session be ready to help facilitate interactions and to assuage any indications of discomfort or discord that may arise.

ii. Music

Having suggested ways to prepare the 'stage' for successful receptive music sessions that include a person who has dementia, this subsection offers recommendations towards the effective use of music during these sessions.

Choosing music necessitates an individualistic approach, as each person will have different musical tastes, and, as with all of us, what someone feels like hearing one day may be different on the next. This study's findings suggest that if the intention is to play familiar music, considerable effort should be made to ascertain if not specific individual pieces of music, at the minimum, the preferred musical genres for each receptive music recipient. In situations where the musical preferences of persons sharing a session diverge, I suggest that the administrator of the session focus on fulfilling the musical requests of the recipient who has dementia. Here is another place where the appropriate training of a 'neutral' person operating the music media device or playing the music live is important, because he or she must be able to monitor nonverbal responses and respond accordingly during each music session.

This study showed that although live-music may more effectively engage and hold the attention of listeners, recorded-music will likely be more readily available, and can be nearly if not equally as effective for many listeners: again, it is important that someone be present to operate the music media, who is appropriately trained in nonverbal responses, and has an understanding of dementia.

The quality of the music played may have considerable impact on its effectiveness in capturing and holding the attention of listeners, perhaps particularly those listeners who have dementia. Therefore it is important that the recorded-music that is chosen, and the live-musicians who play for receptive music sessions be of a high standard, and that recordings are played through high-quality speakers.

B. Future research

Researchers agree regarding the potentially beneficial impact that music can have on recipients in any number of ways and settings, and also concur that there is much that remains to be learned regarding the most effective ways to employ the immense potential of music (Black & Penrose-Thompson, 2012; Särkämö et al., 2012). This is particularly true in the realm of using music with people who have dementia or who are in their final phase of life. This is because of the many ethical and communication difficulties inherently present when engaging within these populations. Due to the heterogeneity of virtually every

major aspect of this branch of research, there is likely to continue to be criticism regarding the lack of large-scale research studies with RCT designs and positivistic outcomes. RE does not expect a single study to generate absolute answers (Marchal et al., 2012), but focuses instead on the importance of building on and adding to past knowledge (Astbury, 2013). The basic tenets of RE have proven to be very helpful as an underpinning and guide for this study, but in agreement with other researchers (Marchal et al., 2012), it is unclear whether it would have been beneficial or even feasible to adhere rigidly to the complexities of RE in its entirety.

For research conducted within care homes or similar institutions, it is imperative that sufficient time and energy be expended getting as much staff as possible informed and on-board prior to conducting interventions. Making presentations to staff (complete with tea and cakes), soliciting staff opinions and feedback, and obtaining permission to disseminate information sheets and to put up informative posters throughout pertinent areas of the fieldwork site, will all go a long way towards making fieldwork run more smoothly.

I recommend that people with all levels of dementia, all levels of hearing (excepting *perhaps* for those who are profoundly deaf), and generally anyone who either is no longer able to attend public activities, or who no longer derives pleasure from public activities, be included in future related studies. This study suggests that *all* people can benefit from receptive music listening, and challenges the exclusion of people considered to be 'past' receiving such

benefits due to their extreme cognitive or physical frailty. The ethical morass pertaining to inclusion of people who are unable to provide direct informed consent requires continued consideration and debate. Perhaps inviting collaboration from groups such as the Scottish Dementia Working Group could prove helpful towards resolving on-going obstacles. For without a significant adjustment in the predominantly biomedically based perceptions of the ethical boards governing research involving people who have dementia, much needed innovative qualitative studies, and the voices of all who have dementia will continue to struggle to be recognised.

Efforts were made where possible to isolate the effects that specific characteristics of the played music had on listeners, and there is much more to be learned. Perhaps future research could compare the analogous effects of different solo instruments playing the same or similar music. There needs to be more research into the comparative effects of truly analogous live and recorded-music.

There is scope for more research into the ability of music to facilitate or encourage interaction, especially within populations such as participated in this study, where conventional forms of communication may have been particularly compromised. Perhaps future studies could compare the effects of music on dyads composed of a person with dementia and a family member or friend, with the effects on dyads composed of a person with dementia and their keyworker or primary professional carer. Regardless, this study has demonstrated that

including a 'carer' to share in the activity of receptive music listening with a person who has dementia has the potential to considerably enhance the experience for both listeners; through shared memories, shared emotions, and collective 'transport' into a communal sense of 'haven'.

Further investigation is also warranted towards determining what the most beneficial timespan for receptive music interventions involving a person with dementia who is very frail. It is important that irrespective of the planned timespan, there that there always be scope for flexibility on the actual duration of similar interventions - as well as most other intervention elements.

Findings from this study suggest that it may not be necessary to include pulse and blood pressure measurements, or VAS in future related research designs. If researchers would like to try using VAS, it may be that a vertical version could be more useful than the horizontal version employed during this study, or it might be worthwhile to compare both versions, as participant self-reports are recognised as being very informative. Also, incorporating the communication tool known as 'Talking Mats' might help in obtaining direct participant feedback from people who have difficulty communicating verbally, and could also prove quite informative.

Video recording of interventions proved invaluable to this study, as it afforded me the luxury of being able to revisit and re-scrutinise real-time observations. Even so, collaborating with an experienced practitioner during interventions

and also during the analysis process could provide significant insights and knowledge that might otherwise be missed:

> "Whilst experienced practitioner's cost in terms of time and expenses, in these cash strapped times, having access to knowledge, skills and experience from a mentor…may save time, offer better longer term outcomes and represent good value for money" (Coeten et al. 2013:13).

Findings from this study and other's experience with this type of research do not support calls for large quantitative RCT studies. Researchers have a difficult enough time recruiting for even the smaller studies within similar populations. Also the sheer number and diversity of variables involved in this type of research makes it impractical to expect a large and potentially more impersonal study to be able to accommodate individual participant experiences and responses when listening to music. RCTs are generally untenable within music related research as music is unlikely to garner consistent homogenous results from individuals. Therefore, it is imperative that smaller creative studies continue forging new pathways into this arena, while also assuring clear, detailed, replicatable procedures are in place, that methods are transparent, and that results are valid. Ultimately, as Clair (2002) suggests, music-medicine is not like a pill: it must be individualised in all ways.

7. Personal reflections

The philosophical basis of both RE and this current study is aptly distilled within the following quote by Chalfont (2008):

> "…an exploratory approach might seek to generate an experience that is not pre-determined, but open to potential synergy of the intervention itself" (Chalfont 2008:124).

Throughout the process of this study, I strove to maintain an open, non-judgemental perspective. I had no set agenda or expectations at the start of each intervention; rather I entered into the unknown experience that was about to unfold, accepting as best I could that I had very little control over what was going to happen, and no knowledge regarding what *should* happen. Had I approached these interventions with preconceived assumptions or agendas, I would have missed the magic that evolved in front of my eyes during each and every intervention. I feel very privileged to have been able to directly and unquestionably know that I was making a positive difference in each of these participant's lives – perhaps only for that moment, maybe for a bit longer. And I felt truly humbled that each of these participants was willing to try something new, to invite me into such an intimate phase of their lives, and to be open to this unusual experience.

A. Music as a 'haven'

I'd like to reflect a bit on the concept of 'haven' and my contention that these music interventions, for varying reasons, at varying intensities, and to varying extents, were able to provide an experience of 'haven' possibly for all who participated in this study. DeNora (2013) states that:

> "When we are captured by music, we are musically recalibrated, removed from one cognitive and/or sensory domain/orientation into another…" (DeNora 2013:114).

Though 'haven' may not be the most accurate term, it is what I have chosen to describe the experience that can occur when all of Kitwood's (1997) basic human needs are met: when one is psychically 'removed' from one's present

reality and 'transported' to a peaceful, nurturing, enjoyable, and healing environment. For this study, 'haven' refers to a sonic space wherein participants ideally were afforded a chance to re-charge in order to cope better with their everyday real life issues: something that people with dementia and people who are very frail, as well as their carers can surely benefit from.

Another wonderful phenomenon that I witnessed and indeed experienced during these interventions was that music eradicated our real-life 'roles' and statuses, and created a space where we three became equals sharing a singular experience together in the 'here-and-now'. It was lovely to witness people who are so often are neglected or marginalised due to their frailty and cognitive impairments expressing themselves as equal members of a select intimate group, and to equally share in this special experience.

Epilogue

"Music is good if it does good" (DeNora 2013:137).

Though larger-scale studies might spur wider acceptance for the beneficial effects of music, the individuality of nearly every factor - not least being that of each individual person for whom the music is played, means this is a difficult if not impossible goal. During her exit-interview, Evelyn, the manager of SunnyBrook, said this of what she had witnessed regarding the effects that these interventions had on resident participants within her care home:

> "...it [music] was bringing out the person that they were, and still are. But because through dementia, they're locked in a place, and it's always a place where we can't access. But through that music, it touched their hearts and their souls. And in doing that, it brought them out to that place they once were. So that they remembered that this music, and what it meant to them. And that gave them meaning and purpose in their lives again. And that's something that, isn't always achieved...And in doing that, you gave them something back in their lives that they've lost. And for that, it's immeasurable. And no amount of money could pay for something like that" (Evelyn).

What is clear is that music can touch all people - even when very little else is able to. Music is mobile, and thus can be brought *to* a person - affording even the most cognitively and physically frail to reap music's benefits. Music can transport listeners back into distant memories, or completely alter a listener's here-and-now reality. Music can heal; it can enhance interactions and reconnect people towards experiencing a sonically shared embodiment of 'haven'.

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APPENDICES

Appendix 1: NHS Scotland Ethical Approval

Scotland A Research Ethics Committee

Ms Claire Garabedian
Postgraduate Researcher
Room 3S37 Colin Bell Building
University of Stirling
Stirling
FK9 4LA

Date: 17 January 2011
Your Ref.:
Our Ref.:   11/MRE00/7

Enquiries to: Walter Hunter
Extension: 35680
Direct Line: 0131 465 5680
Email: walter.hunter@nhslothian.scot.nhs.uk

Dear Ms Garabedian

Study title: **Effects of individualised live and recorded music on people with
                        dementia who are near end of life and their primary carers**

REC reference: **11/MRE00/7**

Thank you for your application for ethical review, which was received on 17 January 2011. I can
confirm that the application is valid and will be reviewed by the Committee at the meeting on 27
January 2011.

Meeting arrangements

**The meeting will be held in the Meeting Room 8, NHS Lothian, 2nd Floor, Waverley Gate, 2-4
Waterloo Place, Edinburgh, EH1 3EG on 27 January 2011 and starts at 12 noon.** The
Committee would find it helpful if you could attend the meeting to respond to any questions from
members. Other key investigators and a representative of the sponsor are also welcome to attend.
This may avoid the need to request further information after the meeting and enable the Committee
to make a decision on the application more quickly.

If you have a disability and need any practical support when attending the REC meeting you may
wish to contact the REC office so appropriate arrangements can be made if necessary.

If you are unable to attend the meeting the Committee will review the application in your absence.

Once you have confirmed your availability and as soon as the agenda has been finalised I will let
you know the time of the review. Please note that it is difficult to be precise about the timing as it
will depend on the progress of the meeting. We would kindly ask you to be prepared to wait

Chairman Dr Ian Zealley
Vice-Chairman Dr Malcolm Booth

Appendix 2: Consent forms

A. Carer consent form

The Effects of Individualised Live and Recorded Music on People Who have Memory Problems and are Frail and Their Carers

Please initial each box.

1. I confirm that I have read and understood the information sheet for the above research and have had the opportunity to ask questions.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.	
3. I understand that all information will be kept confidential.	
4. I agree that the information can be used on condition that it is kept confidential and anonymised.	
5. I understand that all information will be accessed only by the researcher and her academic supervisors.	
6. I give my permission for interviews to be video-recorded.	
7. If my memory gets worse during this study, I give my continued consent/withdraw my consent to be asked to continue with this research.	
8. I agree to take part in the above study.	
9. Any further comments:	

Research name: Participant signature: Date:

Researcher name: Researcher signature: Date:

B. Resident consent form

Effects of live and recorded individualised music with people who have memory problems and are frail and their primary carers

Researcher: Claire Garabedian

Please could you check the ☐ and sign at the bottom to indicate that you have read and understand the information sheet for this study.

I have read the information sheet about ☐

this study or have had it explained to me.

I have been able to ask all the questions I need to.

I agree to take part in this study.

I understand that I can stop being in this study at

any time for any reason.

I understand that my GP will be told that I am participating in this study.

I understand that all information will be kept privately.

I understand that at the end of the study a report will be written.

I understand and agree that I will be video recorded as part of this study.

Name of participant...……

Signature…………………………………………………………….

Date……….

Name of researcher………………… Signature……………………

Date……….

Observer Consent Support Form

Name...

Relationship to participant...

Any comments on the communication observe

I observed the project being explained to...

And feel that they would be happy to take part in the project.

Signature...Date...

Appendix 3: Information sheets

A. Resident information sheet

PARTCIPANT INFORMATION SHEET

The Effects of Individualised Live and Recorded Music on People Who Are Frail and have Memory Problems, and Their Primary Caregiver.

Thank you for reading this.

I am interested in finding out how listening to live and recorded versions of your favourite music makes you feel.

I would like to ask you if I could come and play music that you like for you on the cello.

I would also like to video record these visits.

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This will help me to find out how playing live and recorded music might be helpful for people – especially people that live in care homes like you do.

Someone you know well will also be in the room for each of our visits.

If you do not want me to video record you, you can just say so.

I will not show the videos to anyone else.

If you want me to stop playing music, just say so.

I would also like to ask you if I can quote some of your words when I write the results of this study.

If I do use any quotes from you, I will change your name so that other people will not be able to identify you.

I will let your GP know that you are taking part in this study.

I will also ask your caregiver to make sure that he/she is happy for you to take part in my study.

I will come back tomorrow and talk with you again in case you have any questions.

Thank you.

Claire

UNIVERSITY OF
STIRLING

The Effects of Individualised and Recorded Live Music on People Who have Memory Problems and are Frail and Their Primary Carers

I would like to invite you to take part in this research. Before you decide, I would like to explain why this research is being done and what it involves for you. I will go through this information sheet with you and answer any questions you may have. This will probably take about ten minutes.

What is this research for?

The aim of this research is to find out how live and recorded versions of music that is individually chosen affects people who are frail and have memory problems, and also how live and recorded versions of music that is individually chosen effects the level of engagement between people who are frail and have memory problems those who care for them.

What is involved?

To find this out, I would like to spend time talking with you, and also playing live and recorded versions of preferred music for you and the person with memory problems whom you are caring for. Both the live and recorded versions of the music that is selected

will be played by me on the cello. Your participation is voluntary – if you decide not to participate in the research, this will any support you currently receive. You are also free to withdraw from the study at any time. This study requires several visits, which are detailed below:

- The first meeting will include:
  - A brief questionnaire that asks questions about your age, ethnicity and education.
  - A brief questionnaire that asks questions regarding your musical experiences, background, and tastes.
  - Four different lines where you will be asked to mark a line showing how you are feeling regarding your current feelings of depression, general wellbeing, disinterest, and anxiety.
  - I will also ask you a few questions regarding how you see you current quality of life, what music means for you in general, and your hopes for how this study might be of benefit to you and the person you are caring for.
    - During my first meeting with you, I would also like to discuss with you your wishes as to whether you want to continue to take part in the study should your own memory worsen. I will write your decision in your consent form and will use it for future reference.

- The next visit will take place in a private room, and will simply be for getting used to the two video cameras and me

being in the room with you both. I will stay for about a half-hour, mostly quietly sitting in the corner.

- The next six visits will all take place in the same private room, and will all include up to 30-minutes of me playing live cello music for you and the person you care for. During two of these visits, I will be playing music that you have requested. During two of the visits, I will be playing classical music mainly by JS Bach. And, during two of the visits I will be playing simple melodies that I make up on the spot. All of these visits will be video-recorded using two video cameras. You do not need to do anything but sit back and relax.
  - I will also be measuring the pulse, and blood pressure of both you and the person you are caring for at the beginning and end of each of these visits in order to better understand how the live music is or is not affecting either of you, and I will also be monitoring your respiration.
    - If at any time I think that you or the person you are caring for are experiencing either any discomfort or displeasure from the live music, I will stop playing the cello.
    - You are also free to tell me to stop playing at any time, and there is no need to give me any explanation for this request.

- The next visit will be similar to an earlier visit: I will again be asking you questions regarding your view of your current

quality of life, music, and how you feel that the different types of music have affected you and the person you are caring for. I will also try to answer any questions that you may have.

- The final visit will happen at the end of the study, when I can tell you a bit about what I have learned and also give you and the person you are caring for CD that contains recordings of some of the music I played for you.

I am required to notify your GP of your participation in this research and will ask your permission to do this.

What will happen to the information I give?
- I would like to video-record each visit I have with you, but I will ask your consent to do this each time. If you would prefer not to be recorded, I will respect this and not video-record.
- All the information I collect during our visits will be treated in confidence, and accessed only by myself.
- I will write a report on my findings and may want to quote something you said during our visits. I will make sure that no-one will be identified in any written report.

Who will be doing the research?
The research will be undertaken by myself, Claire Garabedian (xxxxxxxxxx) I am a professional musician (cellist), and a certified

music practitioner; meaning that I have experience playing music in medical settings for those who are in need of palliation or comfort. I am being supervised by Professor Alison Bowes (xxxxxxxxx) and Dr. Fiona Kelly (xxxxxxx) also from the University of Stirling. I am being funded for this study through a studentship from the Department of Applied Social Science at the University of Stirling.

Do I have to take part?

No, it is up to you to decide if you wish to participate. You participation in these interviews is completely voluntary. After reading this information sheet you will be asked to sign a consent form to show you have agreed to take part in this study. You are free to withdraw at any time, without giving a reason.

Agreement to remain in the Study:

In the unlikely event that you yourself experience a worsening or loss of memory while this study is still in progress, I would like to gain your prior consent that you will continue to participate in this study.

What happens after the interviews?

The information obtained from these various visits will contribute to my PhD thesis. In addition, I intend to write academic papers and make academic presentations based upon findings from this study. As stated above, these may include direct quotes provided by you during the interviews or visits; all identifying information

including that of the care home were these visits took place will be removed in order to protect your anonymity.

Will the research benefit me?

I cannot promise that the research will benefit you directly, but hope that you will enjoy the live music and that findings will benefit other people with dementia who are frail and their carers.

Further information:

If at any time you wish to make a complaint, you may do so by contacting my supervisor: Professor Alison Bowes (xxxxxxxxxx). Should you wish to discuss the study further prior to making a decision or if you have any questions or concerns between visits, please contact me: Claire Garabedian (XXXXXXXXXXX).

Thank you for taking the time to read this information sheet. If you are happy to take part in this research we will discuss the main points again when we meet with you and will ask you to sign a consent form then.

Claire Garabedian

Appendix 4: Initial letter – resident's family

The Effects of Individualised Live and Recorded Music on People Who are Frail and Have Memory Problems and Their Primary Carers

Thank you again for taking time to read about this study entitled "*The Effects of Individualised Live and Recorded Music on People Who are Frail and Have Memory Problems and Their Primary Carers*'. I am writing this letter as a follow-up to the information sheet you should have recently received from the care home in which _____ is currently residing.

If you are satisfied with the information you have received regarding this study, would you please be so kind as to fill out the accompanying sheet so I may contact you directly? I would also like to know who you would identify as the primary carer for _____: that is, someone who knows him/her well and might be able to be at each of the music sessions (which will last approximately 30-minutes). This person could be you, someone else in the family, a friend, or a staff member from the care home. If you are unable to identify someone for this role, that is fine, just write that on the accompanying sheet.

If you have further questions or any concerns, please do not hesitate to contact me (all of my contact details can be found at the end of this letter), or you can write these questions or concerns on the accompanying sheet as well.

Thank you very much for your time and consideration.
Best wishes,

Claire Garabedian
PhD candidate – Stirling University
XXXXXXXX – phone XXXXXXXXX – mobile
XXXXXXXXXXXX - email

Appendix 5: Questionnaires

A. Background questionnaire – resident

Effects of live and recorded individualised music with people who have memory problems and are frail and their primary caregivers

Did you go to church often?

Do you listen to music often?

Did you go dancing often?

B. Personal music preference questionnaire – residents and carers

MUSIC IS OFTEN A VERY IMPORTANT PART OF PEOPLE'S LIVES. PLEASE TELL ME ABOUT WHAT TYPES OF MUSIC YOU LIKE.

How important has music been in your life?

_____1. Very Important

_____ 2. Moderately Important

_____ 3. Slightly Important

_____ 4. Not Important

Did you ever play a musical instrument?

     If yes, what instrument did you play?

Did you enjoy singing?

     If yes, what types of places did you sing (examples: around the house, church choir)?

     What types of music did you enjoy singing?

Did you enjoy dancing?

     If yes, what types of dancing did you do? (examples: attended dance lessons, participated in dance contests)

The following is a list of different types of music. What are your three (3) most favourite types of music?

_____ 1. Scottish
_____ 2. Irish
_____ 3. Country and Western
_____ 4. Classical
_____ 5. Spiritual/Religious
_____ 6. Big Band/Swing
_____ 7. Folk
_____ 8. Blues
_____ 9. Jazz
_____ 10. Rock and Roll
_____ 11. Easy Listening
_____ 12. Cultural or Ethnic Specific (such as: Czech polkas, Ravi Shankar Indian sitar)
_____ 13. Other_____

Can you tell me more about your favourite types of music?

Can you tell me the name of some of your favourite songs or pieces of music?

Can you tell me the name of some of your favourite albums or cassettes?

Can you tell me about any music you heard in your home when you were growing up – music your parents enjoyed listening to?

Appendix 6: Tables

Table A. Phases of Study

Task	Purpose	Procedure
Obtain ethical approval for 'phase-I' – University of Stirling	To obtain University of Stirling School of Applied Social Sciences ethics committee clearance for 'phase-I' key-informant interviews.	Complete and submit an application.
Interviews with key-informants ('phase I')	To gain insights and suggestions towards the design and general approach of this present study from experts in related fields.	Contact and conduct a semi-structured, usually face-to-face, interview with fifteen key-informants.
Obtain ethical approval for the core phase of this study - Scottish REC-A ethics Committee	To obtain Scottish REC-A ethical approval and permission to proceed with the core phase of this study.	Complete a lengthy and detailed IRAS form and defend my study design during a meeting of the Scottish REC-A ethics committee.
Recruit care homes for fieldwork	To determine which care homes were willing to participate – and had residents who were eligible to participate in this present study.	Seek suggestions from colleagues, review inspection-rating reports for potential care homes. Make written contact with care home managers. Provide managers with study information sheets.
Recruit participants	To successfully recruit 10-12 resident and carer dyads based on established inclusion and exclusion criteria.	Make presentations at care homes. Visits to care homes. Mail information packets to prospective families of residents and seek initial consent.
Consent	To obtain witnessed signed consent from each	Residents: A staff person was

	prospective resident participant. To obtain signed consent from each prospective carer participant.	present to witness signed consent. Special visually orientated information sheets and consent forms were reviewed prior to consent. Carers: Review of more detailed information sheets and consent forms prior to consent. Administer VAS.
Initial carer intake and interview	To learn more about both members of each dyad: musical background and preferences; and carer expectations and hopes.	Conduct one semi-structured (usually face-to-face) interview with each carer.
Pilot intervention	To introduce the cello to each resident, and to finely-tune specifically chosen music with each resident.	Play brief selections of selected individualised music for each resident. -Pilot interventions were not conducted with every resident.
Music interventions	To explore the effects of live and recorded-music on people who have dementia and a person who is closely connected to them, and on interaction.	6 music interventions: same or similar music played on solo cello, lasting approximately 30-minutes. 3 live-music. 3 recorded-music (ramdomised order). Pulse and blood pressure measurements taken from each carer (and initially from residents) at beginning and end of each intervention. Not all participants were

		completed the full series of interventions.
Exit carer interview	To learn about each carer's experience of their music interventions and how their initial expectations were or were not met.	Conduct one semi-structured (usually face-to-face) interview with each carer.
Thank you letter to each dyad	To express my gratitude and appreciation to each dyad participant.	Included with each letter a CD containing recordings of all the music played during their music interventions.
Select staff interviews	To learn about how key staff and managers experienced this study.	Mostly private on-site interviews with key staff members and managers: not all key staff were available.

Table B: Methods of data-collection

Task	Purpose	Procedure	Data source	Duration	Comments
Carer intake	To learn more about each dyad: including music background, musical preferences, expectations and hopes of carers.	Audio-recorded semi-structured interview either in person or via the telephone – administration of background and musical preference questionnaires – administration of four Visual Analogue Scales (VAS).	Interview transcripts – questionnaires – VAS – field notes.	30-60 - minutes	Administered background and music preference questionnaires and VAS to residents during their consent process -when appropriate to do so. Musical preference questionnaires based on work by Gerdner (2000).
Pilot music intervention with resident	To introduce residents to the cello and fine-tune music choices.	Played various tunes on the cello– generally in residents' bedroom but sometimes in common areas.	Field notes – video-recordings – fieldnotes	Approximately 30-minutes.	I did not conduct pilot interventions with every resident – primarily due to health/scheduling issues.
Live and	To learn	Scheduling	Video-	Six	Not all dyads participated in six music

recorded-music interventions	about the effects of individualised live/recorded—music on people with dementia nearing the end of life and their carers.	predicated on each carers' availability - I called each carer an hour before each scheduled intervention as a reminder and confirmation - I arrived a bit early in order to say hello to the resident and obtain their permission to enter their bedroom and to set-up for the intervention - Set-up included two very small video-recorders on tripods and a portable stool for me to sit on. The live-music interventions required a music stand and my cello. The	recordings (one capturing the facial expressions of the resident, and one wide-angled to capture the entirety of the resident and carer) - field notes.	interventions (3 live-music, 3 recorded-music) each lasting approximately 30-minutes.	interventions, and some interventions lasted significantly longer than thirty-minutes, while others were much shorter, or in a few cases cancelled.

		recorded-music interventions required a battery-operated CD-player, a pre-made individualized CD of me playing the same or similar music on the same cello through a batter-operated high-quality portable speaker.			
Pulse and blood pressure measurements	To obtain another perspective of music's effect on participants.	I used a blood pressure cuff to measure blood pressure and pulse at before and after the music had been played during each intervention.	Measurement readings from blood pressure/pulse device.	3-minutes at the start and end of each intervention.	I quickly desisted from taking these measurements from residents (see chapter 4.4.C.v).
Carer exit intake	To learn more the experiences of each carer and how	Conducted one semi-structured (mostly face-to-face), audio-recorded interview with each carer and	Transcripts of interviews – VAS – field notes.	One meeting lasting between 30-60 minutes.	Some of these interviews took place directly after the final music interview and included the resident as well.

	their expectations were or were not met.	administration of four Visual Analogue Scales (VAS).			
Staff interviews	To learn how managers and key staff members viewed this study and if they observed any changes in resident participants.	Conducted one semi-structured audio-recorded interview with key managers and staff when possible.	Transcriptions of interviews and field notes.	Approximately 30-minutes.	It was quite difficult to schedule interviews with managers and staff due to the nature of their work.

Table C: Music intervention phases

Step	Task	Purpose	Duration	Process	Comments
1	Phone care home	Alert care home that a resident should be ready for upcoming music intervention.		Phone care home 1-hour prior to scheduled music intervention.	For various reasons I was not always able to accomplish this.
2	Find resident	Reintroduction and seek permission to enter private bedroom to prepare for the music intervention.	Approximately 15-minutes prior to each music intervention.	Reintroduction and seek permission to enter private bedroom to prepare for the music intervention.	
3	Set-up for music intervention	To have everything prepared before the resident and carer entered the bedroom.	15-minutes set-up time.	Arrange room and set-up video-cameras, my stool, and stand/cello or CD player/speaker.	Some residents were in wheelchairs. I was not always able to capture the entirety of the dyad due to the restricted area of the room/my inexperience with the video cameras.

4	Invite participants to come to music intervention				
5	Take basic biomedical measurements from carers*	To see if a biological trend emerges from the effects of music on carers.	Approximately 3-minutes	Used a simple pressure cuff that measured both blood pressure and pulse before the music started.	* Initially attempted to take these measurements from residents as well.
6	Reintroduced the 'rules' of the study.	Remind residents that they were in charge of the music and that both they and the carer could respond in any way they wished.	A few minutes		
7	Music intervention		+- 30-minutes	Half of the study cohort dyads received three recorded-music interventions first, while half of the study cohort dyads received three-live music interventions first.	

| 8 | Take basic biomedical measuremen ts from carers* | To see if a biological trend emerges from the effects of music on carers.* | Approximately 3- minutes | Used a simple pressure cuff that measured both blood pressure and pulse after the music ended | * * Originally attempted to take these measurements from residents as well |

Appendix 7: VAS

A. VAS example

VAS - anxiety

not anxious

**very
anxious**

B: VAS measurements
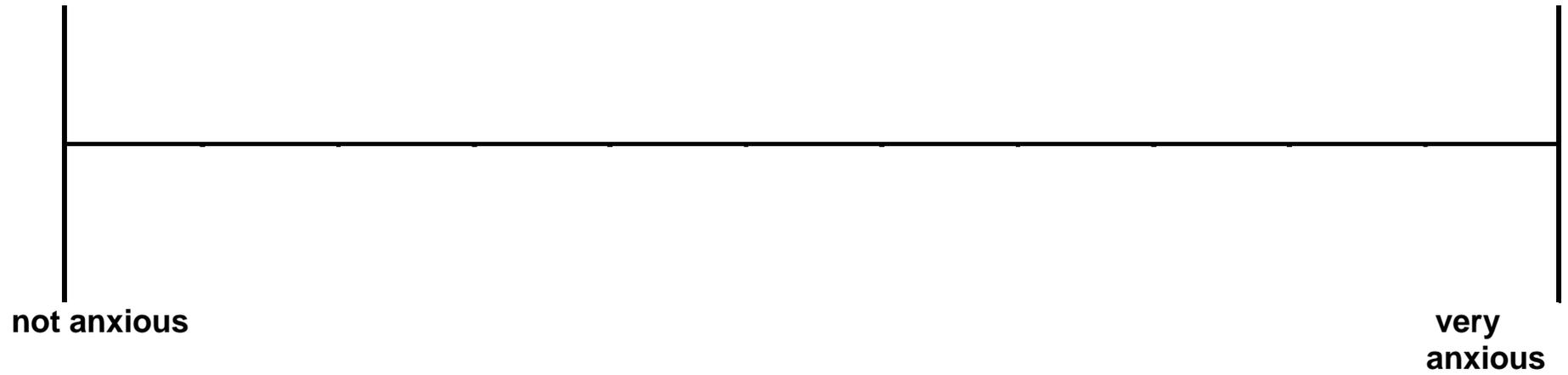
Figure caption: VAS measurements before and after complete series of interventions
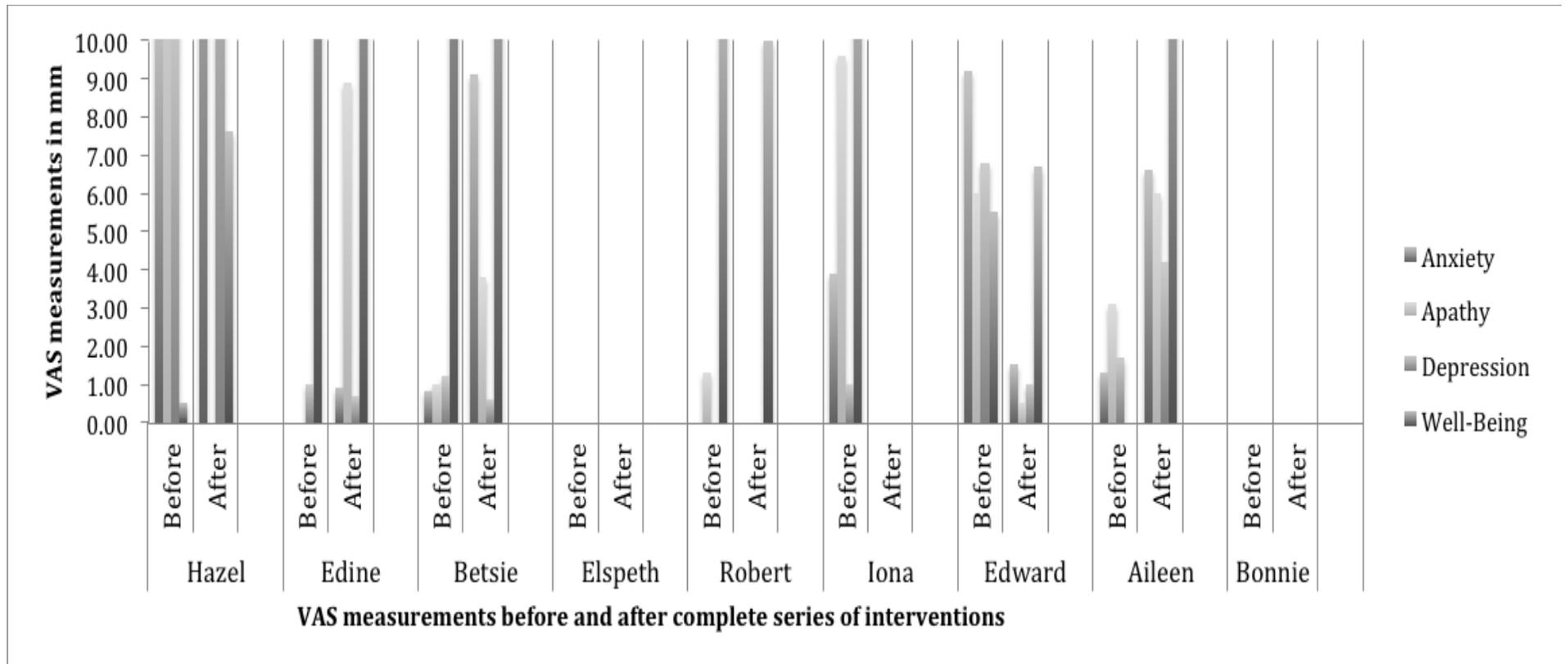
Appendix 8: Interview Topic Guides

A. Topic Guide Initial - Carers

- How old are you?

- What is your educational background?

- (What is your ethnic background?)

- How do you see your current quality of life?

- What place does/has music had/have in your life?

  - Did/do you play a musical instrument?

  - Did/do you sing?

  - Was there a lot of music played in your childhood home?

    - What types of music?

- Can you tell me a bit about _____'s past/background – any interesting or pertinent things that you remember or would like to share?

- What are your hopes/expectations regarding how this study might be of benefit to you or _____?

B. Topic Guide Exit - Carers

- What were your expectations for this study before you participated in this study?

- Can you describe your experience of listening to the music?
  - Were there any differences between how you experienced the live and recorded versions of the music?

- Did you have any experiences that were particularly surprising while listening to the music?
  - Were there any differences between how you experienced the live and recorded versions of the music?

- Did you notice any changes in the person you care for while you both listened to the two different types of music (individualised live and recorded)?
  - Did you notice any changes in how the two of you interacted while listening to the music?
    - Were there any differences in how the two of you interacted when listening to the live and recorded versions of the music?

- Is there anything more you would like to say about your experience of being a part of this study?
- Do you have any questions?

C. Topic Guide Exit - Residents

- How did you feel when listening to the live music?

- How did you feel when listening to the recorded music?

  - Was there a difference?

- Do you have anything you would like to tell me about what being in this study was like for you?

- Do you have any questions?

D. Topic Guide Exit - Staff

- Did you notice any effects from the music interventions with any of the residents who participated in this study?
    - Did you observe and differences in the effects of either the live or recorded music with any of the residents who participated in this study?

- Did you notice changes in either behaviour or level of engagement after the music interventions with any of the residents who participated in this study?
    - Were there any noticeable differences between the live or recorded music interventions on either behaviour or level of engagement with any of the residents who participated in this study?

- Do you have any other comments about this study?

- Do you have any questions?

Appendix 9: PIECE-dem

A. PIECE-dem – Modified observation sheet: 5-minute intervals

Participants:

Intervention #   **Intervention Date:**

'POSITIVE' responses	1-5		5-10		10-15		15-20		20-25		25-30		30 – 35+	
	R	C	R	C	R	C	R	C	R	C	R	C	R	C
Looking towards stimulus														
Tapping feet														
Tapping hand/fingers														
Singing/humming														
Swaying														
nodding														
Whistling														
Verbal interactions														
Facial expressions														
Interaction with another person														

'NEGATIVE' responses	1-5		5-10		10-15		15-20		20-25		25-30		30 – 35+	
	R	C	R	C	R	C	R	C	R	C	R	C	R	C
Looking away from stimulus														
Yawning														
Apathy/non-response														
Focused on another stimulus														
Looking at watch														
Fidgeting														
Disruption/interruption														

Idiosyncratic responses		
Other (describe)		

'POSITIVE' interactions	1-5		5-10		10-15		15-20		20-25		25-30		30 – 35+	
	R	C	R	C	R	C	R	C	R	C	R	C	R	C
Verbal interaction														
Physical interaction														
Looking at other person in dyad														
Singing with other person in dyad														

'NEGATIVE' interactions	1-5		5-10		10-15		15-20		20-25		25-30		30 – 35+	
	R	C	R	C	R	C	R	C	R	C	R	C	R	C
Ignoring other person in dyad														
Interrupting music														
Non-responsive to other person in dyad														

Names of tunes played during each 5-minute interval

1-5	5-10	10-15	15-20	20-25	25-30

Interaction	1-5		5-10		10-15		15-20		20-25		25-30		30 – 35+	
	R	C	R	C	R	C	R	C	R	C	R	C	R	C
Engaged														
Disengaged														
Disruptions/Interruptions														

Type of Interaction	1-5		5-10		10-15		15-20		20-25		25-30		30 – 35+	
	R	C	R	C	R	C	R	C	R	C	R	C	R	C
Resident/Carer														
Resident/Researcher														
Carer/Researcher														

**Time-frame notes: thick description (e.g.
setting/environment/extraneous noise/interruptions/body
language/tunes played/technical and other problems/signs of stress or**

anticipation/changes in participants/emotional responses of myself as observer.

1	
2	
3	
4	
5	
6	

B. PIECE-dem modified questions

- **Health of resident:** What type of dementia does this resident have and when was diagnosis first made? Does this resident have any other physical illnesses or problems that affect their daily life? What medications is this resident currently taking? Could any of these medications have affected this resident's response to the music during the span of these observations?

- **Health of carer:** Does this carer have any other physical illnesses or problems that affect their daily life? What medications is this carer currently taking? Could any of these medications have affected this carer's response to the music during the span of these observations?

- **Music/outside stimuli - resident:** What is this resident's historical relationship to music? Has this changed since the onset of dementia? Are there any other external stimuli that this resident currently responds to?

- **Music/outside stimuli - carer:** What is this carer's historical relationship to music? What is this carer's relations ship to music now?

- **Relationship to carer**: How long has this carer known this resident? What is their relationship? Has the nature of their relationship changed since the onset of dementia? How close are they emotionally? Has that changed since the onset of dementia?

- **Understanding the resident's needs:** Are there any idiosyncratic ways that this resident responds that perhaps their carer will recognise?

- **Differences in reactions to music - resident:** Were there any discernible changes in this resident's reaction to the music interventions overall? What were they? Are there any know reasons for these changes?

- **Differences in reactions to music - carer:** Were there any discernable changes in this resident's reaction to the music interventions overall? What were they? Are there any know reasons for these changes?

- **Differences in resident over span of intervention:** Were there any discernible changes in this resident over the span of these interventions?

If so, what are these differences? Are there any known reasons for these changes?

- **Engagement:** Are there any discernible differences in the level or type of engagement that occurred during the span of these music interventions? What are they? Are there any known reasons for these changes?

- **Comments:**

C. PIECE-dem Summary Questions – modified
Tick which observation block you are summarising:

Morning   Middle of day   Early Afternoon   Late Afternoon

Recorded   Live

Number   Number

Total number of 5min blocks in this session?

Record Number of blocks that each category was observed:

Interaction   Engaged   Disengaged

R=   C=   R=   C=   R=   C=

Summarise your perception of the resident's predominant experience of their world during this time period.

Summarise your perception of the carer's predominant experience of their world during this time period.

To what extent was the resident able to exert control within their world and how was this achieved?

How were the resident's physical needs met?

How were the resident's psycho-social and spiritual needs met?

When do interactions occur, who is the interaction with, what appears to be the purpose of these interactions and what impact do they have upon the resident? What impact do they have upon the carer? Was knowledge of the resident used/relevant to this interaction?

D. PIECE-dem comparative tables
Table D. Resident responses to live-music versus recorded-music:

P=physical responses

V=verbal responses

Resident name	No. and order of interventions	Significantly more response to live-music?	RECORDED-MUSIC		LIVE-MUSIC		Other influences	Comments
			Total no. recorded-music blocks	Total no. responses to recorded-music (Total no. blocks)	Total no. live-music blocks	Total no. responses to live-music (Total no. blocks)		
Aileen	**Record ed 1-3 Live 4-6**	No	16	No. Engaged 23(16) P 24 (14) V N disengaged 9 (7)	15	No. Engaged 24 (15) P 24 (15) V N disengaged 9 (4)	**Fluctuating energy levels and recognition of tunes played, shared experience with carer Tommy. Faster Scottish tunes.**	**Attentive, verbal, singing, occasional gestures during both types of interventions.**
Betsie	**Live 3 Record**	No	21	N engaged	17	N engaged 68 (17) P	**Shared enthusiasm of carer Morven.**	**Singing to every tune, swaying and tapping also.**

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	ed 4 -6			87 (21) P 24 (14) V N disengaged 12 (6)			32 (17) V N disengaged 19 (11)		Very conversational. Many expressions of satisfaction at the ends of tunes.
Bonnie	**Recorded 1-3 Live 4-6**	**No**	**21**	**N engaged 42 (20) P 26 (15) V N disengaged 48 (18)**		**20**	**N engaged 59 (20) P 33 (19) V N disengaged 13 (9)**	**Whether she was getting her dementia medications.**	**Attentive, but also at times highly distracted.**
Edine	**Live 1-3 Recorded 4-6**	**No**	**20**	**N engaged 93 (20)**		**13**	**N engaged 59 (13) P 17 (13) V**	**Frail health.**	**Attentive, smiling, chuckling, swaying, verbal throughout.**

				P 16 (16) V N disenga ged 7 (6)		**N disengaged 0 (0)**		
Edward	**Live 1-3 Record ed 4-6**	**Yes**	**18**	**N engaged 52 (18) P 14 (13) V N disenga ged 17 (8)**	**21**	**N engaged 49 (21) P 25 (13) V N disengaged 3 (3)**	**Health. Faster 40s tunes.**	**Edward was more verbal and appreciative during live-music. More distracted and easily distracted/bored during recorded-music.**
Elspeth	**Record ed 1-2 Live 4-5**	**Yes**	**8**	**N engaged 8 (8) P 10 (7) V N disenga ged 11 (8)**	**14**	**N engaged 17 (14) P 22 (14) V N disengaged 1 (1)**	**Parkinson's medication or time of day?**	**Elspeth was fairly disinterested in the recorded-music, but was very engaged; verbal and singing during the live-music.**

Hazel	**Live 1-3 Record ed 4-6**	**No**	**21**	**N engaged 28 (20) P 13 (13) V** **N disenga ged 8 (6)**	**20**	**N engaged 36 (20) P 17 (17) V** **N disengaged 0**	**Time of day?**	**Attentive, commenting at ends of tunes, smiling throughout.**
Iona	**Record ed 1-3 Live 4-6**	**Yes**	**19**	**N engaged 84 (19) P 42 (19) V** **N disenga ged 2 (1)**	**21**	**N engaged 45 (19) P 39 (21) V** **N disengaged 3 (3)**	**Printed song-sheets.**	**Iona enjoyed both versions of the music, but the addition of the printed song-sheets during her live-music interventions caused her to become totally engrossed with the music.**

Maggie	Record ed 1-3 Live 4-6	Yes	19	N engaged 63 (19) P 26 (16) V N disenga ged 10 (8)		20	N engaged 87 (19) P 31 (20) V N disengaged 0	**Shared/increased enthusiasm of carer Jean.**	**Maggie engaged with both versions of the music, but Jean's evident increased response to the live-music may well have fed into Maggie's increased response to the live-music.**
Robert	Live 1-2 and 6 Record ed 3-5	No	21	N engaged 49 (20) P 44 (16) V N disenga ged 3 (3)		21	N engaged 71 (21) P 33 (19) V N disengaged 1 (1)	**Amount of sleep that Robert had the night(s) previous.**	**Sometimes Robert had not slept the night before his music intervention, and therefore he was exhausted and would fall asleep. Or he would be very edgy and agitated.**

Table E. Carer responses to live versus recorded music:

P=physical responses
V=verbal responses

Carer	No. and order of interventions	Significantly more response to live-music?	RECORDED-MUSIC		LIVE-MUSIC		Other influences	Comments
			Total no. recorded-music blocks	Total no. responses to recorded-music (Total no. blocks)	Total no. live-music blocks	Total no. responses to live-music (Total no. blocks)		
Cait	Live 1-3 Recorded 4-6	No	14	N engaged 45 (14) P 15 (11) V N disengaged 2 (2)	13	N engaged 39 (13) P 20 (13) V N disengaged 0	Faster Scottish tunes and hymns	Cait enjoyed both versions of the music, but she did seem to especially enjoy the faster Scottish tunes and hymns.
Calum	Recorded 1-3 Live 4-6	Yes	19	N engaged 21 (12) P 16 (15) V N disengaged 32 (15)	21	N engaged 25 (19) P 25 (21) V N disengaged 2 (2)	Printed song-sheets	Calum became quite focused on the printed song-sheets that were added during the live-music sessions.

Isla	Live 1-3 Recorded 4-6	Yes	18	N engaged 16 (12) P 9 (9) V N disengaged 21 (17)	21	N engaged 42 (21) P 12 (12) V N disengaged 2 (2)	Anti-depression medication. Dislike of cello as a solo instrument. Historically strained relationship with her father Edward.	Isla's husband had recently died and was experimenting with anti-depression medications during these interventions. Repeatedly told me that Edward was not always the nice gentleman he was today.
Jean	Recorded 1-3 Live 4-6	Yes	19	N engaged 2 (2) P 9 (9) V N disengaged 58 (19)	20	N engaged 38 (19) P 22 (20) V N disengaged 7 (6)	Increased comfort during latter interventions? Classical music. Sense of special occasion during live-music.	Jean appeared quite uncomfortable and bored during first three recorded-music interventions. She was very happy with the few movements of Bach I surprised her with during the live-music interventions and seemed to generally be more relaxed during her least several (live) music interventions.

Mairi	Live 1-2 and 6 Recorded 3-5	No	21	N engaged 40 (21) P 10 (10) V N disengaged 0	21	N engaged 59 (21) P 15 (14) V N disengaged 0	Responses that her father Robert was expressing.	Mairi seemed to enjoy all of the music, but was primarily focused on her father and thus mostly responded to his reactions.
Morven (Betsie)	Live 3 Recorded 4-6	No	21	N engaged 33 (18) P 32 (20) V N disengaged 1 (1)	7	N engaged 24 (7) P 13 (7) V N disengaged 0	None	
Morven (Elspeth)	Recorded 1-2 Live 4-5	No	8	N engaged 7 (6) P 10 (7) V N disengaged 0	14	N engaged 11 (9) P 25 (14) V N disengaged 2 (2)	None	
Nessa	Recorded 1-3 Live 4-6	No	21	N engaged 13 (8) P 17 (14) V N disengaged 0	20	N engaged 21 (17) P 36 (20) V N disengaged 1 (1)	Level of engagement expressed by her daughter Bonnie	Nessa was primarily focused on her mother and thus mostly responded to her reactions.

Sheena	**Live 1-3** **Recorded 4-6**	**No**	**21**	**N engaged 28 (18) P 3 (3) V** **N disengaged 48 (21)**		**20**	**N engaged 35 (20) P 5 (5) N** **N disengaged 0**	**About to go on holiday during recorded-music sessions.**	**Sheena was slightly more engaged with live-music – as she even tapped her foot a bit.**
Tommy	**Recorded 1-3** **Live 4-6**	**No**	**16**	**N engaged 43 (16) P 11 (11) V** **N disengaged 8 (6)**		**15**	**N engaged 42 (15) P 27 (15) V** **N disengaged 4 (4)**	**Energy level and familiarity/comfort level with later sessions.**	**Tommy was fairly engaged throughout all interventions, but this increased with each consecutive session.**

Table F. Comparison of dyad interactions: live-music and recorded-music

Dyad members	Order of interventions	Significant change in interactions between live and recorded?	RECORDED-MUSIC		LIVE-MUSIC		Other influences
			Total no. recorded-music blocks	Total no. blocks resident interacted - Total no. blocks resident did not interact - Total no. blocks carer interacted – Total no. blocks carer did not interact.	Total no. live-music blocks	Total no. blocks resident interacted - Total no. blocks resident did not interact - Total no. blocks carer interacted – Total no. blocks carer did not interact.	
Aileen/Tommy	**Recorded 1-3** **Live 4-6**	**No**	**16**	16 | 0 | 16 | 0	**15**	14 | 1 | 13 | 2	**Time of day. Aileen's energy level.**
Betsie/Morven	**Live 3** **Recorded 4 -6**	**No**	**21**	19 | 2 | 18 | 3	**17**	17 | 0 | 17 | 0	**Betsie's level of pain in broken arm?**

Bonnie/Nessa	Recorded 1-3 Live 4-6	No	20	20 | 0 | 18 | 2		20	17 | 3 | 18 | 2	Bonnie's dementia medications?
Edine/Cait (Bethia 2nd intervention)	Live 1-3 Recorded 4-6	No	20	19 | 4 | 10 | 10		13*	13 | 0 | 10 | 3	Edine's health. *1st live-music intervention video damaged so not counted.
Edward/Isla	Live 1-3 Recorded 4-6	Yes	18	12 | 6 | 8 | 10		21	18 | 3 | 11 | 10	Edwards' general health and ability to communicate.
Elspeth/Morven	Recorded 1-2	Yes	8	5 | 2 | 5 | 21		14	7 | 0 | 3 | 4	Elspeth's Parkinson's medicine/time of day?

	Live 4-5			1 | 0 | 1 | 0		7 | 0 | 4 | 3	
Greer/Brenda	**Live pilot 1**	**NA**	**7**	NA	**7**	7 | 0 | 7 | 0	
Greer/Kirsty	**Live 1**	**NA**	**7**	NA	**7**	6 | 1 | 7 | 0	
Hazel/Sheena	**Live 1-3** **Recorded** **4-6**	**No**	**21**	5 | 2 | 3 | 4 | 7	**20**	17 | 6 | 5 | 15	
Heather/Donna	**Recorded** **1**	**NA**	**7**	0 | 7 | 0 | 7 | 7		NA	
Iona/Calum	**Recorded** **1-3** **Live 4-6**	**Yes**	**19**	17 | 2 | 15 | 4	**21**	19 | 2 | 21 | 0	**Printed word sheets/familiarity.**
Maggie/Jean	**Recorded** **1-3**	**Yes**	**19**	14 | 6 | 9 | 11	**20**	20 | 0 | 20 | 0	**Live music.**

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	Live 4-6						
Robert/Mairi	**Live 1-2 and 6 Recorded 3-5**	**No**	**21**	14 7 11 10		**21**	18 1 14 7

Appendix 10: Music played during interventions

A-Tisket, A-Tasket

Abide with me

Ae Fonde Kiss

All things bright and beautiful

Amazing Grace

Anniversary Waltz

Anything Goes

Auld Lang Sine

Banks and Braes

Barren Rocks of Aden

Begin the Beguine

Bei Mir Bist Du Shein

Blow the Wind Southerly

Blue Moon

Bluebells of Scotland

Boogie Woogie Bugle Boy

Bouree: JS Bach solo cello suite 3

By Cool Siloam's shady rill

Chattanooga Choo Choo

Danny Boy

Dashing White Sergeant

Devil's Tailor

Don't Fence Me In

Don't sit under that apple tree

Gay Gordons

Gigue: JS Bach solo cello suite 3

God be with you

God of our Father

I'll Be Seeing You

I'm Getting Sentimental Over You

In The Mood

Katie Dalrymple

Largo Fairy Dance

Let's Do It

Lili Marlene

Mairi's Wedding

Mona Lisa

My Bonnie Lies Over the Ocean

My Love is like a Red Red Rose

My Way

Neil Gow's Lament for His Second Wife

Night and Day

Nightingale in Berkeley Square

Old 100th

Old Brown Jug

Old Rugged Cross

Polka

Roads and Miles to Dundee

Run Rabbit Run

Salut d'amour: Elgar

Sarabande: JS Bach solo cello suite 3

Scotland the Brave

Soldiers Joy

Somewhere Over the Rainbow

Sound of music various tunes

Stormy Weather

Sunny Side of The Street

Swinging on a Star

Take the A train

The Bonnie Banks o'Loch Lomond

The Swan (Le Cygne)

Unforgettable

We'll Meet Again

When Irish Eyes are Smiling

White Cliffs of Dover

Wind Beneath My Wings

What a Wonderful World

You are my Sunshine

Appendix 11: NVivo (8-10) Coding

A. Nvivo Round 1: Coding Open Nodes

Open Code Names	Code Definitions	No. interviews, thick-description, fieldnotes coded.	No. citations (text segments) coded
Ageing and disability	References to views expressed by interviewees towards ageing and disability	1	1
Attitudes towards study	References to views expressed by interviewees regarding this current study	2	5
Barriers and limitations	References to problems that arose during this study	32	196
Body language	References to nonverbal communications by participants	17	75
Care homes in study	References to the 5 care homes involved in this study	67	163
Care homes not in study	References to other care homes that were not included in this study	6	7
Carer attitudes towards residents	References to carer attitudes towards their resident dyad partner	13	32
Carer concerns	References to concerns expressed by carers	7	14
Carer responses to music	References to verbal and nonverbal responses to music expressed by carers	32	150
Choice of music	References to the music chosen for each resident	24	58
Consultant suggestions for study	References to key-informant suggestions for this study	15	39
Dementia attitudes - consultants	References to key-consultant comments regarding attitudes towards dementia	15	37

Disabilities - consultants	References to key-consultant comments regarding disability and impairment	3	9
Disruptions and interruptions	References to each instance of a participant disruption or a staff interruption	9	26
End of life	References to comments about death and dying	17	37
Engagement	References to comments and observations related to participant engagement with either the music or another person during these interventions	9	53
Entrainment	References to comments and observations of 'entrainment'	3	5
Equality	References to observations of parity within participant dyads	5	16
Ethics	References to comments regarding ethics	12	17
Expectations and hopes of participant carers	References to carer's verbalised expectations and hopes regarding how these interventions might beneficially effect their resident dyad partner	30	47
Family attitudes towards study	References to comments made by kin of residents regarding this study	10	14
Flexibility	References to my need to maintain a flexible stance throughout my fieldwork	20	104
General care home observations	References to my general observations	13	27

	of the care homes I visited		
Impact of carer presence on resident participant	References to observed impact that carer member had on resident dyad partner	12	34
Impact of carer attitude towards the music on resident participant	References to observed impact that carer responses to the played music had on their resident dyad partner	8	25
Impact of historical relations ship on interactions during interventions	References to observed impact that initial rapport between dyad members had on their experience of the played music	14	42
Implications for future use of music	References to this study's findings regarding implications for future practice	14	42
Importance of carer's prior knowledge of resident dyad partner	References to assets that including a carer with prior knowledge of their resident dyad partner	9	17
Importance of residents correctly identifying tunes	References to observed impact that correctly identifying familiar tunes had for some residents	19	131
Indications of residents losing interest or tiring during music interventions	References to verbal or nonverbal indications that a resident was tiring	12	37
Interaction	References to comments and observations regarding interactions during interventions	15	151
Key-consultant attitudes towards study	References to comments made by Key-consultants during phase-1	14	31
Kin attitudes towards family member with	References to kin attitudes towards their family member	18	48

dementia	with dementia		
Live vs. recorded music	References to observations regarding differences in participant responses to live vs. recorded-music	34	123
Loss	References to aspects of loss	34	151
Mood changes in participants	References to observed changes in the moods of participants during these interventions	13	39
My being an 'outsider'	References to my being from the USA	2	9
Palliative care	References to key-consultant comments regarding palliative care	7	12
Personal reflections	References to my personal thoughts and observations	26	203
Recruitment	References to comments and my experiences regarding recruitment	13	24
Regrets; lessons learned	References to personal reflections regarding aspects of this study that could have been improved	14	69
Resident participant concerns	References to concerns expressed by resident participants	10	50
Resident responses to music	References to resident responses to the played music	7	122
Shared experience	References to observed shared experience of each participant dyad	12	76
Special attention – residents	References to the effect that special	7	10

	attention had on resident participants		
Staff attitudes towards study	References to comments made by staff regarding this study	14	31
Staff concerns	References to concerns voiced by staff regarding this study	1	2
VAS and biomedical measurements	References to comments and observations regarding the use of VAS and biomedical measurements during this study	17	31
Video issues	References primarily to technical issues concerning the video use during this study	3	10
Video-observation	References to comments related to video-observation during this study	11	15

B. Nvivo Round 2: Coding Open Nodes

Round 2 Codes	Included codes	No. Interviews, thick-descriptions, fieldnotes coded	No. citations (text segments) coded
Barriers and limitations	Barriers – Disruptions – Interruptions – Flexibility – Implications for future use of music – Issues and thoughts arising – Regrets – Lessons learned – Suggestions for study	113	579
Biomedicals and VAS	Biomedical medical measure – VAS	18	31
Care homes	Care homes in study – care homes not in study	89	227
Carers	Carer attitudes towards resident partner – Carers – Kin attitudes towards resident – Impact of carer attitude towards music on resident – Impact of historical dyad relationship on resident – Importance of carer's prior knowledge of resident	114	285
Communication	Body language – Communication – Indications of residents tiring – Signs of recognition of tunes from residents – Talking Mats	49	233
Concerns	Carer concerns – Resident concerns – Staff concerns	18	66
Dementia	Dementia – Dementia and music – Attitudes towards dementia – Engagement and dementia	28	74
Disabilities	Ageing and disability – Disabilities – Neurological disabilities	5	11
End of life	End of life – Frailty –	32	64

	Palliative care		
Engagement	Engagement – Equality – Effects of music on interaction – Relationship – Shared experience	56	521
Ethics	Ethics	12	17
Interventions	1-6 interventions – Pilot interventions	34	34
Loss	Loss	34	150
Music	Active music therapy – Choices of music for interventions – Entrainment – Iso-principal – Importance of residents identifying music – Live vs. recorded music – Music – Music practitioner – Music research – Music therapy – Receptive music therapy – Responses to music genres – Responses to specific tunes – Suggestions regarding music – Universality of music	71	451
Personal reflections	Impact of my mood on interventions – Me as 'outsider' – Observations of study – Personal emotions during fieldwork – Personal reflections	36	286
Recruitment	Recruitment – Recruitment of care homes	14	27
Residents	Resident engagement with care home life – Resident participants – Resilience	161	88
Responses to music	Changes in participant	159	1191

	mood during interventions – Live vs. recorded music – Reactions to music in common areas – Carer responses – Resident responses – Participant's responses to the music – Effects of individualised music on people with dementia – Effects of music on carers		
Responses to study	Family attitudes – Carer reactions to interventions – Resident reactions to interventions – General reactions to study – Key-informant reactions to study – Staff attitudes towards study	66	284
Staff	All staff including care home managers	38	56
Video	Live observations vs. video observations – Video issues – Video-observation	24	51