How do family caregivers of people with advanced/complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?

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Abstract

This multimethod, qualitative study explored the lived experiences of family caregivers when they engaged in Music Therapy (MT) alongside the person with dementia they were caring for. Six dyads (person with advanced/complex dementia and their family caregiver) were recruited from the collaborating organisation, Mindsong. Each dyad participated in the MT intervention together and were interviewed before the intervention, at mid-point, and after the intervention. These interviews were analysed using Interpretative Phenomenological Analysis. Each caregiver also selected a section of music from their sixth MT session, which was analysed using Trondalen's method of microanalysis. Following the synthesis of findings from both methods, a visual representation of the superordinate themes was created, exploring the relationship between the themes.

The overriding finding was that family caregivers made sense of their experiences of the MT intervention within the context of their relationship with the person they were caring for, which was steeped in their experiences of dementia. MT supported significant aspects of self that have been identified as protective factors against negative experiences of dementia, including a strengthened sense of self, increased self-esteem, feelings of social connectedness and an enhanced sense of meaning in life.

Crucially, the therapy provided opportunities for shared interaction and emotional connection which strengthened relationships within the dyads, and brought moments of joy and hope in the face of challenging dementia experiences. Successful skill-sharing between the therapists and caregivers meant that music was used as a tool beyond therapy, to ease difficult dementia experiences and further strengthen the relationship between the dyad. At the end of the cared-for participant's life, music was also used to maintain an emotional connection and soothe the transition between life and death.

This multimethod study created rich, detailed findings that reinforce the call for sensitive, home-based dementia support that encompasses the needs of the family caregiver, as well as the person with dementia. The experiences recounted strengthen the voice of family caregivers of people with dementia in the research literature. Implications for further research and recommendations for MT practice are presented.

Declaration of Ownership

I declare that this thesis and the work it represents has been created and written solely by myself. All work presented is my own, with the exception of references to other literature and studies, which I acknowledge within the text.

The images exploring the three superordinate themes (chapter 9) were created with the artist, Kate Smith, who has given permission to include them in this thesis. The kaleidoscope image also presented in chapter 9 is adapted from an Adobe Stock Image that I have permission to use.

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Chapter 1: Background

1.1 Introduction

This chapter introduces the research topic and the study itself, including the motivation behind the study, an overview of the main aims, and definitions of key terms from the research question. I also introduce the collaborating organisation, Mindsong, from which participants were sourced, and who provided the Music Therapy intervention. An explanation of the theoretical basis for Mindsong's work is given, as well as a definition of Music Therapy (MT), as applied by Mindsong. Finally, there is a brief overview of the methodology employed in this study.

I am a Music Therapist and Director of Music Therapy for Mindsong, and it is Mindsong's work that has provided the inspiration for this research. My primary role in this study has of course been as a researcher, but I have been aware throughout that I come to this research with a particular perspective, from my experiences as a Music Therapist in this field. I have engaged in reflexive practice throughout, in order to remain aware of the perspective from which I am interacting with the research participants and data. Whilst it can be helpful to view data from different perspectives, bringing to light different meanings (Smith, Flowers and Larkin, 2009), in the presentation of the participants' experiences, my aim has been to be as true to the participants' phenomenological world as I can be. I have questioned and challenged my thinking to ensure that the findings represent my understanding of the participants' understanding of their experiences. For more detail regarding how I engaged in reflexive processes, please see p.60.

1.2 Dementia and Family Caregivers

Dementia is a global crisis. In the UK alone, there are an estimated 944,000 people living with dementia at present (Luengo-Fernandez and Landeiro, 2022a). Globally this figure is at 55 million, and set to rise to 78 million by 2030 (World Health Organisation, 2023). Health and social care costs for dementia are around £25 billion per year in the UK (Luengo-Fernandez and Landeiro, 2022a), while the effect on human life is arguably unquantifiable.

Dementia is an existential threat; its presence undermines every aspect of our being, the way we live our lives and the relationships we engage in (Cheston, 2022; Christopher, 2023). This existential threat is not just present for people who have received a diagnosis, but for all of us; dementia's increasing prevalence means that the likelihood of experiencing dementia, as a

person diagnosed, or a person in relationship with someone diagnosed, is extremely high. It is unsurprising, therefore, that a diagnosis of dementia is often associated with significant anxiety: 'dementia has now superseded cancer as the most feared diagnosis' (Christopher, 2023, p.11).

Somewhat hidden behind the estimated 944,000 people currently living with dementia in the UK are family members or friends who care for people with dementia at home, whose lives are also heavily impacted. In 2014 there were an estimated 700,000 informal caregivers for the then 850,000 people living with dementia in the UK, saving the economy around £11 billion a year (Lewis *et al*., 2014; Carer's Trust 2018). Alzheimer's Research UK (2021) estimates that unpaid caregivers provide around 1.1 billion hours of care for people with dementia each year (Luengo-Fernandez and Landeiro, 2022b), a notably significant contribution.

Caring for someone with dementia can be a positive experience, bringing elements of personal growth and satisfaction, the feeling of making a difference for someone who is loved, and sustaining the relationship between caregiver and cared-for (Quinn *et al.*, 2022). However, also reported are the many strains this can bring to everyday life for a family member (Brodaty and Donkin, 2009; Newbronner *et al.*, 2013). Family caregivers (hereinafter, 'caregivers') are recognised as a population group at risk, being 'twice as likely' to experience poor health compared to non-caregivers of a similar age (NHS, 2019).

From my clinical experience as a Music Therapist working in the context of dementia, I have witnessed the amount of strain a person may experience whilst caring for their family member 24/7. Often the person providing the care is a spouse or long-time partner and therefore may be older themselves, with their own health complications to cope with alongside their caring role. Accessing care and support services can be difficult to navigate, and caregivers are often approaching exhaustion due to the ongoing and increasing role as a caregiver for someone with dementia. There is often little support for this population group: 'As a carer you become invisible as a person' (Oliveira, Sousa and Aubeeluck, 2018, p.9). Attending to their own needs is difficult, yet if they are not supported, their mental and physical health, and that of the person they are caring for, are both at risk (Etters, Goodall and Harrison, 2008).

1.3 The Research Gap

There is a growing body of evidence to suggest that MT is a supportive intervention that can improve quality of life for people living with dementia (McDermott *et al.*, 2012; Ridder *et al.,*

2013; Hsu *et al*., 2015). MT is even suggested as an intervention in the UK National Institute for Health and Care Excellence guidelines for dementia (NICE, 2019). However, evidence regarding caregivers' experiences of MT, and how effective MT may be in supporting them, is less substantial. This is an emerging area of research, and studies relating primarily to the experience of caregivers are few in number.

1.4 Aims and Motivation

This research moves towards addressing this imbalance by exploring the experiences of caregivers of people with dementia whilst they engage in MT alongside the person they are caring for. I intend to relay detailed, rich, idiomatic accounts which, I hope, will add to the current understanding of what it might be like to be a caregiver of someone with advanced and/or complex dementia, and how MT is experienced within this context.

My work for Mindsong has involved the development of a tailored service that provides MT for people with advanced dementia, or dementia with complex symptoms, still being cared for at home (Music Therapy at Home, MT@H). The therapy is for the main caregiver too, and wherever possible, we encourage that family member (or friend) to attend and engage in the sessions alongside the person they are caring for. Both are equally seen as our clients; we are working with caregiver and cared-for dyads. It is my work in this service, both as a Music Therapist, and as director overseeing the service, that has inspired this research. I am keen to find out more about the experiences of caregivers, and hope this will also help to increase their presence in the research literature relating to this topic.

1.5 Mindsong

To this end, Mindsong has agreed to be a collaborating organisation for this research. 'Mindsong' is a Gloucestershire charity specialising in supporting people with dementia using music and MT. Mindsong provides a range of services, including singing groups in care homes led by trained volunteers, community singing groups, MT in care homes, hospices and day centres, and our MT@H service, as mentioned above. At this point in time, Mindsong has over 350 volunteers and a team of 17 freelance Music Therapists working across Gloucestershire.

The MT@H service offers 12 weekly MT sessions for people with advanced or complex dementia and their caregivers, in their own homes. As well as the therapy itself, this also includes the development of personalised musical strategies to support daily care. Results show increases in wellbeing for both person with dementia and caregiver, improvements in

communication between the dyad, a strengthening of identity for the person with dementia, and a decrease in caregiver stress following the intervention (Melhuish, Grady and Holland, 2019).

The research participants for this study are drawn from Mindsong's MT@H service. Examining how and why this intervention supports by looking closely at the experiences of caregivers before, during and after the intervention will give greater understanding of the needs of this population group and whether or how these might be supported through MT.

Mindsong works closely with local organisations, including Gloucestershire NHS, Gloucestershire Alzheimer's Society and Gloucestershire Carers Hub. Receiving NHS funding for the service and attending Integrated Care System Dementia Strategy meetings gives the potential for any findings to influence policy and practice at a local level. In publishing the outcomes of the research, the scope of influence may extend further, with potential interest from other Music Therapists, anyone working in dementia care, and national organisations supporting people with dementia and their caregivers.

1.6 Why Music?

We are all innately musical beings; we have our own rhythms in our heartbeat, breathing rate, walking pace and body clock (Bunt, 1994). Our voices have their own pitch range and vocal timbre that is almost as unique as a fingerprint (Bunt, 1994). Our mother's heartbeat and voice are among the first things we encounter in the womb; an early sensory experience. Research suggests that for the majority of people, there is a universal ability to connect with and respond to music (Sacks, 2007; Levitin, 2025). There are a small number of people who do not, or cannot, connect helpfully to music, or for whom music can be an intrusive or intolerable experience (Sacks, 2007), but for the majority of people, music plays an important part in life throughout the lifespan (Sacks, 2007; Ansdell, 2014; Levitin, 2025), marking special occasions, life-changing moments and often as a daily accompaniment to our lives.

When we listen to or engage in music-making, multiple areas of the brain are stimulated (Hallam and Himonides, 2022; Levitin, 2025). Music is such a successful, accessible tool to use when supporting people with dementia because it engages so many areas of the brain; if part of the brain is damaged, music can still connect via another route (Levitin, 2007; 2025). Thus, music can connect even when language or other forms of communications are no longer accessible (O'Rourke *et al.,* 2021; Waters *et al.,* 2022).

As human beings, we have the capacity to experience deep emotional connections through music. Research evidences that the limbic system is activated when we listen to or engage in music-making (Levitin, 2007; Jäncke, 2008). The limbic system is involved in processing emotions and controlling memory; music stimulates both, creating opportunities for us to be deeply moved by music, and to create strong musical memories (Jäncke, 2008). In addition, musical memory is often preserved in dementia (Sacks, 2012; Jacobsen *et al.,* 2015), making music a medium through which we can connect when verbal language is lost.

Engaging in music listening and music-making can increase our feelings of wellbeing; music triggers reactions in areas of the brain that are involved in the release of dopamine, the pleasure hormone (Salimpoor *et al.,* 2011; Levitin, 2025). Music can facilitate meaningful shared experiences, helping us feel connected to others, and to our world (Sloboda, 1986; Hallam and Himonides, 2022). When we listen to or engage in music-making together, we experience a synchronicity with each other, in terms of pulse, rhythm, pitch, melody and harmony. This can result in feelings of closeness and connection (Tarr, Launay and Dunbar, 2014; Savage *et al.,* 2021).

All these aspects make music a unique and powerful tool when supporting someone in the later stages of dementia. Unlike medication, music is non-invasive, and if used in an appropriate and sensitive way, lacks negative side-effects.

1.7 Why Music Therapy?

Music Therapists are trained to use music spontaneously; creating music in the moment to connect with and support their client (or clients) to therapeutic aims (Bunt, Hoskyns and Swamy, 2021). It is the aim of the Music Therapist to use music in a personalised way to connect with their client/s. This could mean using familiar songs, receptive listening to music together, songwriting, or improvisation of music or sound (Bunt, Hoskyns and Swamy, 2021). The music created is attuned to the client, matching their sounds, movement or mood; meeting them where they are, aiming to 'enter accurately into the patient's world' (Yalom, 2001, p.18). When considered alongside the unique qualities of how music interacts in the brain, this makes MT a compelling intervention to consider when supporting people with advanced dementia and through to end-of-life stage. Extending MT to include a caregiver gives the potential of bringing benefits in wellbeing for both in the dyad, on an individual and a relationship level.

1.8 Definitions

1.8.1 Family / Informal Caregivers

The aim of this research is to focus on the experiences of unpaid, informal caregivers whilst they engage in MT alongside the person they care for. The International Association of Carer Organisations defines informal caregivers as any unpaid individual 'who takes on a caring role to support someone with a diminishing physical ability, a debilitating cognitive condition or a chronic life-limiting illness' (International Alliance of Carer Organisations, 2021). At the start of this study, I employed the term 'informal' or 'family' caregiver interchangeably, so that the research could encompass any person that was providing the majority of care for a person with dementia, without being paid. By not limiting the inclusion criteria to family only, this would allow for partners or friends to be included in the research. However, all of the caregivers recruited for this study turned out to be family members.

Careful thought was given to the term 'caregiver'. From working with caregivers of people with dementia, I found that some people objected to this, or the term 'carer', commenting that they were still a wife, husband, son or daughter. This resonates with the work of Ingrid Hellstrom, and in particular her moving case examples of couples looking after each other where one person has dementia, in her chapter 'I'm his wife, not his carer!' (Hellstrom, 2014, p.53). Here there is a strong sense of 'couplehood' (Hellstrom, Nolan and Lundh, 2007) and both people in the relationship take on elements of looking after the other. Conversely, in some of the clinical cases I have been involved with, using the terms 'carer' or 'caregiver' has helped the family member to come to some level of acceptance that their relationship had changed, and that part of this now included a caring role.

To explore this further, Mindsong held a 'Carer's Forum', where caregivers of people with dementia that had engaged in Mindsong's MT@H service were invited to discuss this issue with members of Mindsong's senior therapy team. Discussions began with how people felt about the term 'carer' and whether 'caregiver' felt more sensitive. Some preferred this and some did not. There was a suggestion of a distinction between the two terms: that 'carer' perhaps indicated an identity change, whereas 'caregiver' sounded more like someone who carries out the act of 'caregiving', with less emphasis on the idea of the caregiver's identity changing. Despite this, no clear preference for either term was established in the forum.

Further discussions explored the term 'informal caregiver', and whether this was preferable to 'family caregiver', but there were thoughts that using the word 'informal' may imply that the

care given was not of a high enough standard. The result of the forum was that people were undecided, and that 'family caregiver' or 'family carer' would be acceptable going forward. Throughout this thesis, the term 'caregiver' refers specifically to a family caregiver.

1.8.2 Advanced or Complex Dementia

It is arguably challenging to clearly define the stages of dementia, since every person's experience is unique, and the various causes of dementia mean that symptoms and their presentations can occur at different points and progress at different rates. The International Classification of Diseases (ICD-11) describes severe dementia as follows:

> Severe Dementia is typically characterized by severe memory impairment, but this varies according to the aetiology. There is often total disorientation for time and place. The individual is often completely unable to make judgments or solve problems. Individuals may have difficulty understanding what is happening around them. Individuals are fully dependent on others for basic personal care in activities such as for bathing, toileting and feeding. Urinary and faecal incontinence may emerge at this stage. (ICD-11; World Health Organisation, 2024)

The Alzheimer's Society give a simpler definition, but one which comments similarly on the global effect to a person's functioning:

> By the later stage of dementia, the condition will have a severe impact on most aspects of a person's life. The person will eventually need full-time care and support with daily living and personal care, such as eating, washing and dressing. (Alzheimer's Society, 2022)

The definition used for Mindsong's MT@H service is more relaxed, in order to extend its reach to people who may be earlier in the progression of their disease, but have complex symptoms, or where there are other compounding challenges alongside. Mindsong's inclusion criteria is as follows:

- The person referred has a diagnosis of dementia and is experiencing moderate to more advanced stages.
- The person referred is still being cared for at home by a family member/ partner/friend.
- The person with dementia and caregiver are experiencing challenging circumstances, which could include difficulties due to dementia symptoms (e.g., communication difficulties, anxiety, low mood, mobility difficulties) and/or caregiver stress, or comorbidities, such as dementia and depression, or dementia and anxiety (Mindsong, 2020).

Complex symptoms experienced with diagnosis of Frontotemporal Dementia, Dementia with Lewy Bodies, and other, rarer forms of dementia, can include changes in personality, the loss of inhibitions and empathy, visual and auditory hallucinations, and disruptions to visual and auditory processing and perception (Rare Dementia Support, 2024).

A diagnosis of Young Onset Dementia (with symptoms aged 65 or younger) can differ significantly from dementias that onset at a later age, and depending on the cause of the dementia, also bring varied and challenging symptoms and experiences (Dementia UK, 2022). In addition, having a dementia diagnosis at a younger age can be compounded by the fact that the person may still be working, or have young or teenage children at home.

This is not to say that symptoms of more commonly occurring causes of dementia, with onset at a later age, such as Alzheimer's Disease and Vascular Dementia, are not experienced as challenging. In addition, the incidence of co-morbidities for a person living with dementia is high, with an estimated figure of 30% of people living with Vascular Dementia or Alzheimer's Disease also experiencing depression, and this rising to 40% for those living with dementia as a result of Parkinson's or Huntingdon's Diseases (Kitching, 2015). Again, this compounds the challenges both for the person with dementia and for family members providing care.

The definition of 'advanced or complex dementia' is therefore fluid, and can cover a range of symptoms and how these are experienced by the person with dementia and caregiver. This flexibility takes into account different individual circumstances, acknowledging that each experience is different. As participants for this study were sampled from Mindsong's MT@H referrals, this loose definition of 'advanced or complex dementia' was applied throughout this study.

1.8.3 Music Therapy (MT)

MT is a clinical intervention, provided by qualified therapists who have completed an accredited course, usually at Masters level. In the UK, Music Therapists are considered Allied Health Professionals and need to be registered with the Health and Care Professions Council to practice. A growing profession, many countries across the world have similar standards of practice for Music Therapists (Kern and Tague, 2017). Participants who engaged in this research received MT from one of the Mindsong MT team, who are all qualified, registered therapists specialising in the context of dementia.

As director of MT for Mindsong, I developed the following explanation of MT, which is presented on Mindsong's website:

> By creating music together, a therapeutic relationship is developed between therapist and client and communications and expressions from the client are heard, valued and supported by the therapist. Each session is client-led and carefully tailored to the client's needs. Music Therapists use a combination of familiar songs and improvisation in order to enable a creative, shared engagement in the music.
>
> For a person with later stages of dementia, this may mean that the therapist sensitively creates music to reflect the person's breathing rate, movements or vocal sounds. Through the music, connections can be made, and a unique musical interaction takes place. (Mindsong, 2022)

This definition reflects my own understanding of how MT works in this context, and has been developed from my clinical work in the field of dementia.

1.9 Theoretical Underpinning

Underpinning my own clinical approach and the work at Mindsong is the theory of personhood, pioneered by Tom Kitwood in the 1990s. Kitwood's work enabled a change in focus in dementia care from concentrating on the disease or dementia symptoms to the person themselves, thinking about the person in a holistic manner, and treating the person with understanding, respect and dignity (Kitwood, 1997; Kitwood and Brooker, 2019).

Kitwood's flower represents his suggested five psychological needs for a person with dementia, which, when met, enable the person to feel safe and to flourish (Kitwood, 1997). Indeed, these needs are crucial not only for a person with dementia, but for everyone, and Mindsong's Music Therapists are asked to extend this thinking to include family members as they work with them alongside the person with dementia. This simple flower representation underpins the work, and the therapists are encouraged to think about ways in which MT can address each need on a personal level for the people they work with.

Figure 1: For a diagram of Kitwood's flower, please see Kitwood and Brooker, 2019, p.92.

Perhaps Kitwood's theories resonate with my own values and approach to MT because both are based within a humanistic philosophy. My MT training at UWE Bristol was steeped in the humanistic approach; based on Carl Roger's tenets of working in relationship with a person with empathy, unconditional positive regard and congruence (Rogers, 1957), and Maslow's idea of 'self-actualisation'; that a person has agency to grow and develop, to work towards personal fulfilment (Maslow, 1943). This approach can be described as 'person-centred therapy' (Pickard, 2018; Kelly *et al.,* 2023, p.198), which has obvious resonance with Kitwood's theory of personhood and his development of 'person-centred care', where the person with dementia is considered a holistic being, with agency and an ethical right to be cared for in a respectful and dignified manner (Kitwood, 1997; Kitwood and Brooker, 2019).

Kitwood's theories, like MT, are relational. His theory of personhood is based on a person being treated with understanding, respect and dignity by another. His flower represents the needs of a person in relation to another; 'attachment' and 'inclusion' are only achieved within a relational context. Arguably, 'comfort' and 'identity' can also be strengthened with the presence of another person.

The relational aspect of MT is, of course, also of central importance. In MT, the therapeutic relationship provides the context within which sound and music is generated in a collaborative manner between client and therapist. Together, the therapeutic relationship and the music created form the therapeutic space wherein change takes place; where the therapist supports the client to work towards therapeutic aims. I find that Polit (1993) summarises this well:

> Humanistic Music Therapy refers to the psychotherapeutic space wherein the personal and transpersonal development of the person through sound and music is facilitated, using an approach emphasising respect, acceptance, empathy and congruence. (Polit, 1993).

Another obvious resonance between Kitwood's theories and the core principles of the humanistic approach can be seen when comparing Kitwood's flower of psychological needs to Maslow's 'Hierarchy of Needs' (Maslow, 1943). Maslow presents his basic human needs as a pyramid, and includes safety and security (perhaps relating to 'comfort' in Kitwood's flower), the need for intimate relationships and social connection (relating to Kitwood's flower petals 'attachment' and 'inclusion'), self-esteem (relating to 'occupation'), and self-actualisation (perhaps relating to 'identity': who a person is, what fulfilment they can achieve; Maslow, 1943). The clear difference between the two models is that Maslow's is a hierarchy; he theorises that the lower needs in the pyramid need to be met before fulfilling the needs placed

higher in the pyramid, whereas Kitwood proposes that his identified needs overlap, and that by addressing one, another may also be addressed to some extent (Maslow, 1943; Kitwood, 1997).

In the centre of Kitwood's flower is the word 'love', which he describes as an 'all-encompassing need' for all people (Kitwood, 1997, p.81). Kitwood explains that the five identified needs come together in the 'central need for love' (Kitwood, 1997, p. 81). Again, this resonates with his principles of personhood, and also with Roger's principle of working in therapeutic relationship with unconditional positive regard (Rogers, 1957). My passion for my clinical work in dementia stems from a similar core belief that a person has the right to be respected, valued and upheld right through to the end of life; this is my interpretation of 'love' in this context, and MT is the means through which I can act on this belief.

In a recent article, Kelly *et al.* (2023), acknowledge the significant influence Kitwood's theories have had on the underpinning theoretical framework and delivery of MT for people with dementia, particularly within the last twenty years. Many studies make reference to his theories, and are given the description of 'person-centred Music Therapy' (Kelly *et al.,* 2023, p.198). Mindsong's MT also fits this description.

Kelly *et al.* (2023) describe Kitwood's five psychological needs, and alongside, reference examples from previous studies that have aligned these needs to MT practice (Kelly *et al.* 2023, citing Simpson, 2000; Hatfield and McClune, 2002; Ahessy, 2017). Inspired by this paper, I initiated a discussion with the Mindsong MT team, within which we explored how we see the needs represented in Kitwood's flower aligning with our MT practice in dementia. The therapists gave examples from their clinical work of where and how MT might be addressing a particular need represented in the flower. I made notes and reflected on this discussion, then created a table to represent our collaborative thinking, which is presented in Appendix 1 (p.241).

From our discussions, there was a general agreement that Kitwood's flower (Kitwood, 1997) is a useful theory to underpin our work in this context, and its simple visual nature allows it to be easily held in mind. It was interesting to hear how the therapists used the flower to identify which particular needs might be helpful to address for their clients, as well as their reflections on which needs the MT was supporting.

The challenge for the team was with the central word, 'love', and how this was interpreted within the context of MT. Some therapists found the word too emotionally charged, and ignore this element of the flower, concentrating on the five petals. Others found the overarching principle of 'love' helpful in approaching the work.

There have been some interesting explorations regarding how 'love' might come into a therapeutic relationship. In her article, 'Dare we speak of love?' Music Therapist Christine Atkinson explores how she felt love for her client, and how this created a strong bond between them in the therapeutic process (Atkinson, 2012). Nye replies in reaction to this, exploring his feelings of love towards a child he worked with, as the child reminded him of himself at a younger age (Nye, 2014). Nye argues that of course feelings of love might be evoked within a therapeutic relationship:

> … therapy is a dynamic process, and it is inevitable that the client will have an emotional impact on the therapist, and vice versa. Feelings of all kinds are therefore going to arise, including the possibility of loving feelings for the therapist towards the client. (Nye, 2014, p.26)

Nye continues, referring to Fromm's interpretation of the therapeutic stance essentially being an act of love in itself (Nye, 2014). Fromm states that:

- The condition for such empathy is a crucial facet of the capacity for love. To understand another means to love him — not in the erotic sense but in the sense of reaching out to him and of overcoming the fear of losing oneself.
- Understanding and loving are inseparable. If they are separate, it is a cerebral process and the door to essential understanding remains closed. (Fromm, 1994, pp.192-193. Also cited in Nye, 2014, p.37).

Here, Fromm is referring to the therapist being open and available for the client in accordance with Roger's three core qualities of empathy, unconditional positive regard and congruence (Rogers, 1957; Fromm, 1994). This interpretation of 'love' seems appropriate for therapeutic work, and strongly resonates with Kitwood's use of the word (Kitwood, 1997).

1.10 Brief Description of the Study Methodology

I have used a multimethod approach to explore the lived experiences of the research participants. This has involved combining qualitative methods, namely Interpretative Phenomenological Analysis (IPA; Smith, Flowers and Larkin, 2009) and microanalysis (Trondalen, 2007), with arts-based research methods, including a visual representation of the

three superordinate themes. Later in the study, I argue that music microanalysis sits within both the qualitative paradigm and an arts-based approach (see p.48). This combination of research methods has created rich data for analysis and deep insights into the understanding of the research topic. For more detail on the study design, please see chapter four, p.64.

1.11 Thesis Structure

I have attempted to organise this thesis in as straightforward a manner as possible. Following this introductory chapter is my Literature Review, exploring existing research relevant to the topic. Chapters 3 and 4 describe my Methodology and the Methods I employed, and chapter 5 focuses on the Ethical Considerations that shaped this study.

My Findings are presented in chapters 6 to 9, with discussions woven into the presentation of findings. Chapter 10 presents a discussion on the methods employed, the limitations of the study and implications for future research and practice.

Chapter 2: Literature Review

2.1 Introduction

This chapter explores relevant literature already published in the subject area, starting from a wide perspective including related areas, then focusing in on research reporting on the effects of MT for family caregivers (caregivers) of people with dementia, including material reporting on caregivers' experiences of MT. As well as underpinning my thinking for this study, this will also identify gaps in the existing literature.

2.2 Challenges for Family Caregivers

Recent literature highlights the many challenges caregivers face in caring for someone with dementia, which can create stress in every area of life, including social, financial, emotional, physical and psychological strain (Etters, Goodall and Harrison, 2008; Newbronner *et al.,* 2013; Alzheimer's Society, 2016; Bressan, Visintini and Alvisa Palese, 2019; SCIE, 2020, Lindeza *et al.*, 2020). In a recent systematic review reporting on the impact of dementia from caregivers' perspectives, Lindeza *et al.* (2020) highlight the emotional toll, as well as the lack of personal life as the family member dedicates their time to caring for their loved one.

The ongoing changes presented as the person with dementia deteriorates can result in multiple losses, both for the person with dementia and for the caregiver. These losses are cumulative and ever-changing; as a result of cognitive decline, the person with dementia may have to give up a job or role in society, sometimes having to leave social groups or hobbies (Cheston and Bender, 2003). A partner supporting alongside may also have to relinquish these, as they commit more of their time to caring (Doka, 2010).

Blandin and Pepin acknowledge the impact these cumulative losses can have for family members, identifying a 'dementia grief' (Blandin and Pepin, 2017, p.67), where the family member is already grieving for the person and relationship they once knew, despite the person with dementia still being alive. The exploration of this particular type of grief presented in this paper has been significant in the development of my own understanding, giving insight into the depth of impact that dementia grief may have for the caregivers I work with. Blandin and Pepin also present a 'Dementia Grief Model'; an iterative process model describing how grief may be experienced and processed (Blandin and Pepin, 2017, p.72). They suggest that the grief process can be supported by 'dynamic mechanisms' for change, which include: 'acknowledging loss' and 'tolerating difficult feelings' (Blandin and Pepin, 2017, p.72). I believe that, in working with the person with dementia and caregiver together, MT provides opportunities to facilitate

these dynamic mechanisms, by providing a safe, therapeutic space for both to express their feelings, musically and verbally. Indeed, I can remember a case where, for the caregiver, this was the critical point of the therapy; to support feelings of loss and expressions of grief, anger and sadness through the music, which, over time, allowed a shift in emotional state to one of more peaceful acceptance.

Alongside ongoing dementia grief is increased social isolation and loneliness, as friends and other family members retreat from engaging as dementia progresses (Brodaty and Donkin, 2009; Carers UK, 2014; Alzheimer's Society, 2016). If the person with dementia is also physically frail, getting out into the community becomes limited and sometimes impossible, and this also impacts the caregiver's ability to connect socially with others, again increasing isolation.

All these factors are compounded if the caregiver is an older person themselves, often with their own emotional, mental and physical health issues to cope with (Cheston and Bender, 2003; Farina *et al.*, 2017). A large quantitative survey, including 195,364 informal caregivers, reported poorer health and patient experience in primary care for caregivers in comparison to non-caregivers of similar ages (Thomas *et al.,* 2015). The poorer patient experience was mostly linked to difficulties in accessing services due to the caring role.

There are positive aspects to providing care for someone with dementia, with research identifying reports of stronger relationships and enjoyment in shared activities (Lindeza *et al.*, 2020), and the caring role contributing to personal satisfaction and growth (Yu, Cheng and Wang, 2018). However, the accompanying challenges are undeniable, and caregivers of people with dementia are more likely to experience depression (Richardson *et al.*, 2013; Huang, 2022) and high levels of stress (Brodaty and Donkin, 2009 Alzheimer's Society, 2016), as well as reduced physical health (Schulz and Sherwood, 2008; Richardson *et al.*, 2013; Oliveira, Sousa and Orrell, 2019).

2.3 Music for Wellbeing

Over the last four years, the UK campaign, 'Music for Dementia', funded by the Utley Foundation, has been instrumental in raising awareness and endorsing the use of music in dementia care. Their recent report, 'The Power of Music', advocates for the use of music across the lifespan to address health and wellbeing challenges of the nation, particularly following the Coronavirus Disease 2019 pandemic (Meadows and McLennan, 2022). Following

this, Music for Dementia, UK Music and the National Academy for Social Prescribing (NASP), with the support of The Utley Foundation, The Rayne Foundation and Arts Council England, have combined forces to create a 'Power of Music' campaign. This has involved the creation of a 'Centre of Excellence' for music and dementia, which aims to further research in this area, promote and develop accessibility to musical activities and interventions for people with dementia, and to embed music into care pathways, on a national level. NASP Chief Executive describes one of the aims of the campaign:

> Through the Centre of Excellence, we aim to demonstrate how prescribing music to people living with dementia can improve quality of life, reduce isolation, and lessen the need for medication, hospital admissions and GP appointments. (Osborn-Ford, 2024)

This campaign, along with popular TV documentaries, such as 'Our Dementia Choir Sings Again' (2022), have increased public awareness of the successful use of music as a tool to support general wellbeing. Indeed, the use of music specifically to provide support for people with dementia seems present in public consciousness, and there currently feels a momentum to make appropriate music interventions, including MT, more widely accessible for people with dementia.

A recent, innovative programme, 'Dementia Enquirers', encouraged people with dementia to plan and conduct their own research studies, on topics that were chosen by themselves (Innovations in Dementia, 2023). In 2022, a group of four people with dementia planned and conducted a study examining the effects of making music on wellbeing and cognition (Ashford Phoenix, 2022). The researchers were supported by a small team of professionals, including a community support worker, clinical psychologist and psychology student. The research team were also the participants, who took part in 12 sessions of music-making together, facilitated by a local community musician. The intervention included learning a new instrument, the ukelele, and creating a new piece of music.

The participants' wellbeing and cognition were measured before and after sessions using the Brief Mood Introspection Scale (Mayer and Gaschke, 1988). Questionnaires, focus group sessions and one-to-one interviews provided additional data. Results showed that the music sessions had a positive effect on the participants' mood, but no impact on levels of cognition. In addition, the qualitative data suggested that the music sessions provided a new focus for participants, and a chance to engage in something together. Participants also commented that the success they experienced in learning a new instrument and creating a new piece of music

had the potential to challenge any existing stigma other people may have around people with dementia not being able to learn new skills or achieve new goals (Ashford Phoenix, 2022).

This interesting piece of research, planned and conducted by people with dementia, adds to the growing evidence base that music-making can support wellbeing in this context. It also strongly represents the voice of people with dementia in this evidence base.

2.4 Music Therapy for People with Dementia

A growing body of research suggests that MT is an effective intervention to support wellbeing for people living with dementia, including improvements in mood and communication, and a reduction in anxiety and agitation (McDermott *et al.*, 2012; Ridder *et al.*, 2013; Hsu *et al.*, 2015). For a person with dementia, the ability to engage with music is preserved longer than verbal communication (Baird and Samson, 2015) and music connects with emotional memories and life history, which can strengthen a sense of self, as well as stimulate interaction and self-expression (Jäncke, 2008; McDermott, Orrell and Ridder, 2014). A recent systematic review found that MT can also positively affect cognitive function, with additional improvements suggested regarding quality of life and depression (Moreno-Morales *et al.*, 2020).

The growing awareness that music is a valuable tool is reflected in the dementia UK NICE guidelines, which suggest MT as an intervention to support quality of life (NICE, 2019). A report from the International Longevity Centre details evidence of how music interventions, including MT, can support people with dementia across the progression of the diseases, and calls for appropriate music interventions to be embedded in dementia care pathways (Bamford and Bowell, 2018). There is also a call for more research in this area, to establish models of best practice (Bamford and Bowell, 2018; Odell-Miller, 2021).

For caregivers, MT has the potential to support in similar ways, encouraging self-expression and a focus on the individual, which often seems lost in the role of caring (Oliveira, Sousa and Aubeeluck, 2018). As MT is an existing intervention already being used to support people with dementia, it seems logical to explore its potential to improve the wellbeing of those caring alongside. Establishing an evidence base is important for the MT profession, from which services and further research can develop. Despite this, there is a relative paucity of research regarding the effects or experiences of MT for the people caring for, and often participating with, the person with dementia.

2.5 Music Therapy including Professional Carers

There are a few research studies and articles that comment on the effects of MT for professional carers or assistants, when they have been present in MT with the person they are caring for. Hsu *et al.* (2015) and Melhuish, Beuzeboc and Guzman (2017) report benefits for staff in care homes; both studies used MT as an opportunity to share skills with staff which resulted in increased insight into residents' circumstances and abilities, learning new ways of communicating and enhancing positive relationships between staff and residents (Hsu *et al*., 2015; Melhuish, Beuzeboc and Guzman 2017).

Research in this area developed further with the publication of the book, 'Collaboration and Assistance in Music Therapy Practice', which presents case study examples in different settings where an assistant attends alongside the client, in order to support the therapy process (Strange, Odell-Miller and Richards, 2017). Within this book, Agrotu (2017), in her work with women with severe learning difficulties, describes how professional caregivers not only aided the therapy process by facilitation, but also learned from it themselves, becoming more aware of how to engage therapeutically with their clients, and developing deeper bonds, which further supported their clients outside therapy sessions.

Also presented in this book, Odell-Miller (2017) describes the collaborative presence of assistants in MT providing 'a link between the inner and outer lives' of participants, suggesting this can aid facilitation of the therapy process, but also potentially influence relationships both within and outside therapy sessions (Odell-Miller, 2017, p.97). This is also reflected in moving clinical vignettes from Freeman (2017), who describes how working with family members can enhance the therapeutic process and optimise effectiveness of the work. Sharing someone's life story, past experiences and preferences can help the therapist to understand the person with dementia on a deeper level, but also strengthens the sense of connection for the family member.

2.6 Music for Family Caregivers of People with Dementia

The last five years have seen a stronger focus on this emerging area of research, resulting in two important reviews that have examined the effects of music interventions for caregivers of people living with dementia.

2.6.1 An Integrative Review - Lee *et al.* (2022)

Lee *et al.,* (2022) performed an integrative review, identifying 33 studies reporting on the effects of music interventions on the health and wellbeing of family caregivers (caregivers) of people with dementia. Not all of these studies involved MT, with other music interventions, such as community choirs and group singing, also included. 11 studies were described as MT, but a further five were 'therapeutic songwriting', facilitated by Music Therapists, therefore, 16 studies included in the review relate to MT practices.

The study designs, outcome measures employed, and quality of the included studies varied greatly, and no study was excluded due to poor quality. However, the authors acknowledge the heterogeneity and variable study quality, and take this into consideration when presenting their results. It is interesting to note that the 17 quantitative studies included in the review employed 50 different outcome measures, making a meta-analysis impossible to perform. The authors report that significant results were only found in 13 of the 50 different measures, with some of these on a sub-scale level, therefore the quantitative evidence found in this review is negligible. The authors call for more quantitative studies, with larger sample sizes and more robust study design for future research in this area.

In the qualitative and mixed-methods studies, the review findings suggest that music interventions may improve the quality of life for caregivers of people with dementia, specifically strengthening emotional wellbeing, reducing social isolation, improving the quality of relationship between the caregiver and person with dementia, and, for the caregiver, improving feelings of being able to cope (Lee *et al.,* 2022).

Most of the interventions described in this review took place within community settings, with only eight of the 33 studies including interventions that took place in participants' own homes. Community-based studies sometimes only involved the caregiver, giving them the opportunity to come together with others in similar caring roles, and away from the pressures of their own caring situation. In these studies, there were reports of increased social connection and an appreciation of being able to share experiences with others (Baker and Yeates, 2018; Clark, Tamplin and Baker, 2018).

There were also community-based studies that included interventions designed to engage both caregiver and person with dementia; for example, a 'Singing Together Group' (Camic, Williams and Meeten, 2013), and joint songwriting sessions (Clark *et al.,* 2020). Although every progression of dementia is experienced differently, it is feasible to suggest that the people

with dementia involved in these community-based interventions may have been in earlier or middle stages of their disease; being both mobile and comfortable enough to leave the home and participate in music-making in a group with other people. This perhaps makes these studies less informative for this present study, which is concerned with the experiences of caregivers of people with advanced/complex dementia and based in participants' own homes.

All eight studies that took place in participants' homes were facilitated by Music Therapists. Three of these focused solely on training caregivers to use musical strategies to support their relationship (Clair, 2002; Hanser et al, 2011; Baker, Grocke and Pachana, 2012); and a further two included skill-sharing within a MT intervention (Melhuish, Grady and Holland, 2019; Dassa, Rosenbach and Gilboa, 2020). There is recognition of how beneficial it might be if, once the input from a trained therapist has come to an end, the caregiver and person with dementia can continue to engage in musical activities and strategies together. I will return to this aspect of skill-sharing in MT later in the chapter (see p.43).

These eight home-based MT interventions, that included the person with dementia and caregiver together, reported a range of benefits, including improvements in mood, enjoyment and happiness (Hanser *et al.,* 2011; Baker, Grocke and Pachana, 2012), increased feelings of being able to cope (Dassa, Rosenbach and Gilboa, 2020), and lower stress levels for caregivers (Melhuish, Grady and Holland, 2019). The MT also helped to strengthen relationships, specifically providing meaningful time together (Clair, 2002; Dassa, Rosenbach and Gilboa, 2020), feelings of connection with each other (Melhuish, Grady and Holland, 2019) and experiencing a closeness and emotional reciprocity (Macgregor, 2016).

Three studies reported some negative findings (Davidson and Almeida, 2014; Holden *et al.*, 2019; Garabedian and Kelly, 2020). Interestingly, the quantitative study by Holden *et al.* (2019) is represented in the review's table of included studies, but not mentioned in the review paper itself. Holden *et al.* (2019) employed Neurologic Music Therapy (NMT) in the home for people with dementia and their caregivers. NMT involves the use of 'standardised clinical techniques supported by scientific evidence' that are applied in certain clinical situations to achieve specific goals (Thaut, McIntosh and Hoemberg, 2014, p.2). In this study, techniques such as *Musical Sensory Orientation Training* were employed. The authors describe this as: 'the presentation of music to stimulate arousal and facilitate meaningful responsiveness and orientation to time, place, and person.' (Holden *et al.,* 2019 p.268). This study experienced a high drop-out rate; from 18 caregiver and cared-for dyads, seven dyads dropped out. In three of these cases the person with dementia moved into a nursing home or was hospitalised; three

cases dropped out due to distress caused by the MT sessions; a further dyad left the study because they could not find time for the intervention. In addition to this, two dyads' data was lost to follow-up.

The fact that three dyads dropped out due to increased stress from the intervention is perhaps concerning, but highlights the complexity of delivering an intervention for people with advanced dementia and their caregivers in their own home. No statistically significant results were found in any of the quantitative measures, which included the Zarit Burden Interview (Zarit, Reever and Bach-Peterson, 1980) measuring caregiver burden, and the Revised Scale for Caregiving Self-Efficacy (Steffen *et al.*, 2002). Although not to a statistically significant amount, some of the Neuropsychiatric Inventory (NPI; Cummings, 1994) scores improved for the participants with dementia, indicating that the NMT alleviated some symptoms, such as anxiety, agitation and delusion (Holden *et al.*, 2019). The authors comment that the high drop-out rate and lack of statistically significant results could be due to the advanced nature and complexity of dementia symptoms:

> Our consensus was that it could be too stressful to add a new therapeutic intervention into the home for people with more advanced dementia, many of whom were nearing the time when nursing home placement was necessary based on their care needs and caregiver burden. (Holden *et al.,* 2019).

Two further studies in the review reported mixed findings. Amongst positive benefits for wellbeing, both Davidson and Almeida (2014), and Garabedian and Kelly (2020), reported incidences where caregivers' mood was not improved by the music intervention. Garabedian and Kelly continue to explain that some caregivers felt increased tension 'due to feeling compelled to focus on their care recipients' responses throughout the music intervention' (as summarised by Lee *et al.,* 2022, p.54).

Within the many benefits reported across the 33 studies in the review, these negative findings are important to consider. The suggestion from Holden *et al.* (2019), that MT in the home for people with advanced dementia might be too stressful is significant, and I cannot find a reason why it is not commented on in the review paper. This finding is perhaps echoed by the tension experienced by caregivers in relation to the music intervention delivered in the study by Garabedian and Kelly (2020). These are helpful findings to be aware of in relation to this study, which is also home-based.

Overall, this review suggests a range of benefits for caregivers of people with dementia when they engage in music interventions. The fact that some of the studies did not employ MT, included interventions for caregivers only, and most were community-based, makes the findings less applicable to the study for this thesis. Despite this, and the high degree of heterogeneity in study design, outcome measures, study quality and intervention methods, these are interesting results suggesting that music interventions may be supportive and beneficial for caregivers of people with dementia.

2.6.2 A Qualitative Review - McMahon *et al.* (2022)

McMahon *et al*. (2022)'s qualitative review only included studies in which the family caregiver (caregiver) and person with dementia experienced interventions together, as a dyad. This review found that shared music experiences fostered connections between dyads, between groups, and into the wider community (McMahon *et al*., 2022). The specific use of music, including the inclusive use of singing, along with the relational skills of facilitators, were key factors in enabling inclusion (McMahon *et al*., 2022).

Many of the reported outcomes focused on the people with dementia, but there were some significant findings for caregivers. Shared musical engagement provided new ways of engaging and facilitated moments of closeness (Macgregor, 2016; Osman, Tischler and Schneider, 2016; Clark, Tamplin and Baker, 2018; Dowlen, 2018; Lee, O'Neill and Moss 2020). In a moving example, the music supported a strengthened sense of self, with reports that the person with dementia was able to 'assume their role' as partner or spouse, perhaps reconnecting the original couple relationship (Dowlen, 2018). Caregivers also reported positive feelings in 'witnessing' their partner's 'enjoyment and strengths' in the music (McMahon *et al*., 2022).

This review is not limited to MT, but includes a range of music interventions. The majority of studies included are community-based, with only two studies reporting on couples engaging in shared music in their own homes. One of these comments on musical activities, and not MT (Elliot *et al.*, 2020) and the other on 'indirect Music Therapy'; this is not explained further, and on searching for the original paper, I cannot find it in full text (Macgregor, 2016). One of the recommendations from the review is that further research into dyads' experiences of home-based music is needed to deepen understanding of the potential of music to support wellbeing and relationships in this context. This directly relates to the study presented in this thesis.

2.7 Music Therapy for Family Caregivers of People with Dementia

Systematic Literature Review and Additional Searches

In preparation for the study presented in this thesis, I undertook a Systematic Literature Review (SLR) to identify the evidence to date. This was completed in 2021, and titled: 'What is the evidence of effectiveness of Music Therapy for improving wellbeing for carers of people with dementia?' (Grady, Hayton and Meyrick, 2021, see Appendix 2, p.243). Since then, I have undertaken further literature searches, to ensure I have identified all relevant current research. The date range of recent searches was widened to include papers up to July 2024, and I also employed broader search terms, to include studies reporting on the **experiences** of caregivers, as well as those reporting on wellbeing.

Together, my SLR and more recent searches identified 23 papers for this literature review. I assessed the scientific quality of the studies using The Effective Public Health Practice Project Quality Assessment Tool for Quantitative studies (Effective Public Health Practice Project, 2009) and the Critical Appraisal Skills Programme assessment tool for qualitative studies (CASP, 2021). For studies employing mixed methods, the quantitative and qualitative data were assessed separately, using the appropriate tool noted above. There was variation in scientific quality, with most ratings from 'weak' to 'moderate'. Some of the more recent studies reported more information and were generally of a higher quality, therefore rated as 'strong'. Ten of the included studies were feasibility/pilot studies, and the quantitative studies mostly had relatively small sample sizes.

Due to the high degree of heterogeneity in study design and the varied quality of the research, the strength of evidence presented in this literature review is moderate, therefore any findings will only be considered a suggestion.

Some of the papers I identified are included in the reviews above (Lee *et al.,* 2022; McMahon *et al.,* 2022) and have already been commented on. I present a summary of the remaining findings from my SLR and recent searches here, categorised into different intervention methods.

2.7.1 Music Therapy for the Family Caregiver on their own

Six studies report on research where the intervention was for the caregiver alone (Klein and Silverman, 2012; Baker *et al.,* 2018; Baker and Yeates, 2018; García-Valverde *et al.*, 2020; García-Valverde, Marta Badia and Begoña Orgaz, 2022; Clark *et al,* 2023). Five of these studies

took place in community settings, with one study not specifying a setting (Clark *et al.,* 2023). Having 'time for themselves' and 'care for themselves' have been identified as factors that may contribute to increased wellbeing for caregivers (Oliveira, Sousa and Aubeeluck, 2018, p.5; Daley *et al.*, 2019, respectively), therefore interventions solely for caregivers have potential to support improved feelings of wellbeing.

The five studies that took place in the community for caregivers alone all employed therapeutic songwriting in MT. This is a well-established practice (Aasgaard and Blichfeldt-Ærø, 2016) but methods may vary from one therapist to another. Three of the included studies refer to underlying theory, citing Baker (2015) as a model and rationale for the intervention (Baker *et al.,* 2018; García-Valverde *et al.*, 2020; García-Valverde, Marta Badia and Begoña Orgaz, 2022). A fourth study is co-written by Baker herself (Baker and Yeates, 2018) and so is likely to follow a similar delivery pattern. Certainly, in the descriptions of these interventions, each employed a time of getting to know people and building trust, listening to personal stories, moving onto lyric and music creation and then a final element of recording the songs created (Baker *et al.*, 2018; Baker and Yeates, 2018; García-Valverde *et al.*, 2020; García-Valverde, Marta Badia and Begoña Orgaz 2022).

Baker and Yeates (2018) found that group songwriting enabled caregivers to explore their changing identities, as the spouses and adult children participating moved into caring roles for their family members. Caregivers were also able to express a range of feelings associated with being a caregiver. Sharing stories and being heard by others who understood, gave feelings of being listened to with empathy and understanding. This was viewed as important, and in contrast to more general experiences: 'Say what you like, they're not going to judge you, you can share what you probably wouldn't say to anyone else' (participant, Baker and Yeates, 2018, p.14).

Interestingly, caregivers found the process of song creation just as valuable as the song product itself, appreciating the opportunities of creative collaboration with others who had shared or similar experiences:

> It probably unloads…all the emotional feelings that you do hang on to that you don't even realise are there, sometimes it helps to get them out…it was good and it was cathartic. (participant in Baker and Yeates, 2018, p.13).

Songwriting encouraged people to express freely, and lyric creation was identified as a mechanism that aided this process:

> At the wrong or right time, the words only can make you cry, without you wanting to and other times it just makes you smile inside because you're doing it and yeah it's a good result (participant in Baker and Yeates, 2018, p.13).

In a pilot study, Baker *et al*. (2018) echo many of these findings, with caregivers appreciating time to share their journeys with others in similar predicaments, which enabled deeper sharing than in other social situations:

> Your friends drop off somewhat...I felt terribly, terribly alone at the early part . . . I've only got two friends that will listen to me occasionally when I'm down. But generally, people don't want to know when you're down, right? Well, with the other caregivers, you're not so intimidated or shy or whatever you want to call it. You know they've got problems too and everybody talks about their problems. And so, you know, you don't feel so alone then (participant in Baker *et al,.*2018, p.7).

García-Valverde *et al.* (2020) employed songwriting in MT for caregivers who attended a community setting without the person they were caring for. This pilot study included a relatively large sample group of 21 participants, with statistically significant findings reported in the areas of improvements for self-esteem, anxiety and depression for caregivers following the intervention (García-Valverde *et al.*, 2020). In a follow-up study using a similar intervention for caregivers, García-Valverde, Marta Badia and Begoña Orgaz (2022) report that the participants felt increased feelings of relaxation, improved mood and greater optimism. This qualitative study also identified that the caregivers found the songwriting intervention allowed them more freedom of emotional expression, and helped them become more self-aware (García-Valverde, Marta Badia and Begoña Orgaz*,* 2022).

Klein and Silverman (2012) undertook a pilot study involving community-based songwriting in MT for caregivers. This involved 14 caregivers participating in a discussion on stress and coping skills, followed by a single MT session focused on songwriting. Participants appreciated peer support and found a togetherness in the songwriting intervention (Klein and Silverman, 2012). The experience was also described as 'fun' and a distraction from stress felt from the caring role (Klein and Silverman, 2012).

The sixth and final study for caregivers alone was a feasibility study, examining a Guided Imagery in MT protocol (Clark *et al,* 2023). The authors employed the 'Bonny Method of Guided Imagery and Music' (BMGIM), describing this as:

> a specialised form of psychotherapy where clients are able to deeply explore their inner experiences, imagery and emotions with a therapist while listening to carefully selected music in an altered state of consciousness (Clark *et al,* 2023, p.222, citing Abbott, 2019; Ventre, 2002).

Seven caregivers completed a course of six BMGIM sessions. The authors report improvements with small to moderate effect sizes for the Patient Health Questionnaire (PHQ-9; Kroenke, Spitzer and Williams 2001), and the Assessment of Quality of Life – 6 Dimension (AQoL-6D; Richardson *et al.,* 2012). Qualitative findings suggest that the BMGIM protocol was experienced as: 'something different that might help; an empathic space with aptly selected music; insightful and transformative, and psycho-educative' (Clark *et al,* 2023, p.220). The authors suggest a further feasibility study with 10 BMGIM sessions and different outcome measures, and following this a randomised controlled trial. This initial study provides some insight into caregivers' experiences of BMGIM, and suggests it may be a helpful intervention to support wellbeing.

Section Summary

From these six studies, it is clear that MT interventions for caregivers alone have the potential to support feelings of wellbeing and social connection. Within this, benefits that participants particularly appreciated included peer support, collaborative creative experiences, a distraction from the stress of the caring role, and feelings of increased happiness and relaxation.

Four of six of the studies are feasibility or pilot studies, indicating an initial exploratory approach to this area of research. Study quality also varied, with some studies being vulnerable to performance bias (Boland, Cherry and Dickson, 2017), as the Music Therapists providing the intervention were also conducting the interviews or collecting data. Nevertheless, these are promising findings, suggesting that songwriting in MT may be a supportive intervention for caregivers.

2.7.2 Community-based Music Therapy for the Person with Dementia and Family Caregiver Together

Seven studies commented on MT interventions where the person with dementia and caregiver attended together, in a community setting (Brotons and Marti, 2003; Allan, 2018; Rio, 2018; Tamplin *et al.,* 2018 / Clark, Tamplin and Baker, 2018; Lee, O'Neill and Moss, 2020; Clark *et al.,* 2020 / Clark *et al.,* 2021; Molyneux, 2024). Four of these studies are presented as partner papers, where two papers report on the same study (Tamplin *et al.,* 2018 / Clark, Tamplin and Baker, 2018; Clark *et al.,* 2020 / Clark *et al.,* 2021). Once again, most are initial exploratory studies, with four being either feasibility or pilot studies.

Building on the research concerning songwriting in the last section, partner papers Clark *et al.,* 2020 and Clark *et al.,* 2021, employed a MT intervention using group therapeutic songwriting for both person with dementia and caregiver together. Despite qualitative results commenting that the intervention was a positive experience, there were no statistically significant quantitative results. This included outcomes that measured depression (PHQ-9; Kroenke, Spitzer and Williams 2001), quality of life (Assessment of Quality of Life–8 Dimensions; Maxwell *et al*., 2016) and caregiver burden (Zarit Burden Interview; Zarit, Reever and Bach-Peterson, 1980). The lack of statistically significant results could be due to the short intervention period, which was just six sessions. The authors report that, in some areas, scores were high at baseline and maintained at post evaluation.

Qualitative results indicate that the couples appreciated being able to attend together, and to share in a new, creative experience. The couples attending seemed to have a close relationship from the start, and the songwriting intervention supported this:

> We don't normally do that [laughing]. We don't normally sing together, do we? ...So yeah, it was completely [different]...[but] over the years, we've done lots of things together, so being together is quite natural. (Participant in Clark *et al.,* 2020, p.8).

The participants commented that the skills of the therapist facilitated the songwriting so that everyone could participate:

> [The Music Therapist] made it a lot easier, you know, by prompting us and coming up with thoughts and things for us to start us off...It made a big difference (participant in Clark *et al.,* 2020, p.9).
>
> Having the slower songs made it so much easier...Mum's got to read it and process it ... [so the] slower song just made it so much easier for them to be able to sing (participant in Clark *et al.,* 2020, p.9).

Brotons and Marti (2003) employed group MT for the participants with dementia and caregivers. They describe their intervention as including: 'music listening, singing, playing, and movement/dance' (Brotons and Marti, 2003, p.143). The authors report no statistically significant results for the Zarit Caregiver Burden questionnaire (Zarit, Reever and Bach-Peterson, 1980), indicating that there were no significant changes in feelings of caregiver burden following the intervention. However, there were statistically significant improvements in the domain of anxiety for the participants with dementia. The authors also suggest a parallel reduction in 'behaviour problems' for the person with dementia and anxiety levels for the caregiver (Brotons and Marti, 2003, p.147).

Unique aspects of this pilot project mean that results are not generally transferrable. Eleven couples (caregiver-cared for dyads) moved into a residential house together for twelve days, where they participated in the MT intervention, along with other singalong sessions, and had professional nurses assisting with care and staff organising activities throughout the duration of their stay. Therefore, the outcomes could have been down to the additional care and activities rather than the MT itself.

Rio (2018) evaluated a community MT support group, using singing, playing and physical movement within MT to support people with dementia and their caregivers. The intervention was evaluated using the therapist's observations and self-reporting from the caregivers. The author reports that the group facilitated closer social connection and that the participants benefitted from emotional and practical support from each other (Rio 2018). Participants also experienced strengthened relationships within their dyads, and increased feelings of happiness (Rio, 2018).

These findings are supported by Allan (2018), who ran a pilot project using group MT in a community setting for people with dementia and their caregivers. This was a smaller study, with four dyads attending the MT intervention, and one of these dropping out after five sessions of MT. The author used his own clinical notes to inform findings, as well as pre- and post-questionnaires that were designed by himself and not validated. Since this is a small study using questionnaires designed by the Music Therapist himself, the findings are limited in scientific quality, however they do suggest that participants felt emotionally connected and benefitted from peer support (Allan, 2018).

In a study using group singing in MT, Lee, O'Neill and Moss (2020) report that the intervention supported the caregiver-cared for relationship, and that caregivers found it was an enjoyable

and meaningful way of spending time with their partner. This qualitative study gives findings from four caregivers' experiences and highlights the enjoyment of finding social connection through singing together.

The use of music was described as inclusive and enabled everyone to take part, sometimes providing reassurance and comfort for the person with dementia:

> She's very cautious about getting involved socially…I think this helped to settle her, just kind of watching other people just letting themselves go a bit you know? …I felt that she was enjoying other people doing what they were doing. (Participant in Lee, O'Neill and Moss, 2020, p.7).
>
> We were all doing one thing whether we were good or bad at it (participant in Lee, O'Neill and Moss, 2020, p.7)

Music and singing in particular enabled people to forget their worries for a while and allowed participants to express more freely; 'to lose their inhibitions and have fun' (Lee, O'Neill and Moss, 2020, p.7).

In a larger study, twelve caregiver-cared for dyads attended 20 one-hour long sessions of group singing. Clark, Tamplin and Baker (2018) again comment on an element of fun, with one participant commenting: 'Singing is a good thing to do. And we are having fun – it is a lot of fun… You can completely switch off from everything else' (participant in Clark, Tamplin and Baker, 2018, p.8). Participants also appreciated feelings of social connection and supportive peer relationships:

> I think it's quite tremendous how that group has really bonded as a group. And that was brought on so very strongly for me when PwD12 was sick for that month – how everyone was just so supportive of me, which I found was absolutely fantastic. That was very beneficial for me (participant in Clark, Tamplin and Baker, 2018, p.7).

The partner paper for this study (Tamplin *et al.,* 2018) reports no statistically significant findings in any of the quantitative measures employed, but suggest this may have been due to high wellbeing and low depression scores at baseline. This was a feasibility study, and the authors argue that they were trying to establish whether this group singing intervention could work for people with dementia and their caregivers, rather than conduct a full evaluation of the intervention (Tamplin *et al.,* 2018).

Interestingly, this study also employed the use of home-based resources for participants to engage with outside therapy sessions (Tamplin *et al., 2018* / Clark, Tamplin and Baker, 2018). This involved creating personalised playlists for couples, with the specific aim to aid 'reminiscence', 'relaxation' and 'agitation reduction/calming down' (Tamplin *et al*., 2018, p.3).

A recent PhD thesis by Music Therapist, Claire Molyneux, provides an in-depth narrative study of 'Together in Sound'; an ongoing, weekly MT group held in Saffron Hall in Essex, facilitated by Music Therapists and professional musicians, for people living with dementia and their friends and family (Molyneux, 2024). Molyneux presents moving vignettes of participants' experiences, in both narrative and arts-based forms, including stories, poems, images and films. Both attending 'Together in Sound' sessions and taking part in the research itself allowed participants opportunities for expressions of individual identity, and the telling of their stories and experiences. It is difficult to summarise the findings from this comprehensive study which brings together many different creative outcomes, but the sense of emotional connection with others facilitated by the intervention seems strong throughout the research. Molyneux highlights the feelings of 'belonging and togetherness' experienced by the participants, and summarises that the group intervention enabled: 'enduring and meaningful engagement with others, creating possibilities to talk about dementia more openly and, for some, an increased use of music in everyday life' (Molyneux, 2024, p.194).

Section Summary

The findings from these seven community-based studies indicate that MT interventions that include the caregiver alongside the person with dementia may be beneficial, particularly in increasing feelings of meaningful social connection, receiving emotional and practical support from peers, strengthening the emotional connection between the person with dementia and caregiver, and increasing feelings of wellbeing, including a sense of fun.

However, this still feels like a developing area of research, with four studies being pilot or feasibility studies, and earlier studies being weak in quality due to vulnerability to performance bias, as the Music Therapists providing the intervention also conducted the interviews. Conversely, there is some stronger qualitative evidence presented in more recent studies, suggesting that group MT including both the person with dementia and caregiver can elicit deep emotional connections and support wellbeing (Lee, O'Neill and Moss, 2020; Molyneux, 2024).

These are helpful findings to bear in mind, however, there are perhaps limitations to their relevance to the study presented in this thesis. The seven studies mentioned here involve people with dementia coming out into the community and into a group context to engage in MT. As mentioned earlier (p.29), although this may be possible for some people with advanced dementia, for others it may be preclusive due to their circumstances. This suggestion is based on my clinical experience; most of the people we work with as part of Mindsong's MT@H service find it difficult to attend community groups, either due to advanced frailty or mobility difficulties, or that coming into a new and different environment and connecting or even tolerating a larger group of people may feel confusing, or frightening. However, this is my own preconception, and it may be that this would be incorrect for the participants involved in the studies mentioned in this section.

2.7.3 Home-based Music Therapy for the Person with Dementia and Family Caregiver Together

Of the 23 identified studies, six employed MT as an intervention for both the person with dementia and caregiver to share in together, in their own homes (Macgregor, 2016; Raglio *et al.,* 2016; Holden *et al.,* 2019; Melhuish, Grady and Holland, 2019; Dassa, Rosenbach and Gilboa, 2020; Rosenbach, Dassa and Gilboa, 2023). Four of these studies also included elements of skill-sharing (Holden *et al.,* 2019; Melhuish, Grady and Holland, 2019; Dassa, Rosenbach and Gilboa, 2020; Rosenbach, Dassa and Gilboa, 2023).

A further four studies focused only on skill-sharing facilitated by a Music Therapist, without employing MT itself as an intervention (Clair, 2002; Hanser *et al*., 2011; Baker, Grocke and Pachana, 2012; Baker *et al.*, 2023 / McMahon *et al.*, 2023). I will return to these studies later in this chapter (see p.43).

I was not able to find the full paper for Macgregor (2016), but findings from this study have been included in the presentation of the two reviews above (see p.29). I have also already discussed the study from Holden *et al.* (2019) in some detail (see p.29), so will not repeat these findings in this section.

Raglio *et al.* (2016) employed a MT intervention for four cared-for and caregiver dyads. Sessions were given twice a week for six weeks and improvements for caregivers were found at a significant level in the tools measuring anxiety and caregiver burden. However, only the mean scores are given and there is no calculation of effect size, level of significance, or confidence intervals, making the results less reliable. One outcome measure is named as 'The

Burden Interview' with no referencing, so it is unclear which tool this is and whether it is a validated measure. Sample size was also small for a quantitative study (four dyads), and there was much missing information in the report, lowering the reliability of the study's findings. This study, however, indicates that MT in the home alongside the person with dementia may help to decrease feelings of anxiety and burden for caregivers.

Melhuish, Grady and Holland (2019) comment on Mindsong's MT@H service; the same intervention used for the study in this thesis. This intervention employed 12 weekly sessions of MT, with elements of skill-sharing, to encourage the dyad to use music beyond the therapy sessions themselves. This study reports on seven couples that completed the intervention, with focused case studies provided for two of the couples. Mindsong's own assessment tool was used to measure changes in wellbeing, engagement and relationships for the person with dementia. Improved scores in all three areas were noted at post assessment, however, these tools have not gone through a process of formal validation, therefore these quantitative results are negligible in terms of strength of evidence.

There were significant improvements for three of the caregivers in relation to the Mental Health Foundation's Carer Checklist (Mental Health Foundation, 1998), with decreased scores in caregivers' perceived levels of stress or burden at post assessment. Conversely, stress was higher at post intervention for two caregivers and remained unchanged for another two caregivers. The authors note that this reflected the caregivers' increased self-awareness that developed during the course of the therapy, and actually prompted positive action in terms of accessing further support:

> For the carers themselves this indicated an increased awareness of the impact of caring for their relative and prompted them to attend to their own needs as well as their caring responsibilities (Melhuish, Grady and Holland, 2019, p.24).

Qualitative comments from participants indicated benefits in terms of wellbeing for the person with dementia: 'He was so alive'. Other benefits included increased levels of engagement and strengthened relationships: 'Obviously lifted, engaging'; 'Singing has given meaning to his visits'; 'My son and grandchildren joined in – my son couldn't believe it' (participants in Melhuish, Grady and Holland, 2019, p.24). Caregivers also commented on their feelings of increased resilience: 'I was in a very different place last time. I'm in control again' (participant in Melhuish, Grady and Holland, 2019, p.24).

Dassa, Rosenbach and Gilboa (2020) ran a pilot study with two couples, where one person had dementia. The couples engaged in 12 MT sessions, which included singing, playing, listening to music and dancing together. As well as MT, the couples were encouraged to use music together beyond session times, and the caregivers were given six counselling phone calls to aid this process. The authors state that the phone calls also gave emotional support for the caregivers. The intervention helped the couples to reconnect and 'revive forgotten roles' (Dassa, Rosenbach and Gilboa, 2020, p.5) bringing to the fore elements of individual identity that also reinforced existing relationships. Sharing in music together brought back memories and allowed times of quality connection, again strengthening individual and relationship identity. Both couples increased their use of music outside session times, with one couple using music as a daily shared activity. The authors comment that the follow-up counselling phone calls were key to the success of the ongoing use of music.

The authors build on the findings of this pilot study with another, using a similar intervention but this time with five couples (Rosenbach, Dassa and Gilboa, 2023). In this study, the couples engaged in ten MT sessions with five phone counselling sessions. This was extended with a further 12-week support period, which included three extra MT and phone counselling sessions. Once again, the authors found that the MT strengthened couples' relationships, creating a 'shared experience, and a break from the caregiver-care recipient roles that had been created as a result of the dementia' (Rosenbach, Dassa and Gilboa, 2023, p.3). The caregivers appreciated having phone call support and were able to share challenges and difficult feelings in this way.

The authors comment that the successful implementation of ongoing music beyond session times was due to the input from the Music Therapist, both within the MT sessions and in the follow-up phone call support. Another key element suggested by the authors was that the person with dementia and caregiver were addressed together, as a unit, rather than focusing on one or the other in the dyad. This approach is mirrored in Mindsong's MT@H service, the intervention employed for this current study, and it will be interesting to see if this element of approach is significant in the findings of the study.

Section Summary

In these studies, home-based MT for the person with dementia and caregiver alongside improved feelings of wellbeing for both, including a reduction in feelings of stress and increased feelings of resilience for the caregiver. The interventions provided opportunities for meaningful connection between the couples and a strengthened sense of identity, both on an

individual and relationship basis. Once again, this feels like an emerging area of research, with only six studies reporting on MT in this particular setting, and with some of those studies including very small numbers of participants, even for qualitative studies. More research in this area is clearly needed to strengthen the evidence of MT as an intervention to support in this context. It would also be interesting to discover **how** and **why** MT interventions in this setting might be successful at supporting both the person with dementia and caregiver.

2.7.4 Skill-sharing in Music Therapy

In addition to the four studies already mentioned above, the element of skill-sharing is the sole focus of a further four studies (Clair, 2002; Hanser *et al*., 2011; Baker, Grocke and Pachana, 2012; Baker *et al.*, 2023 / McMahon *et al.*, 2023). The prevalence of skill-sharing in home-based MT studies suggests an understanding from the Music Therapists facilitating these interventions of the importance of sustained engagement with music; that the benefits of sharing music together can continue beyond the duration of the MT intervention itself, and that Music Therapists can share some of their skills in order to enable caregivers and people with dementia to engage in music making together. In a reflection paper, McDermott *et al.* (2018) identify different studies that have involved Music Therapists sharing their skills to enable others to facilitate appropriate musical engagement. This includes therapists working with professional carers, family caregivers, social workers and health professionals. Key elements identified as important to the success of skill-sharing included the therapist's input on when to encourage skill-sharing, supporting the transition from MT to caregiver-delivered music-making, and considering the risks in encouraging continued use of music-making (McDermott *et al.,* 2018).

Clair (2002) reports on a study that included eight cared-for and caregiver dyads, taking place either in a residential home or in the participants' private homes. Each dyad engaged in eight 40-minute sessions, working with a Music Therapist to identify and develop a personalised musical activity that the couple would continue to engage in, outside of therapy session times. The musical activities were chosen by the participants and the therapist, and included singing and dancing together. The caregivers successfully facilitated musical activities with the person they were caring for without the therapist present (Clair 2002). It is interesting to note that in this study, it is the input of the Music Therapist, supporting the creation and development of the musical activity for each couple, and time spent with the couple to encourage and train the caregiver to facilitate the activity, that seems to have made this intervention successful.

Hanser *et al.* (2011) employed a mixed-methods study examining whether caregiver directed musical activity could improve feelings of distress for both in the couple, whilst also improving feelings of caregiver satisfaction. Eight couples engaged in the intervention, and the authors report that caregivers experienced increased feelings of comfort, happiness and relaxation, to a statistically significant degree. The caregivers also stated that they enjoyed participating in the music with their partner, and found leading the musical activities challenging, but successful (Hanser *et al.,* 2011).

Similarly, Baker, Grocke and Pachana (2012) describe a study involving five couples in their own homes where a Music Therapist supported family caregiver-directed musical engagement. Again, this was a successful intervention which brought improvements in mood for both, reduced stress, and strengthened relationships between the dyad due to shared quality time (Baker, Grocke and Pachana, 2012). There were no statistically significant changes in quantitative results and the authors put this down to a small sample size, and low scores of anxiety and depression at baseline, accompanied with high quality of relationship between the couples.

There is a growing awareness of the benefits of skill-sharing in MT, and particularly in supporting caregivers of people with dementia to use appropriate musical activities to support daily care, wellbeing and relationships at home. Reflecting this, a major international study has taken place, where caregivers of people with dementia were trained by Music Therapists to facilitate musical activities at home with the person they were caring for, to see if this would support quality of life. Homeside (Baker *et al.*, 2023) recruited 432 cared-for and caregiver dyads from five countries (UK, Norway, Australia, Poland and Germany). This was a randomised controlled trial, with the dyads randomly allocated to three separate intervention groups: standard care, a reading group, and a caregiver-delivered music group. Caregivers participated in three online training sessions from therapists, and were then asked to facilitate five 30-minute music or reading activities per week with the person they were caring for, depending on which intervention group they were allocated to. This continued for 90 days.

The study aimed to see if caregiver-directed music could reduce behavioural and psychological symptoms of dementia ('BPSD'; Baker *et al.*, 2023), and this was measured using the validated Neuropsychiatric Inventory-Questionnaire (NPI; Cummings, 1994). At 90 days, there were no statistically significant differences in NPI scores for participants for any of the intervention groups, indicating that neither the reading nor music interventions had any significant influence on the BPSD experienced by the participants with dementia.

Baker *et al.* (2023) report that the caregiver-directed music intervention brought short-term improvements in BPSD that lasted for the rest of the day, but that these were not sustained at post-assessment following the intervention. The authors suggest reasons for this, including that perhaps three training sessions were not enough to enable the caregivers to facilitate the activities successfully. This is perhaps corroborated by findings from the Rosenbach, Dassa and Gilboa, (2023) study, which employed a longer period of training and support for the caregiver, of 13 MT sessions and eight counselling phone calls over a period of four months.

A smaller qualitative study within Homeside, looking at the experiences of six dyads who participated in the caregiver-directed music intervention, reported more positive results (McMahon *et al.,* 2023). Caregivers acknowledged that sharing music was an enjoyable experience, and gained an awareness of the use of music as a resource to support wellbeing for both themselves and the person they were caring for (McMahon *et al.,* 2023). For some of the participants with dementia, an increase in mood and reduction in BPSD was immediately evident. A moving musical moment is described from one of the author's observational notes on watching a video recording of a music-based interview:

> In this moment, Richard appears to be completely in the moment with the music. There is no hesitation in his movement, just playfulness and confidence. He is confident in his abilities, and in expressing himself. Meanwhile, Meg also seems to be connecting to the music as she joins in and sings, laughing intermittently. These laughs appear to be joyous, and as she later emails me, she gets joy from watching Richard in his confident self-expression (McMahon *et al.,* 2023, p.6).

The authors report that there was an element of trial and error for the caregivers as they facilitated the musical activity, and that sometimes the music did not connect. Again, there is acknowledgement of the importance of support from the Music Therapist, and that follow-up support sessions may be useful in sustaining the use of caregiver-directed music (McMahon *et al.,* 2023).

Section Summary

The outcomes from the eight home-based studies that employed skill-sharing indicate that this may well be a supportive intervention, particularly in improving wellbeing, increasing a sense of identity for the person with dementia, and strengthening relationships between the dyad. The fact that skill-sharing is included in so many of the home-based studies indicates the importance and viability of this method of sustaining the use of music for couples. These studies indicate that for this to be successful, the Music Therapist needs to support the

caregiver, to help them to develop an appropriate and personalised musical intervention and the skills to facilitate this. Ongoing or follow-up support from the therapists seems to make skill-sharing more successful.

2.8 Conclusion

Studies to date point towards MT being a successful and useful intervention to support caregivers of people with dementia. However, this feels like an emerging area of research, with a limited number of studies to draw upon. In addition, study quality varied greatly, with older studies often rated as 'weak' or 'moderate' due to a lack of reported information and poor study design, including occasions where the Music Therapist facilitating the intervention also conducted the research interviews or other methods of data collection. There were few occasions where quantitative studies gave any significant results, and in some cases these studies employed measures that were not validated, or even referenced. There were also a high number of pilot or feasibility studies, acknowledging the fact that this is a developing area of research. There is particularly limited research relating specifically to caregivers when experiencing MT alongside the person they are caring for, in their own home.

In conclusion, this literature review suggests that MT may be a supportive intervention for family caregivers, with benefits suggested in areas including wellbeing, relationships and meaningful social connection. This area of research, and in particular, home-based MT involving both the person with dementia and caregiver together, needs more investigation from further quantitative and qualitative studies to suggest any firm evidence that MT supports in this context. This current study moves towards addressing this gap by exploring the experiences of caregivers as they engage in home-based MT alongside the person they care for, providing insight into if, how, and why this intervention may be supportive for both.

Chapter 3: Methodology

3.1 Introduction

In this chapter, I begin with an overview of the study itself, including an explanation of its description as a 'multimethod' study. This is followed by an account of my ontological and epistemological position as a researcher, a description of the methodology within which the study is situated, and justification as to why this is pertinent to the study. A reflexive statement is given, and I describe the attention I have brought to the scientific quality of the study.

3.2 Overview of the Study

This study aimed to discover the lived experiences of family caregivers (caregivers) of people with advanced or complex dementia when they engaged in Music Therapy (MT) alongside the person they were caring for. Six dyads (person with dementia and their main caregiver) were recruited from Mindsong's Music Therapy at Home (MT@H) service. MT@H offers 12 sessions of MT in the person with dementia's own home, working with the person with dementia and caregiver together. This was the intervention for this study.

Each caregiver was interviewed at three points: before the intervention, at mid-point (after session six) and after the intervention. The person with dementia was also included in the interviews wherever possible. The interviews were transcribed and analysed using Interpretative Phenomenological Analysis (IPA; Smith, Flowers and Larkin, 2009). Each caregiver also chose a section of music from their sixth MT session; this was analysed using Trondalen's method of microanalysis (Trondalen, 2007). The results from the two different methods of analysis were combined to produce detailed summaries for each case (see Appendix 3 for an example, p.268). Following this, a cross-case analysis was undertaken, employing the IPA method described by Smith, Flowers and Larkin (2009). This created superordinate and subordinate themes across the whole data set that formed the findings and discussion sections of this thesis. The findings from microanalysis were woven into the findings from IPA, illuminating and illustrating aspects of the superordinate themes.

Finally, an arts-based research method was used to explore the interaction of the main superordinate themes from the findings of IPA and microanalysis. This involved the creation of a visual representation of the three superordinate themes and how they related to each other.

3.3 A Multimethod Approach

This is a multimethod study, primarily rooted in the qualitative paradigm, but also employing arts-based research methods. The term 'multimethod' refers to the use of different types of research methods employed in combination to explore a research question (Johnson, Onwuegbuzie and Turner, 2007; Anguera *et al.,* 2018; Oh, 2024). This differs from 'mixed-method' approaches, which implies the use of methods situated within qualitative and quantitative paradigms (Creswell, 2003). In his thesis, Music Therapist Joon Oh explores the difference between these two terms, commenting that 'multimethod' approaches may include research methods that sit outside the traditional qualitative and quantitative paradigms, and may have a broader and perhaps more creative inclusion of different approaches, such as arts-based research methods (Oh, 2024).

McNiff (2008) defines 'Arts-based Research' as:

> the systematic use of the artistic process, the actual making of artistic expressions in all of the different forms of the arts, as a primary way of understanding and examining experience by both researchers and the people that they involve in their studies. (McNiff, 2008, p.29).

Finley argues that arts-based research offers a different paradigm, outside quantitative or qualitative domains, due to the nature of art itself and the study of the **process** of creation (Finley, 2003; 2008).

This study is primarily situated within the qualitative paradigm, using IPA (Smith, Flowers and Larkin, 2009) to analyse participants' data and uncover rich, detailed, personal accounts of the participants' experiences in relation to the research question. Trondalen's method of microanalysis is also rooted in the qualitative paradigm, following similar steps in analysis as used in IPA, and aiming to discover meaning relating to the participants' experiences (Trondalen, 2007). However, I would argue that this method of microanalysis also sits within arts-based research, as the method is concerned with gaining understanding by analysing the **process** involved in the creation of the music, as well as the **music** itself.

In addition, I created a visual representation of the three interweaving superordinate themes from the findings of the study, in order to further my understanding of how the themes interacted with each other. This study could therefore be described as 'multimethod'; employing different approaches to explore the research question. Employing a multimethod

approach is encouraged when studying complex phenomenon, as it allows a deep exploration from different perspectives, perhaps providing a more holistic understanding (Clarke and Yaros, 1988; Greene, 1994; Oh, 2024).

3.4 Ontological and Epistemological Position

My position as a researcher is influenced by my life history, experiences and clinical work as a Music Therapist. Firstly, I am a musician, with a belief that music provides a means for expression and creativity; elements I believe to be essential for mental and physical wellbeing. Arts-based research that involves the study of the creation of art, and in this case, music and the visual arts, is therefore perhaps a natural choice of research method.

Furthermore, as a Music Therapist by profession, I feel comfortable working with subjectivity. In therapy, we aim to be 'fellow travelers' with our clients (Yalom, 2001 p.6), 'looking out the patient's window' (Yalom, 2001, p.17). We try to understand their perspective; their subjective experience, whilst maintaining a therapeutic stance for 'holding' (Winnicott, 1960) or 'containing' (Bion, 1962) that person's expressions and emotions resulting from the therapeutic journey.

Thus, the qualitative paradigm fits naturally with my thought processes and ontological position: that one person's truth or reality may be different from another's. Indeed, the same person may experience different realities at different times, depending on external influences and experiences at certain points in time.

Reflecting a relativist position, my belief is that reality is constructed from within, where the 'truth' is subjective and all truths or realities are of equal value (Frisby, 2021). This represents a constructivist ontology, where a person's reality is built through their experiences and interactions in the world and is constantly changing as they respond to new experiences (Given, 2008; Leavy, 2014).

My research question is also situated within this paradigm, as I am aiming to look at lived experiences, discovering individual perspectives, and again dealing with the subjective; the truth constructed by each individual, which will be affected by their unique, individual experiences. I find that Giroux expresses this well: 'Experience never simply speaks for itself. The language we bring to it determines its meaning.' (Giroux, 1988, p.99).

The knowledge of an experience that an individual comes to will depend on a myriad of interacting factors, including their personal history, their personality, their social and economic situation, and their interactions with others. Their knowledge and understanding of their experiences is brought to meaning not only by the language they bring to it, but also the sum of their experiences so far (Given, 2008; Leavy, 2014). This constructivist approach suggests that there is no one reality, no one truth to knowledge, but that all can co-exist (Given, 2008; Leavy, 2014). The ontology and epistemology for this study is built on this foundation, and the methods that follow from this are rooted in this belief.

The constructivist ontology resonates with my own practice as a Music Therapist and is also steeped within the ethos of the collaborating professional service within this research, Mindsong. As mentioned in chapter one, Kitwood's concept of 'Personhood' (Kitwood, 1997) influences the work at Mindsong, in that we consider the person we are working with as a holistic being, with a multitude of experiences, interactions and circumstances affecting their being. As expressed in his formula below, Kitwood suggested that a person's experience of dementia (D) is a complex interplay of factors, including personality (P), biography (B), health (H), neurological impairment (NI) and social psychology (SP):

$$D = P + B + H + NI + SP \text{ (Kitwood, 1993).}$$

This certainly reflects understanding derived from my clinical work; although there are some shared, common presentations of dementia, each individual's experience of symptoms and how these interact in their lives is unique and can be quite different from another's, even if they share the same diagnosis. Consequently, each caregiver's experience is equally as unique, as they bring their own mix of previous experiences, personality, health and social psychology which interplays with their relationship with the person with dementia, and how the person with dementia presents and interacts with them.

As such, the phenomenon in question is highly complex, influenced by many different factors and deeply personal in nature. Using an inductive approach, starting with the exploration of individual experiences at a micro level and then gradually broadening the lens to look at these experiences in relation to each other, will give rich and detailed insights into this phenomenon. Both IPA and Trondalen's method of microanalysis provide means for such a deep exploration, allowing the illumination of relevant themes and concepts to be identified (Trondalen, 2007; Smith, Flowers and Larkin, 2009).

3.5 Interpretative Phenomenological Analysis (IPA)

IPA is a systematic method of analysing texts, exploring the material at a deep level and bringing to light relevant themes and concepts relating to a person's experience, as revealed within their text (Smith, Flowers and Larkin, 2009; Hefferon and Gil-Rodriguez, 2011; Ghetti, 2015). This in turn can identify the meaning given to experiences from the participants' perspectives.

The selected text is analysed carefully, in a detailed manner. Understanding is gained from looking at small parts of the text, at word level, using tools such as imagery, symbolism and phonaesthetics, then examining this in relationship to the sentence within which the word sits, then, on a larger level, in relation to the phrase, and then the whole text, and vice-versa. Smith, Flowers and Larkin describe this as the 'Hermeneutic Circle': 'the dynamic relationship between the part and the whole, at a series of levels' (Smith, Flowers and Larkin, 2009, p.27). Other aspects are also taken into account, including the pace of the participant's speech, how fluent the speech is, the use of fillers ('um's and 'ah's), and body language; anything that may reveal something about what is being said (Smith, Flowers and Larkin, 2009). This is an iterative process which can uncover deep meaning within the text: 'Our entry into the meaning of a text can be at a number of different levels' (Smith, Flowers and Larkin, 2009, p.27).

During the analysis stage, the researcher immerses himself/herself/themselves in the data, reading and re-reading, noting exploratory comments and identifying themes that come to light (Smith, Flowers and Larkin, 2009). Crucial to the analysis is the engagement in reflexive processes, including 'bracketing-off', where the researcher acknowledges any preconceptions he/she/they may have, examining from which perspective these may have arisen, noting this down and putting these aside to return to the text with a fresh perspective (Smith, Flowers and Larkin, 2009). The researcher presents their understanding of the participants' understanding of their experiences, aiming to be as faithful to the participants' phenomenological world as possible (Smith, Flowers and Larkin, 2009).

In some ways, IPA places the researcher in a similar position to that of a therapist; just as in MT, the therapist aims to be present alongside the client, in IPA research, the researcher is very much **in** the research process with the research participants. Although I will have an interview schedule, in IPA the aim is to discover rich, personal accounts; to that end, the interviewer may wander from the schedule depending on the answers given by the participant. If a different question could uncover a deeper truth, then the researcher will stray

from the schedule and ask it, directly influencing the course of the data (Smith, Flowers and Larkin, 2009).

In an interesting article, Jackson (2014) highlights similarities between therapeutic and qualitative approaches, including a basic aim of both being to understand the client's, or participant's, perspective: 'looking out the patient's window' (Yalom, 2001, p.17). Jackson also suggests that both approaches use reflective techniques to deepen understanding that can include the client or participant's own language (or music, in the case of MT). Both also depend on the development of a relationship within which honest expressions can be communicated (Jackson, 2014).

Jackson (2014) also highlights a basic difference in the two approaches; that, of course, the contract or agreement is different between the interviewer and participant. In therapy, the aim is to understand the client, to attend to their 'internal state', and to facilitate whatever positive change might be helpful or possible (Jackson, 2014, p.13). In research, the aim is to understand the phenomenon in question as experienced by the participant; to have some understanding of the participant's understanding of their experience. This does not include a mandate for change, and focuses on answering the research question rather than any development or change for the client.

This impacts on the level of the duty of care held in these different roles. As a therapist, there is a duty to respond to concerns that arise within the therapeutic process, as is appropriate and within the best interests and wishes of the client. As a researcher, the duty of care is reduced, as the contract between researcher and participant does not include a mandate for change. However, if upsetting experiences are recounted and the participant becomes distressed, there is an ethical duty to respond in a sensitive manner. This may mean stopping the interview and perhaps signposting to supportive resources or organisations. Of course, as a therapist or a researcher, if any disclosure is made, or a safeguarding concern becomes apparent, both have a duty of care to act on this in the best interests of the participant/client, or whoever might be at risk.

I was aware of both the similarities and differences between these two roles during the interviews for this study and kept a reflective journal to help process my thinking (see Appendix 4, p.284).

3.6 Music Microanalysis

As the main medium of delivery in the intervention for this study is music, it seemed important to include an element of this in the research design. Employing microanalysis to selected clips from the MT sessions also gave the potential for the person with dementia to be represented more fully in the research data, as they participated in the intervention with their caregiver. There is also an argument that music created in therapy sessions may uncover deeper revelations of participants' experiences than verbal interviews alone (Wosch and Wigram, 2007). Music microanalysis therefore has potential to add to the findings from IPA to create rich, multi-layered data to help understand the lived experiences in question.

Microanalysis in MT is the practice of examining, in minute detail, the music and interactions that happen within the therapeutic process (Wosch and Wigram, 2007). Some Music Therapists use microanalysis in everyday clinical practice as a reflective tool to identify what is happening in the therapeutic process. Microanalysis is also used in training student Music Therapists to help them develop their observational skills. It is also useful for researchers, who may wish to examine a certain phenomenon to a detailed level, as is the case with this study (Wosch and Wigram, 2007; Ridder, 2007; Pavlicevic, 2007; Flower, 2019; Lockett, 2022).

As well as a focused exploration of the music itself, microanalysis allows for a study of interactions between client/s and therapist; in this study, between the caregiver, person with dementia and therapist. This provides illumination of the processes and relationships within the therapy session, and has the added benefit of ensuring the inclusion of the person with dementia in the research.

3.6.1. Trondalen's Method of Microanalysis

I was particularly influenced by the work of Norwegian Music Therapist, Gro Trondalen, when designing this study. Building on a phenomenological approach first developed in MT by Ferrara (1984), Trondalen's method of microanalysis aims to understand the subjective lived experience of the client in MT, but through the interpretative lens of the context of the therapy process, and of the researcher (Trondalen, 2007).

Many of the processes used in IPA are paralleled in Trondalen's method of microanalysis, including the bracketing-off of pre-conceived ideas and assumptions, a deep immersion in the text (music in this case), and the use of the hermeneutic circle; examining the music as a whole and at part level, including phrases, intervals, timbres, tempo, and then relating this back to the music as a whole (Trondalen, 2007). The difference between IPA and Trondalen's method

is, of course, that the predominant medium for IPA is written text (often transcribed from verbal interviews), whereas for microanalysis, the medium is music.

This is where there is an overlap with arts-based research methods, as the microanalysis is concerned with analysing both the **music** created and the **process** of creation itself, resonating with McNiff's definition of arts-based research being concerned with 'the actual making of artistic expressions…as a primary way of understanding and examining experience' (McNiff, 2008, p.29).

3.7 Theoretical Underpinning

IPA is informed by three main philosophical areas: phenomenology, hermeneutics and idiography (Smith, Flowers and Larkin, 2009). Trondalen's method of microanalysis is also developed from a phenomenological approach, and shares the same theoretical underpinnings (Trondalen, 2007).

3.7.1 Phenomenology

Phenomenology is an approach to studying the nature of lived experience and aims to discover the 'essence' of a particular experience for a particular person (Leavey, 2014). It involves 'bracketing' everyday things and consciously engaging in reflexive activity, to focus on the nature of the subjective experience (Smith, Flowers and Larkin, 2009, p.13).

Reductions – Bracketing Off

Drummond (2019) explains Husserl's (1962) philosophy of phenomenology, including the importance of the use of 'reductions'; setting aside prior beliefs and expectations in order to examine experiences from a more objective standpoint (Husserl, 1962; Drummond, 2019). In IPA, Smith, Flowers and Larkin (2009) interpret this as looking at an experience through different lenses to discover different elements at the core of the subjective experience. During the analysis stages of this study for both IPA and microanalysis, it was important for myself, as researcher, to think about through which lens I was examining the data; was I truly bracketing off my own preconceptions? Was I looking at the text as a Music Therapist? As a researcher? These different lenses could produce different interpretations, all of which may be helpful in the aim of discovering the essence of the participants' experiences and understanding, but some of which could hold too much influence from my own position. I needed to remain aware of this possibility throughout, and in order to do this, I engaged in a number of reflexive practices (see my Reflexive Statement, p.60).

As well as my own reflexive processes, it felt important during the interview stage that I, as interviewer, also facilitated a reflective process for the participants, encouraging them to reflect in on their own subjective experience. I was also careful not to lead participants unnecessarily; to keep focused on **their** experience and what **they** wanted to share. During the interviews, I realised that the caregivers were also reflecting on their experiences from their own different perspectives, including from within their relationship with the person with dementia, but also as a person providing care for that person, from the role of 'caregiver'. A past perspective was also sometimes relevant, where the music would bring reminiscence and thoughts relating to how things 'used to be' as a couple. The research participants (the caregivers) therefore, also had their own set of contrasting lenses through which to reflect on their experiences.

Throughout the study, I remained aware that each participant brought their own personal journey, past experiences, and perspectives to their interpretation of these current experiences, resulting in different, rich, personal qualitative data. The concept of our subjective experience interacting with the world in which we live was highlighted by Heidegger, who argued that our experiences are always influenced by our situation within this context (Heidegger, 1927; Horrigan-Kelly, Millar and Dowling, 2016). Every experience happens within the context of our engagement and interaction with everything in the world, including objects, people, language and environment. Our experiences are therefore always from a certain perspective within the world (Eatough and Smith, 2017).

Becoming Ourselves

Sartre developed this further, suggesting that our experiences and perceptions are shaped by the presence or absence of relationships with others (Sartre, 1943, cited in Smith, Flowers and Larkin, 2009). He also argued that we are never fully finished beings, that we are constantly developing and 'becoming ourselves' (Sartre, 1943; cited in Smith, Flowers and Larkin, 2009, p.19). This again seemed particularly relevant in this study as caregivers experienced elements of changing identity, for example, from spouse to 'caregiver' (Hughes, Locock and Ziebland, 2013). Arguably, any experience of change influences how a person grows and develops, how they may continually 'become themselves'. These particular changes, where the family member increasingly takes on more of a caring role, interacting with their loved one in, perhaps, different ways, and experiencing changes in their relationship because of this, gives another opportunity for growth. Perhaps, in these situations, the caregiver 'becomes more themselves' by understanding who they are within this changing relational context.

Embodied Experiences

We engage in music-making via our bodies. In MT, often our identity, communications and expressions are embodied through music (for example, in our playing, singing, movements, conducting, dancing). This resonates with another perspective in phenomenology; the suggestion that our relationship with the world is 'embodied'; that we experience and interact with everything in the world through our bodies (Merleau-Ponty, 1945; cited in Smith, Flowers and Larkin, 2009, p.19). In a recent study, Music Therapist Rebecca Lockett explores musical improvisation in terms of embodiment, and how this relates to Merleau-Ponty's theories (Lockett, 2022). In relation to this current study, it was interesting to think about how the participants engaged in their music-making; how they may have been experiencing the music in an embodied way. I was able to reflect on this during the microanalysis process, whilst watching the participant-selected clips from the sixth MT sessions. This was another lens through which to analyse the music, and gave additional insight into how people experienced and connected to the music in the MT sessions. For example, in case four, caregiver Theresa often moved to the music as we watched the video of the sixth MT session together. Her physical engagement with the music added weight to her comments about how she felt about music in general: 'I'm a great lover!'. In the selected clip of music from the sixth MT session for case six, Hazel improvises with the Music Therapist on a djembe drum, engaging her whole body in her expressions, which feel free and creative. In this moment, Hazel is embodied in the music and is in control of her movements, in stark contrast to other times when she experiences uncontrollable movements and unsteady balance due to Parkinson's Disease. Again, this emphasises the depth of connection to the music for this participant.

In addition to these examples from the research participants, 'body listening' is a key stage within the method of microanalysis employed, requiring the researcher to listen carefully to the music with their body; allowing free bodily expressions and noting what happens with the body whilst listening or watching (Trondalen, 2007). My comments from a body listening to the music from case two reveal more about how the person with dementia may have been feeling physically during MT:

> I felt an inner warmth when listening again to this passage of music. As the song progressed, I also found myself feeling tight or breathless in my chest, noticing at the same time that on the video, Louisa seemed to find catching her breath more difficult as the song went on. I felt a sense of the vulnerable and fragile nature of the human body in this later stage of life.
>
> (Taken from Microanalysis of Case Two, Body Listening)

3.7.2 Hermeneutics and The Double Hermeneutic

Hermeneutics, the study of interpretation, offers perspectives on the challenge of maintaining a reflexive stance. Schleiermacher argued that any text created is shaped by the author, and also by the person reading or interpreting the text (Schleiermacher, 1959; cited in Smith, Flowers and Larkin, 2009). He suggested that an interpreter should look at the meaning and the wider context within which the text was produced: the perspective of the author.

In this study, the primary authors are the research participants, for it is their narrative that creates the research text; the data. However, the interviewer (myself) must surely be a secondary author, as the interviewer asks the questions, responds to the participants' answers, and guides the participants through the interview. Together, the research participants and interviewer create the text through the context of the research interviews. This context includes the relationship between research participant and interviewer (myself), our conversations and interactions.

As researcher during the analysis stage, it felt important to interpret the text within the context of our interviews, holding in mind those experiences, and how they may have influenced the creation of the text. This involved further reflexive thinking; acknowledging my own experience of the interviews and then stepping outside this, examining how the interview itself may have influenced the participants' responses. For example, the first interview for case two felt quite intense, with some passionate and negative views expressed by the caregivers about the care system. I was aware that during the interview I felt great compassion for the family, and shock in relation to some of the experiences they recounted. I felt my therapist role on my shoulder as I empathised, and this seemed to allow an even greater freedom of expression from the participants. Whilst I believe this was a good thing, I think I did influence the flow of the conversation by being empathetic. I noted this in my reflective journal after the interview (see Appendix 4, p.284). When coming to the analysis of the transcript of this interview, it felt important to acknowledge these feelings I had experienced, but to then put them aside and examine the text from a less emotional standpoint.

The Double Hermeneutic

This relates to the double layer of interpretation that is inevitable within IPA and also in microanalysis. Firstly within the interviews, and potentially within the music-making in MT, the research participant is commenting on their experience, coming to an understanding of that experience and of their interpretation of that experience. In turn, during the analysis stage, the researcher is coming to an understanding of the research participant's experience, bringing

their own interpretation of the research participant's interpretation of their experience: the double hermeneutic.

Heidegger suggests that, because of our experiences and interactions within the world, it is impossible to approach a text in a pure sense, without any assumptions, preconceptions or 'fore-understanding' (Heidegger, 1927; cited in Smith, Flowers and Larkin, 2009, p.25). He suggests that we sometimes do not know what our preconceptions might be until we have read and engaged with the text, and so the process of bracketing preconceptions needs to be iterative and cyclical (Heidegger, 1927; Horrigan-Kelly, Millar and Dowling, 2016).

I became aware of an unexpected preconception during the 'bracketing-off' stage within the IPA analysis of case one. In our first interview, the person with dementia (Lucy) seemed withdrawn and did not engage much with myself or with Gordon, her husband and caregiver. I assumed this might be the case for interviews two and three, and it was not until I started analysing the transcript from interview two, engaging with the bracketing-off process, that I realised I had this assumption, and that it was not at all true. Lucy spoke quite a lot during interviews two and three, revealing aspects of her personality, and initiating interactions with Gordon. Although I had also interacted with Lucy during these interviews, it was not until the analysis stage that I realised I still held this preconception that had formed following the first interview, and that Lucy's interactions were actually frequent and insightful in terms of her and Gordon's experiences.

The double hermeneutic highlights the researcher's dual role in the interpretation of research data. In both IPA and microanalysis, the researcher examines the text or music in a systematic and detailed manner, with the aim of getting to the real meaning within the text, from the research participant's perspective. However, the researcher also has oversight of the whole dataset, and knowledge of the research area in question, therefore bringing another perspective to this understanding, and in IPA this is also valid (Smith, Flowers and Larkin, 2009). A reflexive position with openness and an acute awareness to my own preconceptions throughout the research process was crucial in order to remain aware of the different levels of interpretation and from which perspective they were likely to have arisen.

3.7.3 Idiography

'Idiography' relates to the study of the particular (Smith, Flowers and Larkin, 2009). In IPA, 'idiography' relates to the study being focused on a particular experience (or phenomena) understood by a particular group of people within a particular context, and also focusing **in** on

the particular; a detailed, in-depth analysis of the phenomena (Smith, Flowers and Larkin, 2009).

This resonates with the aims of this study: to discover in-depth personal, lived experiences, and to use these to try and understand experiences more fully.

To follow the idiographic approach, a small, purposively selected sample size is needed, with the focus on single experiences being just as valuable as studies with large sample sizes. In this study, I recruited and interviewed seven caregivers from six different cases. Using an inductive approach, starting with the exploration of individual experiences on a micro level and then gradually broadening the lens to look at these experiences in relation to each other, has allowed for a rich and detailed insight into this phenomenon.

3.8 The Relationship Between IPA and Microanalysis

Eatough and Smith (2017) suggest that IPA lends itself well to working alongside other qualitative methods. The congruence in stages of analysis and theoretical underpinning for IPA and Trondalen's method of microanalysis made this combination of research methods an obvious choice, and created a rich data source for analysis and discussion stages. Synthesising the findings from both methods into individual case summaries felt like a natural development, and produced detailed accounts of individual experiences. As a final synthesis, the findings from both IPA and microanalysis were explored in a visual representation (see p.194).

There are examples in MT research literature of the combined use of IPA and music microanalysis. In her PhD study, Music Therapist Rebecca Lockett uses both methods to explore an understanding of the lived experiences of music and MT students who are learning to improvise (Lockett, 2022). In another study, Music Therapist Claire Flower synthesises results from IPA within a graphic score created from music microanalysis (Flower, 2019). Both authors held the data from music sources in equal value to the data created from semi-structured interviews, and comment that the findings from microanalysis corroborated findings from IPA but also revealed new themes and insights (Flower, 2019; Lockett, 2022).

Similarly in this study, the findings from IPA and microanalysis were held in equal value, with both being important sources from which to elicit understanding of the participants' lived experiences. Often, the microanalysis corroborated the findings from IPA, with similar themes being present in the discussion of each microanalysis. In addition, the microanalysis provided new illuminations, particularly with regards to aspects of relationship and interactions

between the caregiver and person with dementia within the MT session. Further information on how the two methods interact can be found in the Methods chapter (see p.82).

3.9 Reflexive Statement

As I have mentioned previously, I have been aware throughout the research process that I come to this study not only as a researcher, but as a Music Therapist and director of the MT@H service within which the intervention is situated, and from where participants have been sourced.

My frame of reference, therefore, has the potential to influence my thoughts, analysis and findings to an overly positive degree, particularly in relation to the experiences of MT. I have been aware that I may be tempted to exaggerate positive findings, or not pay enough attention to negative experiences related by the participants. My intention has been to present the participants' lived experiences, interpreted within the context of my knowledge, experience and understanding of MT and dementia, but above all, remaining true to the 'essence' of the participants' phenomenological worlds.

To aid this, I implemented a number of processes within the study design that I hoped would help myself step outside my usual role of Music Therapist, and enter more fully into the role of researcher. During the recruitment stage, I was not involved in the identification of potential participants; this process was undertaken by Mindsong's Carer Support Team (see p.66), and therefore I had no influence over who might take part in the study.

Regarding the MT intervention, I did not provide any of the MT myself, nor did I supervise any of the Music Therapists who facilitated the MT within the timeframe of the study.
I engaged in a number of reflexive practices throughout the course of the research. I kept a reflective journal throughout, collecting my thoughts and responses to the interviews, transcripts and music, reflecting on these to see if they were useful and relevant within the analysis process (for an example of my reflective journal, see Appendix 4, p.284).

During the analysis process, I engaged rigorously in the 'bracketing off' stages; putting aside my own assumptions and pre-conceptions and coming to the data with as fresh and open a mind as possible, as directed by Smith, Flowers and Larkin (2009) and Trondalen (2007). I watched the videos of the interviews repeatedly, cross-referencing with the transcripts to make sure I had an accurate record. I also reflected on my analysis, challenging my thoughts, responses and understanding of the texts and music, to ensure that I was representing the participants'

experiences to the best of my understanding, always reflecting on the lens through which I was interpreting the data.

For example, during the IPA analysis stage for case four, I realised I was viewing the data through a Music Therapist's perspective. Whilst in some respects this was helpful, it was important to review the data again, bracketing-off my reactions as a therapist and thinking about the text from the perspective of the caregiver. Theresa (caregiver, case four) had commented that her husband Julian sometimes became overwhelmed by emotions during the MT sessions and had cried, and this had been difficult for her to endure. On examining this in the text, I initially responded as a therapist, thinking that this release of emotion may well have been a cathartic process for Julian. On realising that this was from a MT perspective, I looked at the text again, thinking about this from Theresa's perspective, and this allowed me to acknowledge how difficult this must have been for Theresa (see Appendix 5, p.285). In the findings chapter, I have been able to present both perspectives, and hope I have done so in a balanced manner (see p.167).

As well as challenging my own thoughts and analysis, I also checked my findings with my supervisory team and research buddy to make sure I had not over-inflated positive elements or missed negative points about the MT.

Reflection

I was fortunate to be able to share my findings with a research buddy. Ruth Melhuish is an experienced music therapist and a colleague of mine at Mindsong. Part of her clinical role is to share oversight (with myself) of the MT work undertaken by Mindsong. Therefore, Ruth had knowledge and understanding of the MT for the six cases included in this research. I wanted to share my findings with Ruth to ensure I had not missed anything important or, conversely, exaggerated any findings. Being the only other person to know all six cases of MT in some depth, Ruth was in a unique position to be able to help me with this.

3.10 Scientific Quality

In order for research to be considered trustworthy, valid and reliable, attention must be paid to scientific quality, both overall and whilst undertaking all aspects of the study. Rigour and validity are important hallmarks of any good piece of qualitative research, and Smith, Flowers and Larkin (2009) suggest adherence to Yardley's four key concepts: sensitivity to context;

commitment and rigour; transparency and coherence, and impact and importance (Yardley, 2000).

There is no mention of scientific quality in Trondalen's method of Microanalysis (Trondalen, 2007), and looking back at Ferrara's method which inspired Trondalen's, the only mention of evaluating the quality of the microanalysis is that the analysis itself should be 'grounded in the [musical] work' (Ferrara, 1984, p.372). Ferrara describes this as the researcher being so 'rooted' in the music that this creates an 'organic bond' between the musical work and the analysis itself. This is reflected in the multiple listenings that both Ferrara (1984) and Trondalen (2007) require of the researcher, and the different ways of listening, including open listening, with all preconceptions put aside; listenings that focus on particular meanings, for example, identifying semantic meaning; and, in Trondalen's method, body listening, where the researcher concentrates on her/his/their own bodily responses to the music as they listen. Also in Trondalen's method is a heavy emphasis on 'bracketing-off' to ensure the researcher returns to each music listening with a fresh perspective, to allow new interpretations to develop and come to light (Trondalen, 2007). In addition, as this is a phenomenologically inspired method which closely follows the procedure of IPA, I employed Yardley's four tenets used in IPA to also ensure scientific quality during microanalysis (Yardley, 2000).

I will now consider each in turn and explain how I aimed to address the need for high scientific quality within this study.

1. **Sensitivity to context** – that the research is sensitive to the context of the participants, that it acknowledges existing relevant literature and examines the research in this context, and that the material from the participant is treated in a sensitive manner (Yardley, 2000; Smith, Flowers and Larkin, 2009).

As an experienced Music Therapist having worked in the field of dementia for many years, I believe that I have held this study within the knowledge and understanding I have developed relating to this context. I have a good knowledge of the existing research in this area, which is illustrated in my Literature Review chapter. The wellbeing of the research participants has been of paramount importance throughout my research. I gained ethical approval for the study from an NHS Research Ethics Committee, which was then ratified by UWE Ethics Committee (see Appendix 6, p.286). The ethical considerations and agreement have been adhered to throughout the study. Within the IPA and microanalysis processes, I have been sensitive to each research participant's personal context, and have situated the research within this, sometimes adjusting the research process in order to do what has felt ethically

right for the participants at that time (see chapter on Methods, p.75). I have adhered to the privacy policy and confidentiality agreements throughout, keeping the research material pseudonymously and confidentially held.

2. **Commitment and rigour** - that the study is performed in a systematic, consistent and thorough manner (Yardley, 2000; Smith, Flowers and Larkin, 2009).

I developed a Study Protocol early on in the research process and have adhered to this throughout (see Appendix 7, p.293). Whilst engaging with IPA, I followed the steps suggested by Smith, Flowers and Larkin (2009) in a systematic manner for each of the 18 interview transcripts. Similarly, I followed Trondalen's (2007) suggested steps for microanalysis for each of the six selected moments of music.

3. **Transparency and coherence** – that the stages of research are clearly described and are reproducible, and that the arguments presented are clear, with evidence supporting them and related to underlying theoretical approaches that have been expressed (Yardley, 2000; Smith, Flowers and Larkin, 2009).

I believe I have described my methods clearly (see Methods chapter, p.64) and hope that the reader will find these reproducible. I have described the findings of the research in discussion with other relevant literature and theories, using verbatim quotations from the participants' transcripts, and descriptions of the music from microanalysis as evidence for the points I have made. Pseudonymised extracts of the transcripts and analysis were shared with a research buddy and the supervision team, to check for quality of analysis, validity and reliability of results.

4. **Impact and importance** - that the research creates 'interesting, important or useful' data (Yardley, 2000, as cited in Smith Flowers and Larkin, 2009 p.183)

I believe that the findings from this research will give increased presence to the voice of family caregivers in the research literature. I am hopeful that the research findings will be of interest to Music Therapists working in this field, and to other professionals who support this particular client group and who may design support services in the future.

Chapter 4: Methods

4.1 Introduction

In this chapter I describe the methods used, including a summary of the overall research design and more detailed information on participant recruitment, intervention, interview design, analysis and synthesis.

4.2 Research Design

This is a multimethod study employing Interpretative Phenomenological Analysis (IPA; Smith, Flowers and Larkin, 2009), music microanalysis (Trondalen, 2007), and the creation of a visual representation as a final synthesis of the findings. For an explanation of why I chose to use these methods, please see my Methodology chapter (p.49).

The study design is summarised as follows:

- Six dyads (family caregiver and person with dementia) were recruited from Mindsong's MT@H service.
- Each dyad received the MT intervention, consistent with Mindsong's MT@H service.
- The caregiver was interviewed at three points: before the intervention, at mid-point (after six sessions), and after the intervention. The person with dementia was included in the interviews wherever possible.
- The transcripts of each interview (three per dyad, 18 in total) were analysed using IPA.
- A clip of music from the sixth MT session, selected by the caregiver, was analysed using microanalysis.
- This clip was also analysed with reference to Kitwood's flower of psychological needs (Kitwood, 1997).
- Results from all methods of analysis were combined to create individual case summaries.
- Following this, a cross-case analysis across the six cases created the findings for this study.
- A visual representation of the three superordinate themes from the findings was created to explore the relationship between the themes.

4.3 Participants

Potential research participants were identified from Mindsong's MT@H service. At the time of the research, this service was already well established in Gloucestershire and receiving regular referrals from local GPs, Community Dementia Nurses, Mental Health Teams, and Alzheimer's Society Dementia Advisers.

I chose to only recruit from referrals to this service because it is uniquely designed to provide support for people with advanced/complex dementia and their caregivers who provide home-based care, and therefore is directly relevant to the research question. Recruiting only from this service also ensured a degree of consistency in the delivery of the intervention; although facilitation may vary from therapist to therapist, there is consistency in the therapeutic underpinning, the number and frequency of sessions delivered, duration of sessions and overall aims. Although I am the clinical director for MT@H, for the research participants and MT work included in this study, I passed this role to my colleague, so that I could remain in the role of researcher throughout.

4.3.1 Inclusion and Exclusion Criteria

Potential participants matched the following **Inclusion Criteria**:

- A family caregiver and person with advanced/complex dementia, where the person with dementia was being cared for in their own home.
- The person with dementia had a formal diagnosis of dementia (of any cause).
- The caregiver was the main caregiver: this could be a spouse, partner, daughter, son, friend.
- The caregiver was living with the person with dementia and/or was the primary caregiver.
- As Mindsong is a charity operating in Gloucestershire, participants would be from the Gloucestershire area.
- In case of Coronavirus Disease 2019 (COVID-19) restrictions: as interviews and therapy may be conducted online, research participants would need access to a computer or tablet and have a basic level of computer literacy. [N.B. Mindsong was able to provide individual technical support to assist access to Zoom, the preferred method of online delivery.]

Any participants who fell into the following categories were excluded from the study:

Exclusion Criteria

- Paid/professional carers, as the focus of this research was on the experience of unpaid caregivers.
- Those with earlier stages of dementia, as the focus was on more advanced stages of dementia (see p.16 for a definition of this).
- Caregivers who do not speak English (unless a family member can translate). The researcher is not fluent in any language other than English.
- In case of COVID-19 restrictions: caregivers with no access to a computer or tablet, or who would find online methods difficult (even with a level of support).

4.3.2 Sample Size

Six couples (six people with dementia and their main family caregivers) from Mindsong's MT@H referrals were recruited for the study.

Since the intention was to discover detailed accounts of personal experience, a large sample size would be too unwieldy. This study aims to concentrate on producing in-depth data from personal accounts with richness and depth of understanding coming from the many levels of interpretation consistent with IPA and microanalysis. Smith, Flowers and Larkin (2009) recommend an ideal sample size of between three and six, this being small enough to manage the amount of data, and large enough for comparisons to be made across the individual accounts (Smith, Flowers and Larkin, 2009, p.51).

4.3.3 Recruitment

People referred to Mindsong's MT@H service were asked by Mindsong's Carer Support (CS) team if they would be interested in taking part in the research. This is a team of people who have received training from Mindsong's senior Music Therapists to provide assessments over the phone. When a referral is made to the MT@H service, one of the CS team will make an initial phone call to find out about the situation and circumstances of the person/couple referred. The CS team member explains the basics of the intervention and asks the potential client if this is something they and the person they are caring for would like to engage with. Listening to the caregiver about their experiences gives understanding of the situation and helps the senior MT team at Mindsong assess whether MT might be a helpful intervention. For this study, the CS team member asked participants if they would like to take part in the study during this initial phone call. This was to avoid any risk of undue pressure to take part

that might be felt if I (as researcher) had asked, and to ensure that I did not bring any bias into participant selection.

It was made clear to participants that the MT would still be available to them if they declined to take part in the study. If participants expressed a wish to take part, Mindsong's Administrator shared the referral form for the participants with myself using secure OneDrive, in compliance with this study's data sharing agreement. The referral form contains contact numbers as well as basic demographic information (such as type of dementia and care provision). Following this, I phoned the potential participants to explain more about the research and ask if they were still interested. If they said yes, I sent out the Participant Information Sheets with details of the study (see Appendix 8, p.322), the Participant Privacy Notice (Appendix 9, p.348), and relevant consent forms, which included a 'Consultant Information Sheet and Declaration Form' for when the caregiver was making a decision on behalf of the person with dementia (Appendix 10, p.352). Issues around informed consent were considered carefully; please see chapter 5, 'Ethical Considerations' (p.85). I offered further phone conversations and asked the potential participants to consider their decision carefully, giving them time to think about this before they confirmed or declined their participation. The relevant consent forms were completed by the participants and given to me at the beginning of the first interview.

4.3.4 Participant Characteristics

Of the six couples, four were spousal, one was a father and daughter dyad, and one a mother, daughter and grandson triad. Although I had not envisaged including a case with three people, here, the daughter and grandson both gave significant amounts of time caring for their mother/grandmother, and the caring role had a considerable impact on their lives, so it felt important to include them both in the interviews.

Three of the people with dementia were female and three were male. There were four female caregivers and three male caregivers (including the grandson). Cause of dementia was varied, with two people diagnosed with Alzheimer's Disease, one with Vascular Dementia, two with Alzheimer's and Vascular ('Mixed') Dementia, and one with Parkinson's with Lewy Body Dementia. This resulted in a range of dementia symptoms experienced by the participants. There was no one with Young Onset Dementia and the ages of the people with dementia ranged from 77 to 84. Caregivers age ranged more widely, from 23 to 81.

All participants were white British in ethnicity, and from a range of social class, including two from more deprived areas. All participants with dementia lived at home and the main caregiver lived with them for five of the six cases, with one caregiver (daughter, in case three) living apart but providing and overseeing care for her father. In case two, the grandson (Leo) lived with his grandmother and provided much of her care, but his mother (Maria) provided oversight and took on some of the caring role, despite living separately. Participant characteristics are presented in table 1 (p.69).

4.4 Intervention

The intervention consisted of 12 weekly MT sessions in the couple or family's own home, working with the person with dementia and caregiver together, as is consistent with Mindsong's MT@H service. The Music Therapists providing the intervention were all experienced in working in the context of dementia care, and have a special interest in this work. Five different Music Therapists were involved in delivering the therapy. Each couple had the same therapist for the duration of the 12 sessions. One Music Therapist delivered the intervention for two different couples.

The intervention delivered was as consistent as possible, given that MT is always personalised and tailored to best match and support clients' needs. Each therapist held the same theoretical underpinning to the work (see chapter one, p.18) but the methods used within the therapy sessions varied, as the therapists employed whichever approach connected most readily and appropriately for the participants. These approaches included improvisation, the use of well-known songs, listening or singing along to recorded music, and a mix of these approaches. The Music Therapists each have a small, transportable kit of good quality musical instruments to use in the sessions. The MT sessions were delivered in-person, in the participants' own homes, lasting around an hour each time.

As well as the therapy itself, Mindsong's Music Therapists are asked to work with the family to identify particularly challenging circumstances or times of the day, to see if a personalised use of music may support these situations. In the past, this has included using personalised music during personal care, music to dance together during times of anxiety, and using particular songs to help initiate movement (for more examples, see Grady and Melhuish, 2020).

Table 1: Participant Characteristics

Case No.	Pseudonyms	Caregiver/Person with Dementia (gender)	Relationship	Dementia Diagnosis	Age	Reason for Referral (from Mindsong referral form)	Circumstances
1	Gordon	Caregiver (M)	Husband		81	To support communication, provide stimulation.	Gordon and Lucy live together. Gordon provides care 24/7. Lucy is dependent for all care needs. Minimal help from professional carers to use a hoist to lift Lucy from chair to bed and vice versa.
	Lucy	Person with dementia (F)	Wife	Alzheimer's Disease	78		
2	Maria	Caregiver (F)	Daughter		53	For stimulation and to lift mood. To help with anxiety for caregiver.	Leo lives with Louisa and provides almost 24/7 care. Louisa is dependent for all care needs. Maria visits three or four times a week. No respite or help from professional carers at time of research.
	Leo	Caregiver (M)	Grandson		23		
	Louisa	Person with dementia (F)	Mother / Grandmother	Mixed Alzheimer's and Vascular Dementia	84		
3	Nia	Caregiver (F)	Daughter		55	To help with frustration and to feel connected to the world.	Nia lives separately to SJ but is the main caregiver and visits two or three times a week, including providing care for two full days. SJ is not completely dependent but needs support with most things. SJ also has a live-in professional carer.
	SJ	Person with dementia (M)	Father	Mixed Alzheimer's and Vascular Dementia	81		
4	Theresa	Caregiver (F)	Wife		79	To offer opportunity to engage with music and others. To support caregiver.	Theresa and Julian live together; Theresa provides care 24/7. Julian is dependent for all care needs. No respite or professional carers at time of research.
	Julian	Person with dementia (M)	Husband	Alzheimer's Disease	84		
5	Kelly	Caregiver (F)	Wife		63	To provide opportunities for interaction and enjoyment. To support caregiver and reduce stress for Kelly.	Kelly and Ray live together. Kelly provides care 24/7, although Ray is not completely dependent (e.g. can manage meals and dressing with some support). No respite or professional carers at time of research.
	Ray	Person with dementia (M)	Husband	Vascular Dementia	84		
6	Daniel	Caregiver (M)	Husband		76	To help with low mood, anxiety and delusions / hallucinations.	Daniel and Hazel live together. Daniel provides care 24/7. Hazel is not completely dependent but needs support to do most things. No respite or professional carers at time of research.
	Hazel	Person with dementia (F)	Wife	Parkinsons with Lewy Body Dementia	77		

4.5 Coronavirus Disease 2019 (COVID-19) Safety Measures

The MT intervention and research interviews took place between September 2021 and June 2023. In September 2021 COVID-19 restrictions had lifted but advice regarding vaccinations, wearing a face mask and ventilation was still in place. Mindsong had its own guidance to keep clients and therapists as safe as possible, and these were followed for the MT intervention and research interviews (see Appendix 11, p.359).

All MT sessions and research interviews took place in-person, in the research participants' own homes. During the first interviews for the first two couples (cases one and two), I wore a mask and sat a distance from the participants. This may have resulted in less engagement from the person with dementia, especially in the first interview with the first couple. I always phoned ahead to check that everyone was well, and to reassure that I had tested negative and had no symptoms. Mindsong collected information about COVID-19 vaccinations, so were able to confirm that I and the research participants were up to date with relevant vaccinations.

4.6 Data Collection

4.6.1 Interpretative Phenomenological Analysis

Interviews

All caregivers completed three interviews each: before the intervention, after the sixth session of MT, and after the intervention. Where possible, the person with dementia was also included in the interviews. All interviews took place in-person, in the participants' homes, and were video recorded on an encrypted device. The interview schedule was followed, but with flexibility to explore different questions or thoughts as they arose, in response to the participants' comments. All data was pseudonymised at point of collection.

Social Positioning

Despite concerted efforts to educate societies about dementia, there remains stigma and negative stereotyping towards people living with dementia (Sabat, 2018). Social positioning, how one person is held in regard by another, can significantly affect a person's self-esteem and quality of life, and there are many accounts of people with dementia experiencing negative social positioning from others, resulting in feelings of depersonalisation and disempowerment (Sabat, 2018). Snyder (2009) recounts interviews from people with dementia about their experiences of receiving their dementia diagnosis, and even here, when interacting with dementia specialists, there were elements of negative positioning towards the person with dementia from the professional (Snyder, 2009). By extension, this must also affect family

members caring for a person with dementia, who are often intimately involved in their partner's dementia journey.

Due to the awareness of negative stereotyping and perhaps past experiences of negative social positioning, a caregiver may naturally assume a protective stance when interacting with a new person about their loved one's dementia and their own experiences of caring. As well as protecting self-esteem and dignity for themselves and the person they are caring for, they may also feel the need to protect themselves against any potential judgement by a visiting professional as to how well they might be caring and coping in their current, often challenging, situation. This feeling may be intensified when the visiting person is coming into their private home. In these situations, it is understandable for a caregiver to extend their protective 'mask' around the situation.

In my clinical experience, it can sometimes seem that there is some protective masking that occurs on first talking to a caregiver about their situation. I recall situations where, whilst visiting a couple on an assessment visit, the caregiver has commented that everything is fine and that they are coping well, brushing off the possibility of the challenges of caring in initial conversations. Of course, in some cases, the caregiver is coping well and this reflects how they genuinely feel. However, there are cases where, over time, as the couple get to know their Music Therapist and build a relationship with them, the caregiver feels more able to express honestly, acknowledging that the caring role brings stressful and exhausting situations. Sometimes, in the evaluation of MT@H, post-intervention scores looking at wellbeing have been worse than pre-intervention scores, and when this is examined, it has been due to the caregiver feeling more able to talk honestly about their situation once familiarity and trust have been established.

Building Trust

Building trust in the researcher–participant relationship has been identified as a key factor in the successful creation of rich qualitative data (Guillemin and Heggen, 2009; Costas Batlle and Carr, 2021). With this, and my clinical experience in mind, I felt it was imperative to build trust in the relationships between myself and the research participants. I was going to be asking intimate details of the participants' caring experiences, and for them to be able to respond honestly, I wanted to instil confidence that I would treat the material given with respect. The method of participant recruitment, interview process and ongoing contact was thought through carefully with this in mind. Personal phone calls to introduce myself as researcher and allow the research participants opportunities to ask questions not only ensured they were

clear from the outset regarding the purpose of the research and what it would entail, but also allowed for the beginnings of a trusting relationship to develop.

There is also a need for a balance within the developing trusting researcher–participant relationship. There is a risk that within this trusting relationship, where the researcher is asking the participant to engage in conversations about their personal life, and perhaps intimate details about their experiences and how they feel, that the participant may share deep, personal insights they may later regret (Brinkmann and Kvale, 2008). It is the researcher's responsibility to remain sensitive to the participant, and if intimate, personal material is shared, to check with the participant following the interview that they are still happy for this to remain as part of the research data (Brinkmann and Kvale, 2008). In this study, there were some insights shared regarding sexual intimacy; this required sensitivity on my part as I presented this data. In writing up this section, I decided to summarise the findings instead of including verbatim quotations, as this felt more respectful and less intrusive to the personal lives of the participants.

Another risk within the trusting researcher–participant relationship is that, as this develops, the participant may want to please the researcher, and say things that he or she thinks the researcher may want to hear (Farnsworth, 2019). This is known as 'participant bias' (Farnsworth, 2019), and again, I needed to be sensitive to the risk of this happening during the research interviews, especially in interviews two and three, where I was asking participants about their experiences of the MT intervention.

Public Engagement

The interview schedules were developed following guidance from Smith, Flowers and Larkin (2009) and included open-ended questions that focused on experiences, with the aim of encouraging each caregiver to express their thoughts and feelings in a free manner. Prior to the start of data collection, I asked three caregivers (who had previously used the MT@H service) for their feedback on the questions I had developed. As the phenomena being studied is a potentially emotive subject, I wanted to ensure the questions were sensitive, gently inviting participants to share their experiences, without being too challenging or probing. The feedback was that the questions were challenging but not unreasonable, and made the caregivers reflect on their experiences. I was careful to frame the questions in a sensitive manner and let participants know that they could decline to answer a question if they felt it too personal, and to only share what felt comfortable to them. This information was

communicated in the Participation Information Sheet (see Appendix 8, p.322), and conveyed again at the first interview.

The Three Interview Structure

Interview One

The first interview aimed to further the participant-researcher relationship, the sense of getting to know someone; developing familiarity and trust. I also felt it was important for each caregiver to have the opportunity to tell their story, to have someone listen closely to the details of what they and their partner had been through to this point, and how this had felt. In my clinical experience, this has been an important part of the MT@H service. It is often the case that this is the first time in the couple's experience of dementia that anyone has sat down with them for a good length of time and really listened to their experiences. Thus, ethically, it felt important to include this within the research process. It also has the benefit of situating the research; of giving the findings for that couple context, and considering the effects of the intervention within the context of the relationship and experiences of the couple concerned. The interview schedule is presented in Appendix 12 (p.361).

Interview Two - Interpersonal Process Recall

The second interview, an Interpersonal Process Recall interview (Kettley, Kettley and Bates, 2015) aimed to focus on process; the process of the therapy itself, encouraging the caregiver to reflect on how they were feeling or what they were thinking at moments during the MT session. A video recording of the sixth MT session was watched by the caregiver and myself, and sometimes the person with dementia too. I asked the caregiver to comment on the video as they watched it, to talk about what they were thinking at the time, how they were feeling, and any reflections that came to mind. This interview was also recorded, so that the comments from the participants could be analysed using IPA.

Interview Three

The third interview occurred within a week or two after the 12 sessions of MT had been completed and provided an opportunity to reflect on the intervention as a whole, how the caregiver experienced this, and if the intervention had any effect on daily life for the couple. The schedule for these interviews is presented in Appendix 12 (p.361).

4.6.2 Microanalysis

The second interview also provided the opportunity for the caregiver to choose a section of music for microanalysis. Wherever possible, the person with dementia was also included in

this decision. In four of the cases, the person with dementia was present at the second interview and watched the video of the sixth session of MT with their caregiver and myself (cases one, two, four and six).

Whilst watching the video, the participants were asked to choose a musical moment for analysis. Trondalen's approach suggests sections of music may be selected where they reflect 'significant moments' (Trondalen, 2007, p.200). I offered guidance to the participants, suggesting that they could choose a moment in the therapy that demonstrated joint engagement, or where a creative impulse comes from the person with dementia, or a special moment for themselves or the couple. Once this guidance was given, I endeavoured not to lead participants and invited them to choose specific moments themselves. In five of the six cases, the caregivers identified the musical moments for analysis. In cases one, two and three, the participants with dementia were present but unable to comment verbally on the selection of the musical clip. However, in all three cases these selected moments provoked smiles, and in one case, laughter, and these reactions seemed to help the caregivers confirm their decisions in their choice of clip.

For one couple (case six), the interview ended early, as the person with dementia (Hazel) was anxious and unsettled when I arrived, and this became heightened during the interview. As Hazel became more anxious, it felt inappropriate to continue, so I stopped the recording and video and we listened to music together. Daniel (Hazel's husband and caregiver) held her and sang to her, and Hazel calmed. I restarted the interview and captured some more comments, but felt it might be too overwhelming to re-introduce the video recording of the MT session, so we were unable to choose a moment for microanalysis.

A different method was therefore required, so I asked their Music Therapist to suggest two clips for the participants to choose from, and Daniel chose one of these clips. This was communicated via email correspondence, but I also checked again with Daniel and Hazel at the start of the third interview, playing the selected clip of music and asking if they thought it was a good clip to choose for analysis, to which they agreed.

Reflection

Case Six - During this second interview I was concerned that watching the video of the sixth MT session may have exacerbated Hazel's anxiety. In the video, there is a conversation about Hazel's hallucinations and the therapist addresses this with a shared musical improvisation. This may have reminded Hazel of her hallucinations. Hazel was also listening to herself sing and commented that she thought she sounded awful. In addition, Daniel talked about potential triggers for Hazel's anxiety, commenting that there seemed to be no consistent reason for them, along with what helps (which is mostly music). It could have been any of these things, or a combination, that felt too much or in some way exacerbated Hazel's anxiety, although I couldn't know for certain. This reminded me of the findings from Holden *et al.,* (2019), where three couples withdrew from the MT intervention because of the stress it caused. I felt terrible about this, and although I couldn't be sure that it was the video that triggered anxiety for Hazel, I stopped the MT video and didn't return to this during the interview.

4.6.3 Variations in Intervention and Interview Delivery and Timings

There were some further differences in the overall duration of the intervention and interview process due to events including illness, a hospital admission and in one case, the death of the person with dementia before the intervention ended. This gentleman (SJ, case three) had participated in eight MT sessions and then suddenly became unwell with a chest infection, and sadly died. On offering my condolences, his daughter (Nia) expressed her wish to continue with the research but requested some time before the final interview, which was respected, and this took place two months after SJ died (see reflection below).

Reflection

Case Three - I was aware that talking about the MT intervention Nia had shared with her father so soon after he passed away might be upsetting for her. Instinctively, I had my therapist and researcher hats on during this third interview and made sure the pacing was gentle, altering the questions where necessary. For example, instead of asking question 1: 'How are things for you both at the moment?' I began by thanking Nia for her time, especially in the circumstances, and asked how the funeral service for her father had gone. This opened up the conversation and Nia reflected on the service and how music played a key part:

> **Nia: It was beautiful, really lovely. I found, quite last minute, I found a cellist … and also, we played, the organist had a keyboard and he played the fugue that Dad played … so we had those which was lovely. Yeah, it was really beautiful, I think he would have loved it.**

There was a flow in Nia's conversation and I allowed time for this, so she could express her thoughts and feelings as freely and deeply as she wanted to. I think I held this interview well; Nia was reflective but seemed comfortable being so, and happy for this and her father's clip for microanalysis to be included in the results.

There was also a delay in conducting the last interview for Hazel and Daniel (case six), because after the 12th MT session, Hazel became unwell and needed a hospital admission. Daniel wished to wait for her return home so she could be present in the final interview, so this took place a month after the 12th MT session. The therapist had extended the therapy to be able to support Hazel whilst in hospital and following her return home, therefore, it should be taken into account that Hazel and Daniel had received 16 sessions of MT at the point of the final interview.

The implications of differing intervention lengths and interview timings are discussed in the limitations section of chapter 10 (p.206).

Reflection

Case Six - I was acutely aware of what had happened in the second interview and so was careful when showing the clip from the sixth MT session for microanalysis, to check the couple's consent for this. Again, wearing my therapist hat, I carefully observed Hazel's body language and vocal sounds to alert myself to any signs of her becoming distressed. This time, she remained calm. I only played this one clip to the couple, and then returned to the schedule for interview 3.

Another participant died not long after the MT intervention and interviews had been completed (Louisa, case two). Her family expressed their wish for their data to continue to be included in the study.

Reflection

Again, this needed a sensitive and empathetic approach, and I was aware of my therapeutic skills being employed. I allowed some time after Louisa had died before contacting her daughter, Maria, and expressing my condolences. Maria was pleased to hear from me and recounted some of her experiences with her mother in her final days. Music played a significant part, and Maria expressed her gratitude to Mindsong for providing 'a bright star in a dark time'.

4.7 Data Analysis

4.7.1 Interpretative Phenomenological Analysis

Transcripts

Each interview was transcribed following guidance from Smith, Flowers and Larkin (2009). This involved watching each video recording, then carefully transcribing it into the transcript format (see Appendix 13, p.362). This is a lengthy process involving re-watching and multiple checks for accuracy. As each case involved three interviews, this resulted in three transcripts per case (18 transcripts in total).

Analysis

I worked systematically on one case at a time. Using the transcripts as the participants' text, I analysed each of the three transcripts chronologically (i.e. transcript relating to interview one first, then the transcript relating to interview two, and finally the transcript relating to interview three). The analysis process for each transcript is described below:

Step 1: reading and re-reading

- Reading the transcription along with watching the video – checking for accuracy and immersing myself in the interview.
- Thinking of the interview itself and identifying my own views, preconceptions or expectations – writing these down and bracketing them off: putting them aside in order to read again in an open manner.
- Reading the transcription through again without the video.

Step 2: Initial noting

- Reading through and making initial notes ('exploratory comments') in the right-hand column of the transcript. This was done by hand and the key employed was: descriptive comments in black pen, linguistic comments in green or blue, conceptual comments in red, body language comments in pencil. For an example, please see Appendix 14, p.363.
- Repeating this but starting at the end of the transcript and working backwards, in case of any tiredness by the end of the transcript in the first instance.
- Going through a third time thinking about initial notes/exploratory comments.

Step 3: Developing emergent themes

- Looking at the exploratory comments and trying to summarise the essence of what they were saying, writing these in the left-hand column. These became the 'emergent themes'.

Step 4: Searching for connections across emergent themes

- I chose to write down the emergent themes, cut them into strips and put them on the floor in order to group them into superordinate themes. Smith, Flowers and Larkin (2009) suggest methods to aid categorization, including:
  - Abstraction – finding similar themes and grouping them together under a new 'superordinate' theme that summarises at a higher level
  - Polarisation – the development of a superordinate theme by grouping opposites of the same element together, for example, the positive/negative experiences of dementia, under 'Experiences of dementia.'
  - Numeration – the number of times something is mentioned may indicate its importance and justify becoming a superordinate theme.

  These different methods were employed where appropriate to help identify the superordinate themes in the data.
- I then created a table, listing the superordinate and subordinate themes alongside evidence in the text with verbatim quotations (see Appendix 15, p.364 for an example).

(Smith, Flowers and Larkin, 2009, pps.82-107)

This was an iterative process which required revisiting the different steps to enable a deep examination of the data. The hermeneutic circle was key in the analysis process; looking for meaning in its smaller parts (e.g., words, sentences, phrases) as well as the data set as a whole (the whole interview), and how these interrelate (Smith, Flowers and Larkin, 2009).

During this stage, the data was considered and interpreted within my knowledge of the wider context of MT and dementia, including in relation to existing literature about caregivers' experiences. One helpful aspect of my understanding gained from working as a Music Therapist in this context, was that I expected each participant's experience of dementia, whether as the person with the disease or the caregiver, to be different and unique to them, and result in unique circumstances. I believe this helped me to keep an open mind throughout the study, including during the analysis stages. Conversely, my many positive experiences of using MT to support people with dementia and their families had the potential to colour my interpretations of the participants' experiences. I was aware of this possibility throughout the process, and attended to this vigilantly during the analysis stage, to make sure that I understood from which perspective I was interpreting the data. As commented on in my reflexive statement, I continually questioned through which lens I was examining the data, challenging my understanding in order to interpret the findings in a manner that stayed as true as possible to the participant's meaning and understanding.

Steps one to four were repeated for each interview transcript.

I decided to undertake the music microanalysis after I had competed the IPA for interview two for each case, as this fitted naturally with the time schedule of the interview; participants had chosen the clip for microanalysis during interview two. I felt this also helped to embed the microanalysis within the IPA process. I returned to complete the IPA for interview three after I had completed the microanalysis.

4.7.2 Microanalysis

Taking the section of music selected by the caregiver for the same case for which I had just completed the IPA for interview two, I engaged in microanalysis of that music, following the steps suggested by Trondalen:

1. **Acknowledging any known aspects of the case**, for example, dementia diagnosis, clinical history, any prior knowledge of social or personal history, and bracketing these aside so that I could approach the music in an open, unbiased manner. This was an

important step as I had just completed IPA for two interviews, and so had prior knowledge about the participants' situation and experience from this. Bracketing off this knowledge to the best of my ability allowed a fresh approach to the microanalysis.

2. **Immersing myself in the data** with 'open listening': repeated listening to the music so I became very familiar with it. This included body listening; noting any movements I made in response to listening to the music.

3. **Listening again with a focus on structural elements**. This included completing a graphic sound intensity profile, which describes the intensity of sound experienced over time for each clip of music (see Appendix 16, p.365 for an example). Trondalen also suggests completing a 'Structural Model of Music Analysis' (SMMA; Grocke, 2007), which facilitates the recording of specific musical elements, including style, form, texture, harmony and rhythm. I completed a SMMA for each clip of music, but made an alteration to the SMMA for the purpose of this research (see explanation below, p.81).

4. Listening again with a focus on how the elements above might relate to any comments or movements made by the participants; **looking for explicit and implicit** meanings within the music.

5. Listening again with a focus on **looking for the potential effect of the music** within the overall MT process, e.g., 'What is happening at this moment in the music?'

6. **'Phenomenological horizontalization'**: noting all the themes that have come to light with the aim being to 'dwell within the results so far' before bracketing them off (Trondalen, 2007, p.202).

7. Engage in another **open listening, including a body listening**. Noting any responses.

8. Creating a **'Phenomenological Matrix'**: summarising the data in terms of the music itself, the potential meaning of the music, and the potential effect of the music within the therapeutic process (Trondalen, 2007, p.203).

9. Write a **summary of the findings** from the microanalysis for this individual case.

(Trondalen, 2007, pps.200-209.)

Altering the SMMA

Trondalen (2007) suggests using Grocke's 'Structural Model of Music Analysis' (SMMA; Grocke, 2007) to facilitate the recording of specific musical elements within the section of music being analysed. This is a table that prompts the analyst to identify particular elements of the music, including style, form, texture, rhythmic features, tempo, melody and harmony (see Appendix 17, p.366). I chose to complete this for each musical clip selected for analysis. However, there were sections within the SMMA that did not feel appropriate for the purposes of this analysis. This applied particularly to the 'Performance' section of the SMMA, which asks the analyst to comment on the integrity of the performers, how well the piece was performed, whether it was authentic to the composer's wishes, and elements of stylistic interpretation. Since the music created in MT sessions is part of the therapy and not a performance, the outcome is never judged, and musical merit is irrelevant. For moments of improvisation, there are also no previous composer's wishes, as the piece is created in the moment.

It is the process of creating the music itself that is of interest and can give insight into how participants may be feeling, or what they may be communicating. I therefore ignored the 'Performance' section of the SMMA. Instead, I found myself being aware of the techniques the therapists were employing to try to elicit the most engagement from the participants, and to provide containing music in order for participants' expressions to be freely communicated. I therefore created my own subsection, 'Therapeutic Techniques' and noted down examples of 'holding, matching, pacing and inviting' as I saw them in each musical clip. An example of this can be seen in Appendix 17 (p.366).

4.7.3 Analysing the MT clip using Kitwood's Flower

As Mindsong's MT@H service is underpinned by this theoretical framework (Kitwood, 1997, see p.18), I thought it would be interesting to see which elements (if any) of the five suggested psychological needs were being addressed in these short video clips of MT. I used my knowledge gained from the microanalysis of each case to reflect on if and how the five needs identified by Kitwood were being addressed for the participants. I think of this extra stage of analysis as an extension of microanalysis, and have included a summary of how the MT relates to Kitwood's flower at the end of each presentation of the microanalysis findings (see p.117, for example).

4.8 Synthesising the Findings

I employed my own method of bringing IPA and microanalysis together, which included taking each individual case and juxtaposing the results from IPA and microanalysis. I was particularly looking for anything in the microanalysis that resonated with the findings from IPA, or that contradicted them. I was also looking for any new themes or understanding that emerged from the microanalysis. Taking the findings from both methods of analysis, I then wrote these up into an individual case summary. The case summaries were crucial in synthesising the findings from IPA and microanalysis, and give an in-depth account of each dyad or triad's experiences, as I have understood them. I have been unable to include all case summaries in this thesis due to the word count limitation, but an example can be found in Appendix 3 (p.268).

Step 5: Moving to the next case (Smith, Flowers and Larkin, 2009)

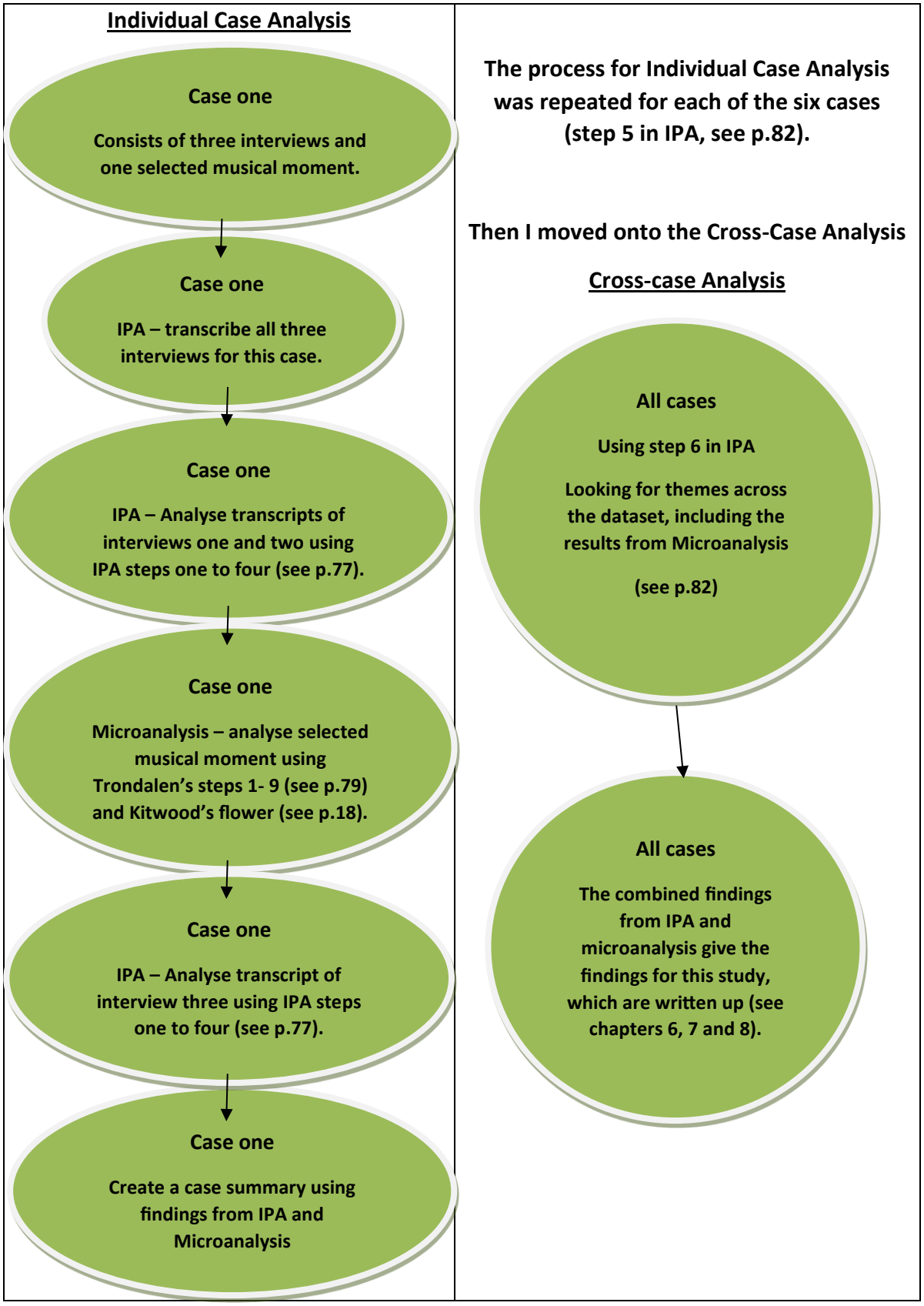
Once I completed a case summary, I moved onto the next case, and repeated the steps above, for both IPA and microanalysis. I did this for all six cases.

Step 6: Looking for patterns across cases (Smith, Flowers and Larkin, 2009)

On completion of the six case summaries, step 4 was applied again, but across all six cases, to create superordinate and subordinate themes for the whole dataset. I did this by revisiting the superordinate and subordinate themes of each case and comparing them across the six cases, identifying repeated themes across the data, re-grouping, and in some cases, re-naming superordinate themes. The case summaries were useful in giving an overview of the individual experiences. There were some themes that were common across many of the cases. Other themes were less frequently mentioned, but nonetheless, seemed important to the participants' experiences, so have been included in the findings of the study. I then created a table, listing the superordinate and subordinate themes for the whole dataset, alongside evidence in the text with verbatim quotations (see Appendix 18, p.372). Finally, I wrote my Findings chapters, taking each superordinate theme in turn (see pp.99-193).

The analysis and synthesis processes were lengthy and complicated, and in the interest of transparency, I have created a diagram for clarification (see figure 2, below). The process presented in the left-hand column is repeated for each of the individual six cases, before moving onto the cross-case analysis, presented in the right-hand column.

Figure 2: Diagram to illustrate Analysis Process



4.8.1 Creating a Visual Representation

Throughout the analysis stages and in writing up the findings from both IPA and microanalysis, I was aware that the three superordinate themes resulting from the data overlapped and interwove with each other. I wanted to reflect more deeply on the relationship between these themes, so I turned to an arts-based approach to help further my understanding, creating a visual representation.

I initially worked with an artist to create the images, using paint as a medium to explore different shapes, colours and patterns to represent each theme. This helped to confirm which images I felt best represented the themes, and resulted in a final kaleidoscope image. I explain this process in chapter 9 (p.194).

4.9 Conclusion

This chapter has presented my methods in detail, including the early research stages of participant recruitment, the delivery of the intervention, data collection stages and data analysis, including how I synthesised the different methods of analysis employed. The chapter also includes some reflections on the research process, particularly in relation to the research participants.

Chapter 5: Ethical Considerations

5.1 Introduction

This chapter describes the consideration given to ethical issues within the research, and reflections on the process of applying to an NHS Research Ethics Committee (NHS REC), including using the Integrated Research Application System (IRAS, 2023).

Although this study focuses on the experiences of family caregivers (caregivers), people with dementia are integral to the research, being in relationship with the caregiver and of central importance within the MT sessions. Indeed, it is the caregiver's experience of being with, or caring for, the person with dementia that makes them eligible for the MT and this study. The inclusion of microanalysis of selected moments of music from the participants' sixth MT sessions allows the possibility of representing the participants with dementia more fully in the research data. As the Music Therapists tailor the therapy to best attune and connect with both person with dementia and caregiver, it is often the connection with the person with dementia that becomes the focus of the work (as described in Melhuish, Grady and Holland, 2019). Wherever possible, the participants with dementia were also included in the research interviews, as their experiences of the therapy are of equal value and importance, and add to the understanding of the wider context.

This study therefore involved working with vulnerable people, whose mental capacity may or may not be in question due to advancing dementia. As a clinician working in this field, acting in a sensitive and ethical way is of paramount importance, and it follows that this would also be a central tenet to my research. Indeed, I feel that the whole study is shaped around ethical concerns, and this is why I have dedicated a chapter to this subject.

5.2 Ethics in Dementia Research

5.2.1 The Mental Capacity Act – Informed Consent

This was one of the main ethical considerations for the study, as the participants with dementia involved would be in advanced stages, and therefore may or may not be able to give informed consent. The Mental Capacity Act (2005) states that a person is not able to make decisions if they are unable:

(a) to understand the information relevant to the decision,

(b) to retain that information,

(c) to use or weigh that information as part of the process of making the decision, or

(d) to communicate their decision (whether by talking, using sign language or any other means).

(Mental Capacity Act, 2005)

The Act also states that, wherever possible, a person should be supported to make a decision where they can, which may involve presenting information to them in a tailored way relevant to their circumstances: for example, with the use of visual aids, talking, or sign language. Where informed consent is not possible even with support, a 'Best Interests' decision may be made on their behalf (Mental Capacity Act, 2005). This involves another person, usually a significant other to the person with dementia or a professional working with them, making a considered decision, based on what would be in the best interest of the person with dementia, and taking into account any knowledge of that person's previous decisions, views and beliefs. For this study, any best interest decisions were made by the caregiver, who sometimes discussed with other family members before making the decision. The Mental Capacity Act (2005) legislation informed this study throughout.

5.2.2 The 'DEEP-Ethics Gold Standards for Dementia Research' (DEEP, 2023).

Between 2019 and 2022, an innovative programme, 'Dementia Enquirers', supported people with dementia to create and conduct their own research studies on topics relevant to their situation (Innovations in Dementia, 2023). This included subjects such as discrimination in dementia (Beth Johnson Foundation, 2021), post-diagnostic dementia support (The Forget Me Not Research Group, 2022) and driving and dementia (Shindig, 2022). Following the success of this programme, people with dementia involved in the research and collaborating university researchers worked together to create the 'DEEP-Ethics Gold Standards for Dementia Research' (DEEP, 2023). This tool identifies six key standards to follow when conducting research within the context of dementia. The inclusion of people with lived experience of dementia in the creation of these standards makes this an important development in the consideration of ethics in dementia research studies.

Although the first version of this tool was published in 2020, I was unaware of it at the time I planned this study and applied for ethical approval. Nonetheless, I feel it is important to include it here, and to reflect on my research processes in relation to it.

The standards are summarised as follows:

1. **Working in real partnership (co-production)**

   Involving people with dementia from the start, including identifying research topics and the development of study design, as well as conducting the research. This standard is about valuing and respecting the lived experience of people with dementia, their views and knowledge.

2. **Respect and acknowledgement**

   This standard goes into more detail about how researchers can facilitate participation for people living with dementia, including guidance on use of language, avoiding stereotyping and assumptions; making the study as inclusive as possible.

3. **Safety and wellbeing**

   Researchers should ensure that the risks and benefits of participating in the study are clearly identified and communicated. Practicalities, such as timings and locations for research interviews, should be taken into account, and any extra support that the person with dementia might need in order to take part should be facilitated. This standard also covers emotional wellbeing and reminds researchers to use 'emotional intelligence' whilst conducting research, and to offer support or signposting where this would be helpful.

4. **Informed consent and capacity**

   This standard reflects the legislation from the Mental Capacity Act (2005, see p.85) but goes into more detail regarding how this can relate specifically to participants living with dementia. Researchers should always start from the viewpoint that the person with dementia has capacity to understand and make informed decisions about the study, and has the ability to give informed consent. Information should be tailored in whatever way makes it easier to understand. If a person lacks capacity to make an informed decision, a consultee can help to establish whether taking part in the study is in the person's best interest and something they would have chosen to do. This standard also acknowledges that capacity can fluctuate, and consent should be an ongoing process throughout the study.

5. **Confidentiality and anonymity**

   All information collected during a research study should be confidentially held, with features that might identify a person removed. Researchers should be transparent about what the research is for and how data will be used, including how results will be disseminated.

6. **Information that is simple, accessible and open**

   Information should be presented in a way that does not overload and is comprehensive but clear, using visual aids or other forms of appropriate communication where necessary, to make the information as accessible to the person as possible.

   (DEEP, 2023)

5.3 Reflecting on this study

The standards created by DEEP (2023) are comprehensive and rightly imbued with a respect for the views and experiences of people living with dementia. Although I did not know about this tool until the final stages of my research, some aspects of the standards are reflected in the study design and decisions I made during the research process. These were also guided by the application to NHS REC, which I will comment on later in this chapter. I now present how each of the standards relate to this study.

5.3.1 Working in real partnership (co-production)

I cannot claim that this study was designed in co-production, either with people living with dementia or their caregivers. However, the inspiration for the study came from my clinical work in this context, from reflecting deeply on my perception of the experiences of people with dementia and their caregivers who participated in Mindsong's MT@H service. Therefore, the study creation and design were informed by my experiences and interactions with people in this context. In addition, I took advice from people who had previously participated in the MT@H service in the development of the interview questions (see p.72, on Public Engagement).

5.3.2 Respect and acknowledgement

I believe I have held the views and experiences of all the research participants in high regard throughout the study. The inclusion of microanalysis of music from the sixth MT session has

ensured a fuller presence of the person with dementia in the research data, and wherever possible, the person with dementia was also included in the interviews. To aid this, the interviews were conducted with sensitivity to pacing, leaving space for extra processing time for the person with dementia (where necessary), acknowledging and validating their contributions as well as those of the caregiver, and taking into consideration vocal expressions and body language as communications, as well as conversation.

There were also a number of adjustments made to the interviews in response to situations that arose in the moment. In the middle of one interview, the person with dementia exclaimed 'Let's sing!' and so we did, and this brought eye contact, smiles and a sense of fun to the interview, following which conversations seemed to flow more easily.

Other adjustments to interviews and the intervention have already been described in the methods chapter (see p.75) but, in brief, included adjusting interview timings, interview questions, and overall intervention length, in order to facilitate optimum participation in the research process, and to suit what seemed best for both the person with dementia and caregiver.

5.3.3 Safety and Wellbeing

The risks of this study were clearly communicated in the Participant Information Sheets (see Appendix 8, p.322), which included a clear but simpler version produced for the person with dementia in mind. This was on advice from the NHS REC (see section 5.4.2, p.96).

I considered the risks and benefits of the study as follows:

The Clinical Intervention

The MT@H intervention is designed to be person-centred and to support the wellbeing of both the person with dementia and caregiver, therefore it was anticipated that there would be benefits for participants engaging with this intervention, with no specific risks identified.

From previous clinical experience, there have been a few cases where a person with dementia has not engaged with MT or has found MT too much and withdrawn from sessions. Sometimes, the therapist, working in a highly sensitive manner, has continued to work with the person through to a helpful outcome. In other cases, the therapy has ended early. Mindsong Music Therapists always respect the decisions made by the person/couple, taking into account the non-verbal communications that may indicate a person wishes to stop. These

cases are rare, as the therapy is personalised and responsive to each person the therapist is working with. However, it was made clear to each participant (or dyad) that they could withdraw from the intervention at any point should they wish to. As it happened, none of the participants requested to withdraw from the intervention.

Mindsong's Music Therapists are specialists in working in dementia care, and all therapists involved in this study were already experienced in this context. All Mindsong therapists are DBS checked and attend safeguarding training every three years. A risk assessment was developed for the study, along with individual risk assessments completed for work with each participant (following standard Mindsong practice). The Music Therapists also follow Mindsong's Safeguarding and Health and Safety policies.

Interviews with Family Caregivers

Because the focus of the research was on discovering caregivers' experiences, I was aware of the potential for some upsetting material to arise. I was careful to stress to participants at the start of each interview that they should respond as openly and honestly as they felt comfortable, and that they could stop the interview at any time.

Being a therapist myself, with 17 years' experience of working with people living with dementia, including talking with family members about their experiences, I felt confident that I could conduct the interviews in a sensitive manner, with the participants' wellbeing remaining paramount throughout. There was a small risk of covering topics that may have been distressing to the caregiver, and a risk of the person with dementia feeling excluded. I was attentive to these risks throughout the interview process and tried to anticipate and mitigate them, for example, by using sensitive pacing in order to facilitate the participation of the person with dementia. In addition, I agreed with Mindsong that a member of the therapy team would be available for a participant to talk to, if they found the intervention or interviews upsetting in any way. Although this was communicated to the participants, this extra support was not required during the process of the study.

Considering the Music Therapists

The Music Therapists facilitating the intervention for this study were all experienced in working with people with dementia and their families. However, dementia can cause challenging circumstances, and the MT@H service involves working with people towards the end of their lives. This can sometimes be upsetting for the therapists themselves, particularly as they build trusting relationships with each person they work with. All Mindsong therapists are

encouraged to engage in ongoing clinical supervision, which can help to support personal feelings that arise during or after delivering a course of therapy. In addition, Mindsong provides phone call support should any challenging circumstance arise. For this study, my colleague, Ruth Melhuish, an experienced Music Therapist, was the first point of contact for any difficulty. This was reiterated to all therapists who participated, although in the event, this support was not required.

COVID-19 Considerations

This study began in the midst of the COVID-19 pandemic, during one of the UK lockdown periods. When I began the research, it was unclear if the MT intervention or the interviews would take place in-person or online. I was hopeful that by the time data collection was due to start (September 2021), we would be able to conduct the interviews and MT in-person, and indeed, this is what happened. However, at the time of submission to the Ethics Committees, this was unclear, so I developed a separate study protocol and relevant documents to cover any further COVID-19 lockdown periods.

Some of the main ethical considerations in the protocols relating to COVID-19 included supporting people to access the intervention and interviews online, encouraging the participants to find a safe and private space in their house for the Zoom sessions, and using passwords to keep the Zoom meetings secure from any online hackers.

5.3.4 Informed consent and capacity

In accordance with the Mental Health Capacity Act (2005), issues of informed consent and capacity were considered as paramount during the design of the study and throughout the research process.

Informed Consent

After potential participants had indicated their interest in the study and given their consent to share their contact details (see p.66 on Participant Recruitment), I made an initial phone call to discuss the study and to provide an opportunity for the potential participants to ask any questions. During this phone call, I also asked if the person with dementia would be able to make an informed decision about taking part in the research. Two of the caregivers said yes, therefore, in these cases, I sent both versions of the Participant Information Sheets (PIS, Appendix 8, p.322) to them in the post, including the simplified version for the person with dementia (see Appendix 8c, p.335). For the remaining four couples, the PIS and Consultee

Information Sheet and Declaration forms were sent (see Appendix 8e, p.342 for the Consultee Information Sheet, and Appendix 10e, p.357, for the Consultee Declaration Form). The Consultee Information Sheet explains the person with dementia's part in the research so that the caregivers could make informed decisions, based on their partner's 'best interest'.

Potential participants were encouraged to take time to read through the PIS and carefully consider their decisions, both for themselves and when making decisions on behalf of the person they were caring for. I offered phone calls to talk through the research, answering any queries, and suggested that participants could talk the decision through with other family members or friends, if that felt helpful to them. Following the initial phone call and posting out the information sheets and consent forms, I rang the participants again after a week, to ask if they had come to a decision about taking part.

It was important to reassure caregivers that the MT intervention would still be available to them if they declined to take part in the research, and that there was no pressure to take part. It was also made clear that participants could withdraw from the MT or the study at any time and could also withdraw their data up until the point of analysis, where the data would be pseudonymised and obvious identifiable information removed.

The participants were asked to sign the Consent and Consultee Declaration forms and return to me at the start of the first interview. In addition to this, the participants were asked again for their consent at the start of each interview, both to take part in the interview and to have the interview recorded.

Due to the lengthy duration of this study and being conducted only part-time, I knew it could be some time between interview stage and the study being finished, and that during this time there could potentially be some difficult developments for the participants, including the possibility of increased dementia symptoms, and even the death of one or both people within a dyad. I therefore kept in contact with all the participants during the course of the study, writing annually to update them to reassure that I was still working on the study, and to give them an opportunity to respond. As anticipated, there were some significant changes for the participants during this time, including the death of three of the participants with dementia. These moments were responded to in a sensitive manner, as I have reflected on in chapter four (see pp.75-77).

Informed Consent to Music Therapy

Mindsong's standard practice is to ask for written consent from each person before MT commences. As many of the people who access Mindsong's MT@H service are experiencing advanced or complex dementia symptoms, family members are often involved in making this decision on behalf of the person with dementia. Consent is recorded on written forms and stored securely. Mindsong's Music Therapists are also encouraged to ask for verbal consent at the start of each session, making sure that ongoing consent is obtained. In some respects, asking for consent to a MT session seems easier than requesting consent to a research study. For example, the Music Therapists can make use of visual aids, such as the instruments themselves, to support understanding. This is more difficult regarding consent to a research study, which may feel quite abstract and more difficult to communicate in comparison.

The Music Therapists were reminded of the request to ask for verbal consent for sessions for the purpose of this study. They also asked for consent verbally when recording the sixth MT session (for research purposes). Consent to record the sixth MT session is covered in the initial consent forms, but it felt important to also check in the moment that the participants were still happy for this to happen.

Informed Consent from the Music Therapists

This study involves Mindsong's Music Therapists, and in particular, the recording and analysis of music from the sixth MT session that they facilitate with the participants. It was therefore necessary to also gain consent from each Music Therapist involved.

The study was explained to the therapy team at a Mindsong team day, with written explanations also given in the form of a PIS (see Appendix 8c, p.335). The Music Therapists had opportunities at this meeting and afterwards, via phone call, to ask any questions about the study and their involvement.

The MT@H administrator asked for the Music Therapists' consent to be involved in the research. This was to avoid any pressure that the therapists might have felt if I had asked them directly. It was made clear to the therapy team that there was no obligation to take part, and that their decision either way would not affect any future employment opportunities with Mindsong. The therapists would be able to withdraw at any point up until data analysis, where their data would also be made pseudonymous. In the event, all of the Music Therapists gave

consent to be involved in the research, and no one requested to withdraw their participation or their data.

5.3.5 Confidentiality and Anonymity

Confidentiality and management of research data relates directly to the safeguarding of participants, and was considered carefully in relation to this study.

A Data Management Plan, Participant Privacy Notice and Data Protection Impact Assessment were created and followed to ensure the research data was GDPR compliant and confidentially held (see Appendix 19 for the Data Management Plan, p.404). In accordance with the data management plan, all documents relating to the study were securely stored and only shared where necessary, using secure UWE OneDrive.

The research interviews were recorded by myself on a secure device and kept in a locked filing cabinet, to which only I had access. Back-up recordings were stored on UWE OneDrive. All research documents were either stored securely on UWE OneDrive, or, in the case of hard copies, in a locked filing cabinet, in accordance with the Data Management Plan.

To ensure continued confidentiality, each participant was given a pseudonym and personal identifiable data was removed from the point of the first interview. Therefore, all data stored had no obvious identifiable features.

At the end of the research period, after the thesis and related papers have been written, all collected data will be destroyed, according to UWE's secure waste disposal system; electronic data will be deleted and hard paper copies shredded.

As the collaborating organisation, Mindsong also agreed to the terms of the Data Management Plan. The Music Therapists involved in the study made video recordings of the sixth MT session on secure devices. These recordings were uploaded, stored and shared with myself via OneDrive and accessed by myself on a secure laptop. Once uploaded, recordings made on the original devices were deleted.

In addition to these steps, all information about the MT intervention was held as confidential. As the MT@H service is a clinical intervention, all clinical notes, referral forms and any assessments made are held confidentially and stored securely. This is standard practice at Mindsong. The Music Therapists follow standard therapeutic practice and do not discuss any

details of the therapy, except within the confidential space of supervision, or with a senior member of the team if necessary (for example, if there were concerns regarding the case, or issues of safeguarding raised).

5.3.6 Information that is simple, accessible and open

The Participant Information Sheets (PIS) were designed to be as clear as possible, with the relevant information provided in a straightforward format. The PIS and Consent form designed for people with dementia aimed to include the key information points in an accessible manner (see Appendix 8, p.322 for the PIS, and Appendix 10, p.352 for Consent forms). In addition, participants were given the opportunity to ask questions about the research over the phone, and at the start of the visit for the first interview.

5.4 Application to NHS and UWE Research Ethics Committees

As this study involved people who may not be able to give informed consent, and participants who may have been referred to Mindsong by NHS professionals, I needed to gain ethical approval from both NHS and UWE Research Ethics Committees before I could begin the research process. This involved completing an application via IRAS and attending an NHS Research Ethics Committee (NHS REC) meeting, as well as submitting paperwork to a UWE Research Ethics Committee (UWE REC).

5.4.1 Process and Reflections

Following advice from my supervisors, I began the NHS REC application early in my studies, once I was clear about my study and the methods it would involve. The IRAS is a responsive, online form in which all data relating to the study is entered and, once completed, submitted to an NHS REC for consideration. I started work on this in October 2020, and finally submitted to NHS REC on 6th April 2021.

The application also requires the submission of all supporting research documents, so this involved the early development of a study protocol and all participant information documents, as well as an agreement between UWE Bristol and the collaborating organisation, Mindsong. In total, 32 supporting documents were submitted along with the application (see Appendix 7, p.293 for the Study Protocol).

Following submission via IRAS I was invited to attend an NHS REC review meeting, where NHS representatives, with particular experience and excellence in ethical review, considered the

application. The committee looked at the study in detail and considered it from the potential participants' perspectives.

5.4.2 Unanticipated issues arising from the ethical review

Despite my careful consideration, issues were raised that I had not anticipated, and adapting the study to address these concerns has made the study more ethically robust and sensitive to each participant's circumstances.

Creating simplified Participant Documents for the Participants with Dementia

The committee suggested that I created a simplified version of the PIS and Consent form for participants with dementia, as the original versions were detailed and might overload a person's decision-making capacity. I found it challenging to ensure all the key information was kept in the document, whilst reducing the amount of text. I also wanted to make sure I presented the information in a non-patronising manner. I managed to do this, and the committee agreed these new documents after my resubmission (see Appendix 8c, p.335 and 10c, p.355).

Allowing flexibility to the time and location of the research interviews

In my original ethics application, I suggested that each interview might take approximately an hour, thinking this would be a good length of time for some rich conversations, but not too long to be intrusive into the participants' valuable time. However, the NHS REC advised that I should build more flexibility into this approach, and to consider that for a caregiver looking after someone with dementia, an hour may be too long. The suggestion was that an interview could take place over two or three different sittings of shorter time periods.

Consideration was also given to the venue for the interviews. I had suggested that the interviews could take place in the participants' own homes; I thought this might be the easiest way for both the caregiver and person with dementia to be able to take part in the research interviews, that they might be more comfortable in their own home and would not be required to travel to a venue. This was informed by my clinical experience; knowing that challenges in leaving the house due to frailty, reduced mobility, or issues regarding confusion and anxiety about coming to a different place for the person with dementia, may make attending an alternative venue impossible. The committee suggested I allow additional flexibility here; that the interviews could take place in the participant's home, at an alternative venue, or online, should the participants prefer this option.

In short, I had made assumptions based on my clinical experience, and the NHS REC challenged these, suggesting that I allow flexibility, giving the participants the choice as to where the interviews took place, and how long they would last.

I built these alterations into the study, and when planning the interviews with each participant, I offered these flexible options. However, in each case, the caregivers preferred the interviews to happen in their own homes, and were happy for the interviews to take place in one sitting.

Considering COVID-19

I had already created a second study protocol and documents in case another wave of COVID-19 and subsequent lockdown affected how the research might safely be carried out. The NHS REC suggested that instead of these being separate documents, that I merge the two protocols, so I could move easily between online or in-person methods should I need to do so. The combined study protocol can be found in Appendix 7 (p.293), with text relating to COVID-19 in green.

5.4.3 Ethical Approval

I incorporated all the committee's requests into my research process and documents, and on resubmission, the committee gave their ethical approval on 10th May 2021. I sent this along with the research documents to the UWE REC, and their ratification followed on 3rd June 2021 (see Appendix 6, p.286 for letters of ethical approval).

5.4.4 Requesting an Adjustment to the Study

The selected musical moments for microanalysis provide illustrative examples of how MT can support people living with advanced dementia and their caregivers. In each case, these video clips show the MT enabling a time of engagement, shared interaction, and in some cases, moments where the person with dementia engages in complex cognitive processes, that family members comment were not seen at any other time. These short clips exemplify how MT can empower the person with dementia, and support the relationship between the dyad.

In my original application for ethics approval, I had not anticipated how insightful and powerful the video clips might be and did not think to include them in the final thesis submission. However, following the analysis and synthesis process, I realised that their inclusion could make the thesis richer and perhaps add extra depth and understanding to the findings. I therefore applied to the NHS REC for an adjustment to the study, in order to include them in my thesis submission. This would involve asking the caregivers and people with dementia for

consent for this purpose. At this point in the research process, three of the participants with dementia had died, and dementia had progressed for the other three participants, so they would not be able to give an informed decision. I therefore proposed to ask the caregivers to give their consent and to make a 'best interest' decision on behalf of the person they were, or had been, caring for. I sent the proposed Consent and Consultee Declaration forms to the NHS REC, along with my suggested change, stating that I would keep the videos securely stored, and that the examiners and any future readers of the thesis would have access to the videos by contacting myself for a secure link to access them.

Unfortunately, my request for this adaptation was given an unfavourable decision, so I have not been able to include the video clips within this thesis submission. The main reasoning behind this decision related to maintaining the privacy and safeguarding of the participants, and what would happen to the videos if I became unable to respond to requests to view, or to manage the secure storage of the videos. Of course, I have respected this decision.

The musical moments remain important elements of this study, and as I am unable to share these via video, I have included written descriptions of each musical moment within the microanalysis findings of each case. For an example, please see p.115.

5.5 Conclusion

I believe that the considerations given to ethical issues have shaped this study from the start and have remained of central importance throughout the research process. The value placed on the participants' engagement and contributions has been paramount, and their wellbeing has always been of fundamental importance, informing both study design and how the research was conducted.

Chapter 6: Findings:

Overall Summary and Superordinate Theme 1: Relationships

6.1 Introduction

In this chapter, I introduce the main findings from Interpretative Phenomenological Analysis (IPA) and music microanalysis. During the analysis stage as the findings came to light, it became clear that, in addition to Kitwood's theories referred to in chapter one (see p.18), the theory of Attachment would also be an important framework through which to consider the data. Smith, Flowers and Larkin (2009) acknowledge that new theories and literature may be introduced at this point, as they relate to the findings. Therefore, I begin this chapter with a summary of my understanding of Attachment, and how this relates within the context of dementia.

Following this, I present an overall summary of the findings, including the superordinate and subordinate themes from IPA. Superordinate themes refer to the main, over-arching themes that were generated from the data during the analysis stage, and the subordinate themes are the themes that sit within each superordinate theme, exploring specific areas within the superordinate theme (Smith, Flowers and Larkin, 2009). Verbatim quotations are included from the data to evidence and illustrate, where appropriate. In the presentation of data, I use italics when describing non-verbal communication.

I have presented the findings from microanalysis within the findings from IPA, situating them within the superordinate theme with which they most resonate. For example, the microanalysis findings from cases one and five are strongly concerned with the relationship between the person with dementia and caregiver, so I have included these findings within superordinate theme one, 'Relationships.' In this way, relevant findings from microanalysis corroborate, contradict or shed new light on the findings from IPA, within each superordinate theme. The microanalysis findings are highlighted in light blue to clearly distinguish them from the results from IPA (see p.115, for example).

Rather than a separate discussion chapter, I have chosen to discuss the research findings as I present them. Smith, Flowers and Larkin (2009) suggest that for most IPA studies, a separate discussion section is recommended, especially for researchers who are new to IPA. However, they also acknowledge an alternative approach, that it is possible to discuss the findings as they are presented (Smith, Flowers and Larkin, 2009). As I reflected on the findings, this latter

approach felt more natural; discussing the findings as they were presented followed the pattern of my thinking.

6.2 Theoretical Framework – Attachment Theory

There has been much exploration of the importance of 'attachment' in dementia (Miesen, 1992; White, 2019; Balfour, 2020), and this is a significant theory to hold in mind during the presentation of findings from this study.

6.2.1 Attachment Theory

The basic human need from birth for a safe, trusted relationship with a significant other in order for healthy psychological and emotional growth to take place, was first identified by psychologist John Bowlby (Bowlby, 1969). From our early existence, a secure attachment to a reliable, significant person in our lives (such as a parent), enables us to grow socially and emotionally; to understand who we are and develop a sense of self-worth (Holmes, 2014, in reference to Bowlby, 1979).

The need for a safe, trusted relationship with a significant other continues throughout our lifetime (Bowlby, 1979; Balfour, 2020), as our understanding of ourselves and our sense of worth continues to be shaped by our interactions and relationships with others (Harris and Orth, 2019; Balfour, 2020). If we are denied meaningful, caring relationships, we are at risk of losing a sense of self, becoming isolated, lonely, and without hope (Christopher, 2023).

6.2.2 Dementia and the Need for Attachment

In times of emotional or psychological distress we need the support of someone close; someone who knows us and in whom we trust. In dementia, where our very being is under threat in every domain, this need is brought sharply into focus (Miesen, 1992; White, 2019; Balfour, 2020; Cheston, 2022; Christopher, 2023). In a close, loving relationship, it is natural that partners lean on each other for this support.

As a dementia progresses and a person experiences significant cognitive decline, memory loss, and a loss of previous roles in life, a sense of self can feel diminished, and feelings of safety and security become under threat. The person with dementia needs emotional and psychological support and containment to increasing degrees (Balfour, 2020; Cheston, 2022). The caregiver becomes increasingly crucial in providing not only practical support but also emotional and psychological containment: 'symbolising their [partner's] emotional security' (Cheston, 2022,

p.45). Compounding this challenging role is the fact that their partner with dementia becomes less able to provide emotional support and containment in return.

Andrew Balfour (2020) sensitively considers the depth of impact placed on couples as they face dementia together. From the perspective of the caregiver, there is acknowledgement of their own feelings of loss, sadness, frustration and fears for the future in the face of their partner's diagnosis. In addition to this is their increasing physical and practical responsibilities: taking over household chores, finances, caring for both themselves and their partner. Compounding this, and within the context of their existing relationship, is the need to provide emotional and psychological containment for their partner, to be an available and open mind that can listen and hear the thoughts and feelings of their loved one, to be able to hold those feelings and provide a level of understanding (Balfour, 2020). These are profound challenges, and the risk of carer burnout, stress and depression is substantive (Brodaty and Donkin, 2009; Huang, 2022).

Balfour explains that stepping into the role of an attachment figure (to increasing degrees), is all the more difficult if that person does not experience containment themselves: 'caregivers who are themselves less contained may be less able to tolerate emotional contact with the person with dementia' (Balfour, 2020 p.123). It is therefore just as crucial that the caregiver is considered and supported emotionally and psychologically alongside the person living with dementia; that they are given containment in order to provide containment for the person with dementia they are caring for. Balfour summarises this as the need to 'contain the container' (Balfour, 2020, p.127).

The need for continuing support for caregivers is echoed by White (2019), in an exploration of her own understanding of attachment within her relationship with her husband, who has Alzheimer's Disease. A poignant element of this account is that White comments that her understanding has grown from a joint endeavour, that she and her husband have discovered the importance of attachment in their relationship together: 'Attachment theory is our shared secure base for exploration and soothing in times of both turmoil and joy' (White, 2019, p.13). One of White's main recommendations is for support in dementia to be 'relationship centred' (White, 2019, p.15). She comments that, in her experience, successful interventions have been helpful: 'because they are based on attachment principles and involve both carer and cared for together by offering the possibility of lasting relational change' (White, 2019, p.31). This is interesting to hold in mind, especially regarding the MT intervention employed in this study, which supports both person with dementia and caregiver together.

As not all relationships in this study are spousal, it is also worth considering how attachment relates when the caregiver is not a partner, but a child or grandchild. Once again, the role of attachment figure is taken on in addition to many other responsibilities, and within an existing relationship. Here though, the roles are reversed; the parent or grandparent that once provided emotional security and containment for their child or grandchild, is needing that security and containment in return. The child or grandchild steps into this role without any warning or perhaps any conscious thought.

The theory of attachment has been central to my thinking and in developing my understanding of the participants' experiences, and is relevant to all three superordinate themes presented in the Findings chapters.

6.3 Overall Summary of the Findings

The overriding finding from this study is that the participating family caregivers (caregivers) made sense of their experiences of Music Therapy (MT) within the context of their relationship with the person they were caring for. Perhaps this is not a surprising outcome, as the dyads in this study were all in longstanding relationships, whether as spouses or child-parent/grandchild-grandparent relationships. However, in some cases, the caregivers' experiences of MT seemed embedded so deeply in their relationship that they struggled to express their own feelings and referred only to how they perceived their loved one was experiencing the therapy. It was clear from the data that their relationships were central to their experiences, and so 'Relationships' is the first superordinate theme presented from the research findings (see p.104).

Because the caregivers that participated provided the majority of care for their loved one, they experienced the MT intervention at a time when they were steeped in their experiences of dementia and their caring role. Their own experiences of dementia shaped how they experienced the MT, and this came across strongly in the data. Therefore, 'Experiences of Dementia' is the second superordinate theme presented (chapter seven, p.131).

The third superordinate theme is 'Experiences of Music Therapy' (chapter eight, p.162), which provides a focus on the caregivers' experiences of MT but also incorporates the experiences and views of the person with dementia, wherever this was possible.

6.3.1 Overview of the Superordinate and Subordinate Themes

Table 2: Overview of the Superordinate and Subordinate Themes

	Superordinate Themes		
	1: Relationships	**2: Experiences of Dementia**	**3: Experiences of Music Therapy**
Subordinate themes:	1.1: Closeness in familial relationships between the person living with dementia and caregiver	2.1: The Caring Role	3.1: Impact of MT
	1.2: Couplehood in spousal relationships	2.2: Fear	3.2: Creativity and Magic
	1.3: Symbiosis in the relationship between person with dementia and caregiver	2.3: Views of the Care System	3.3: The Therapist
	1.4: Relationships reconfigured by dementia	2.4: What helps?	3.4: MT at End of Life

Although I have addressed each of the superordinate themes separately, they interweave and interact with each other, becoming entangled and difficult to separate, and so there is some overlap within the findings presented in the following chapters.

I will now move on to the first superordinate theme, 'Relationships'.

6.4 Superordinate Theme: 1. Relationships

Table 3: Superordinate Theme 1: Relationships

	Superordinate Theme 1: Relationships
Subordinate themes:	**1.1: Closeness in familial relationships between the person living with dementia and caregiver** 1.1.1 Social Positioning 1.1.2 Spousal Relationships 1.1.3 Other Familial Relationships 1.1.4 Caregivers Participation in the MT
	1.2: Couplehood in spousal relationships 1.2.1 Exploring meaning around Marriage 1.2.2 Depth of Relationship 1.2.3 Couple Identity 1.2.4 Openness and Humour 1.2.5 Nurturative Relational Context 1.2.6 Examples from Microanalysis 1.2.7 Winnicott's Mirror
	1.3: Symbiosis in the relationship between person with dementia and caregiver
	1.4: Relationships reconfigured by dementia 1.4.1 Relationship between the Caregiver and the Person with dementia 1.4.2 Other relationships reconfigured by dementia

6.4.1 Relationships between the Participants

Before I embark on an exploration of the themes within this superordinate theme, it may be helpful for the reader to have a reminder of the participants and their relationships with each other, which I have presented in the table below. More information about the participants is presented in table 1 (p.69).

Table 4: Relationships between Participants

Case No.	Pseudonyms	Caregiver/Person with Dementia (gender)	Relationship	Age
1	Gordon	Caregiver (M)	Husband	81
	Lucy	Person with dementia (F)	Wife	78
2	Maria	Caregiver (F)	Daughter	53
	Leo	Caregiver (M)	Grandson	23
	Louisa	Person with dementia (F)	Mother / Grandmother	84
3	Nia	Caregiver (F)	Daughter	55
	SJ	Person with dementia (M)	Father	81
4	Theresa	Caregiver (F)	Wife	79
	Julian	Person with dementia (M)	Husband	84
5	Kelly	Caregiver (F)	Wife	63
	Ray	Person with dementia (M)	Husband	84
6	Daniel	Caregiver (M)	Husband	76
	Hazel	Person with dementia (F)	Wife	77

6.5 Exploration of Themes

1.1: Closeness in familial relationships between the person living with dementia and caregiver

In this study, all seven caregivers that participated were related to the person they were caring for. Friends or other unpaid caregivers were not excluded from the research, but the participants that chose to take part all happened to be family members who were providing the majority (or all) of the care for the person with dementia. A significant finding is that all seven caregivers described or demonstrated a close bond with the person they were caring for, no matter what type of familial relationship they had. It is possible that this study was more likely to attract caregivers who had a close relationship with the person they were caring for, and that their decision to take part was reflective of their high level of commitment to the care of their loved one.

1.1.1 Social Positioning

During the interviews, I was aware that the caregivers' presentations of their relationships with the person with dementia may have been affected by an element of social positioning; of the way they presented themselves in light of their particular situation (Sabat, 2018). I had not met any of the participants prior to this study, and in each case, our first meeting was the occasion of our first interview. Before any trust had been built between participant and researcher, I had anticipated there may be a risk that participants might present themselves as coping well and paint an overly positive picture of their relationship with the person they were caring for, to pre-empt any judgements by myself as researcher (see chapter 4, pp.70-71 on social positioning and building trust). However, in all six cases, the caregivers soon spoke freely

about the challenges and demands of caring with some intimate and upsetting experiences relayed, and this concern became unfounded.

1.1.2 Spousal Relationships

All four spousal relationships (cases one, four, five and six) came across as being close and loving. Whilst this is perhaps not surprising, in my clinical experience it is certainly not always the case. In all four spousal relationships there flowed a strong sense of couplehood; a togetherness and love shared between the couple that dementia did not appear to have diminished:

> Gordon (case one): We've been married, what, 56 years next week! *[says with eye contact and a smile]*
>
> Theresa (case four): We been good friends, as well as been in love with each other all these years.
>
> Kelly (case five): It's true, there was no beginning and we both feel there'll be no end. Yeah.
>
> Daniel (case six): *[Daniel sings 'Make You Feel My Love', Hazel joins in, words not discernible. I join in too. Daniel has his arm around Hazel and keeps looking down at her.]*

The theme of 'Couplehood' is important in the findings of this study and explored more fully below, but as indicated earlier, all these themes interweave and interact with each other, and I have found it difficult to separate them completely.

1.1.3 Other Familial Relationships

The remaining cases (two and three) both involved daughters caring for a parent, and also a grandson providing the majority of care for his grandmother (case two). Despite these being different familial relationships, a prevailing closeness between the caregiver and person with dementia was still evident in the way the caregiver spoke about the person they were caring for. In addition, in case two, the person with dementia, Louisa, was present for the second interview, and I witnessed some warm and gentle interactions, initiated by both Maria and Leo (daughter and grandson).

In case two, Maria and her mother, Louisa, had always been close. Maria commented: 'I'd been with my mum all through my life, every single day.' Despite significantly challenging experiences due to dementia that interacted with their relationship, Maria remained close to her mother: 'Mum is my life, she's my world.' Maria described her mum as 'very, very family orientated', and Louisa's grandson, Leo, also seemed wrapped in this close family dynamic,

having committed to look after his grandmother, despite the effect this had on his own life: 'It's very *[pause]* but you've got to get through, you've got to be there for Nan.' His silence in not describing how hard his experience of caring had been adds weight and significance, exemplifying his level of love and commitment to his Nan, but also hinting at some of the feelings around the sacrifice he had made.

Despite not living with him, Nia (case three) also felt close to her father; their bond grew stronger following her father's diagnosis: 'we have a relationship we would never have had if it wasn't for Alzheimer's, and I'm much, much, much closer to him now.' Nia commented that the responsibility of her father's care and wellbeing fell to her as she was the only female sibling in her family: 'so I am the only girl, so I have inevitably, but with absolute willingness, been the person that [oversees the care]'.

Although there are many men who provide care for people with dementia (three in this study), in family situations with adult children, it is not unusual for the main caring responsibilities to fall to daughters. This gender imbalance is prevalent (American Sociological Association, 2014; Botek, 2023), so it was perhaps not surprising that Nia felt a responsibility to take on the role of caring for her father. As a single mother, Nia also held the responsibilities of bringing up her family and working as an artist, juggling all three roles within her daily life. Maria (case two) and Nia fall into the 'sandwich generation', caring for generations both older and younger than themselves, stretched both ways in order to fulfil these different roles (Vreugdenhil, 2014). This inevitably adds to the challenges and stresses of being a caregiver, however, despite this, both appeared to accept the caring role without question.

In my clinical work with people with dementia, I have come across grandchildren helping out with care, but I have not before encountered a grandchild moving in with the person with dementia and giving up their job to concentrate on the caring role. Although this seems relatively rare, a recent systematic review identified 12 studies reporting on grandchildren providing care for their grandparent with dementia (Venters and Jones, 2020). The review identifies changes in the relationship as a result of dementia and the caring role, as well as reporting on different experiences encountered; some being negative but with a high degree of positive experiences identified. However, there is much heterogeneity in terms of demographics and how much care is provided. Only two of the studies report on adult grandchildren, most of whom are female, and most of the studies do not specify whether the grandchild is the primary or auxiliary caregiver. It is clear that more research in this area is

required to identify differences in experiences between a grandchild providing auxiliary care, in comparison to one undertaking a primary caring role.

In this study, Leo (case two), explained that he had 'completely lost my life' in order to care for his grandmother. This caring role had a significant impact on Leo, and I will focus on this in more detail in chapter seven under the superordinate theme, 'Experiences of Dementia' (see p.131). Despite this, Leo demonstrated much love and compassion for his Nan; from his perspective, their family bond remained strong.

1.1.4 Caregivers Participation in the MT

All caregivers participated in the MT sessions alongside the person they were caring for, as was the requirement of the study. In some cases, this was fluid, for example, sometimes Leo participated alongside his grandmother; at other times, it was Maria (case two). All four spousal caregivers engaged and interacted in the music with their partner. Maria and Nia engaged to varying extents; sometimes sitting back, being present but not participating quite as much as the spousal partners. This is an interesting finding, with different possible explanations. It may be that living separately to the person with dementia gave a feeling of space and permission to step back, or perhaps participating to a lesser extent reflects something of the relationship between caregiver and the person with dementia.

In the video clip from the sixth MT session for case two, Maria sits behind her mother (Louisa), still singing with her and giving words of encouragement, but almost out of sight. This could be due to the presence of the video camera, but Maria does not hide from the camera in our interviews. In our second interview, Maria comments to Louisa about the MT session as she watches her sing and play: 'You're the star there, love, you're the star.' Rather than avoiding the camera, it felt as if Maria wanted the spotlight to be on Louisa, to uphold her and celebrate her abilities in music-making.

In contrast, Leo, who lived with Louisa, seemed to have joined in sessions more fully; in interview three he talked of playing his guitar with Louisa in sessions: 'it's absolutely lovely to be able to join in, to see her smile'. Again, however, the emphasis is on Louisa and not so much on his own experience.

In case two, Nia described sitting back and watching her father (SJ) play piano with the Music Therapist, commenting: 'it was like they were in their own…thing going on.' Nia sometimes played alongside SJ in the sessions, but expressed a lack of confidence in this: 'because I'm not

very good', and a concern that SJ would think she wasn't good enough: 'I was probably annoying him because I'm not doing it very well'. This was perhaps reflective of their past relationship, where SJ did not understand Nia's passion for art and creativity: 'When I was growing up and going to Arts School, and he just couldn't bear the mess and you know…he just didn't understand it.' This may also be an acknowledgement of aspects of SJ's character, as Nia commented: 'He's not an easy man'. So perhaps the fact that Nia was present, but not as involved in the music as some of the spousal caregivers were, was reflective of a pre-existing dynamic within their relationship.

Inevitably, caring for a parent or grandparent is going to feel different in comparison to caring for a spouse, someone that has been chosen as a person to live life alongside, with all the joys and challenges a lifelong journey may bring. Additionally, a daughter or grandson may have made no prior commitment to provide care for their parent or grandparent, yet in these two cases both daughters and grandson appeared dedicated to ensuring their loved one was cared for to the best of their abilities.

No matter what the familial connection is, on the surface, a close relationship between caregiver and person with dementia can indicate a secure attachment between the two. Accompanying this is the increased possibility of containment for the person with dementia, and perhaps the caregiver as well. Research suggests that couples who report a lower relationship quality prior to dementia are more likely to experience greater stress, strain and depression in a caring role (Gilleard *et al.*, 1984; Knop, Bergman-Evans and McCabe, 1998; Morris, Morris and Britton, 1988, all cited in Balfour, 2020). This view is supported in this study by Theresa (case four) who believed that her strong relationship with Julian helped sustain her in her care for him: 'I think that does help, if you have a loving relationship before.'

1.2: Couplehood in Spousal Relationships

The term 'couplehood' has been used in dementia literature to refer to how strongly two people in a partnership feel connected and that they belong to each other; the strength of 'we' in their lives and relationship, as opposed to 'I' (Kaplan, 2001; Hellstrom, Nolan and Lundh, 2007). In all four spousal relationships, the couples had been together for a long period of time, ranging from 27 years (case five) to over 60 (case four). It is not always the case that couplehood remains strong for this length of time, and here the couples talked about 'ups and downs' in their relationships, but despite this, the strength of couplehood seemed significant in all four cases.

1.2.1 Exploring Meanings around Marriage

Three of the spousal caregivers talked about their marriage. At the start of the first interview, Gordon (case one) proudly stated with a smile: 'we've been married, what, 56 years next week' and continued, describing their marriage as 'a kind of adventure' as they had travelled and lived in different places. Theresa (case four) smiled as she reminisced about her courtship with Julian: 'He just wanted to marry me,' and continued to talk proudly of their marriage: 'We're in our diamond year this year'. Kelly (case five) commented: 'We have literally been together, more or less, 24/7…we've had our ups and downs, everybody does.' Ray validated this with humour, commenting: 'we've adjusted to each other quite well.'

Although there was a sense of pride from participants in the longevity of these marriages, accompanying this seemed an underlying sense of duty; a feeling that the person doing the caring needed to stick with their spouse no matter what. Theresa directly linked her marriage vows to her caring role: 'when you get married, you say your vows, in sickness and in health, you know, for better, for worse, this is that bit. Isn't it? It's that bit.' The repetition of 'It's that bit' and question to me, 'Isn't it?' felt like a clear communication that despite their strong relationship, this was a challenging time, and one that Theresa felt she must persevere with. This was reinforced by Theresa as she later commented she must 'do my job' and 'be on duty.' Gordon also alluded to this sense of duty, commenting: 'over the 50 odd years we've been married, just got to, take the rough with the smooth.'

There feels a risk here, that this level of commitment which stems both from a loving relationship and a sense of obligation, might leave a spouse feeling guilty when the caring role feels overwhelming, and perhaps prevent them from reaching out for support. All four couples adopted marriage vows, committing to love each other 'for better for worse, in sickness and in health' (Church of England, 2020). However, these commitments were made a long time ago, and at the time, the thought that this might mean caring for your spouse with dementia may not have even been considered (Christopher, 2023). Do marriage vows add an increased sense of duty in a relationship? Since there were no participants in this study who were unmarried long-term partners, this is only presented as a question, but there seems a possibility that caregivers who are married to the person they are caring for may be at a higher risk of caregiver exhaustion than those who are not married.

1.2.2 Depth of Relationship

Accompanying the longevity in these relationships was an intimate familiarity. In case four, Theresa commented: 'You know, when you've been together like us, over 60 years, because

you know each other well. You know each other's moods, instinctively know.' Theresa described the depth of their relationship: 'we been good friends, as well as been in love with each other all these years.' However, this also made it harder to entrust care to anyone else: 'You know, when you've had such a relationship as we've had, you can't bear to, in fact you almost don't want to trust anybody else to look after him.'

Depth of relationship was also evidenced by the physical closeness of some of the couples. In my second interview with Theresa and Julian, they watched the MT video sitting closely together on the sofa, often holding hands, looking at each other, and sharing smiles and laughter. Theresa initiated interaction with Julian by commenting on the video to him and this brought him into joint attention and a shared experience with her.

Both Theresa (case four) and Kelly (case five) talked about their physical intimacy with their husbands, and how this was an important element of their relationship. During the second interview, Kelly chose the song 'Love is All Around' for microanalysis, commenting that this was the couple's special song, and was playing the first time they spent the night together.

Daniel and Hazel (case six) also demonstrated a depth of relationship through physical closeness, which was particularly evident in the first two interviews, where they sat closely together on the sofa. I noticed Daniel mirroring Hazel's body language, for example, sitting forward on the sofa when Hazel did. Daniel also used physical contact to comfort and reassure Hazel when she became anxious, including a moving moment in our second interview where Daniel sang to Hazel and held her in order to comfort and reassure her from a moment of anxiety. This seemed a clear example of Daniel providing emotional containment for Hazel through physical touch.

In addition, close physical touch also seemed important in the relationship between Maria and her mother, Louisa (case two). Maria described how, after experiencing MT, they used music to initiate movement, and to provide both physical and emotional feelings of stability:

> Maria: We sing little songs all the time to motivate her to move around…because it's the basic rhythm for her to want to patter, and you know when she, when she comes and gets up from the chair, you know you can have a little dance with her and have a little singsong with her and, which also makes her feel more stable.

Appropriate physical touch is an important expression of love in close relationships, with studies suggesting higher levels of loving physical touch correlating with stronger and closer relationships (Gulledge and Fischer-Lokou, 2003; Field, 2010). In dementia, where verbal communication may become less accessible, touch can become an even more important element in a relationship, strengthening a couple's connection, providing containment, and enhancing feelings of love, reassurance and comfort. In the wider context of dementia care, touch has long been recognised as an important tool, with methods of 'therapeutic touch' developed and used by nurses and care staff to uphold wellbeing (Doherty *et al.*, 2006).

1.2.3 Couple Identity

There was a sense of a shared identity communicated by the caregivers as they talked about their relationship with their spouse. This was clearly illustrated in some of the language used, particularly in cases one and six:

> Gordon: I always tried to get something most days, er, activity to help us.
> Daniel: We've managed really well…we get on with it.

In case one, Gordon alluded to a sense of individual and shared identity by describing his and Lucy's relationship as 'our own personal Battle of the Roses'. This analogy gives acknowledgement of two different individuals, and perhaps a sense of the tussle between two individuals within an ongoing relationship, but also the identity of 'us,' again indicated by the use of the word 'we', and by being in something together: 'We haven't decided yet which, there's the house of Lancaster and the house of York, that's won yet!'

The use of 'us' and 'we' suggest a feeling of 'team' in Gordon and Daniel's approaches to tackling the challenges dementia was presenting to them. Cheston (2022) suggests that couples face the challenges of dementia as they would have approached any challenge in their lives together, and this suggests that these two couples worked as a team. This made me wonder how difficult it must feel when, due to progressing dementia symptoms, your teammate is increasingly less able to contribute to facing challenges together.

1.2.4 Openness and Humour

The four married couples had grown their relationships and couple identity over many years, and some individual elements within these relationships were evident during the interviews. Daniel and Hazel sometimes bickered a little; a clear reminder to me that I was stepping in on a

longstanding relationship with all its 'ups and downs'. The bickering was accompanied by an underlying thread of humour:

> Hazel: I'm not like that
> Daniel: Yes you are
> Hazel: No I'm not
> Daniel: Yes you are
> Hazel: You're annoying as well
> Daniel: I'm annoying as well?

And later in the interview:

> Daniel: *[to interviewer]* She's going to go off [to sleep]
> Hazel: I'm not
> Daniel: You're not! *[Laughing]*

Black humour seemed to be an important element in Kelly and Ray's relationship:

> Kelly: He's, as we jokingly call it, losing his marbles!
> Ray: Demented!
> Kelly: … so we are jokey, and because the alternative is sit and cry and be miserable.

There was an openness within this relationship, exemplified by the way the couple talked, passing the conversation from one to the other, but also in what they were prepared to openly share with me, for example, when talking about sexual intimacy. There was open conversation about dementia and its effects too. I felt concerned for Ray when Kelly compared looking after him to looking after a child, but Ray replied with a humorous comment that also revealed self-awareness:

> Kelly: It's worse than having a child actually, because it's more responsibility.
> Ray: This little child argues!

I felt compelled to reply to this interchange with: 'It's amazing that you're so open with each other, that you can have these conversations.' On reflection, I realised that this was my interpretation of this aspect of their relationship. Kelly affirmed my point, acknowledging that being open with each other is another coping strategy within their relationship: 'yeah, oh no, we always have been, that has been a big help, I think'. There was a risk here that Kelly was

perhaps wanting to agree with what I had said, however, her comment in agreement with me seemed reinforced by her previous point, where she shared that they used humour to help them cope. Openness and humour within their relationship seemed key methods of coping during difficult times.

1.2.5 Nurturative Relational Context

To sustain 'couplehood' in dementia, Hellstrom, Nolan and Lundh (2007) suggest there needs to be a 'nurturative relational context'; where both people in the couplehood take an active part in nurturing their relationship through actions such as positive shared interactions, affection, and appreciation of each other. The authors acknowledge that, as dementia progresses, this becomes more difficult to maintain, and falls more to the person without the diagnosis of dementia.

Arguably, all four spousal caregivers were constantly working at sustaining their couplehood, as their daily lives were centred around caring for their spouses. However, despite advancing dementia, there were also examples of the person with dementia contributing to their relationships in a nurturing manner.

In case one, Lucy's verbal comments often seemed incoherent, disjointed or not related to moments in the present. However, following a conversation with myself about dancing, Lucy appeared to invite Gordon to dance: 'but I was referring to Gordon, cos that's a possibility if we'd like to do that.' In this moment, it felt as if Lucy was working at strengthening their partnership, inviting Gordon to join her in a shared, intimate activity.

In Theresa and Julian's relationship, Theresa initiated most of the interaction and physical contact, but during the video clip chosen for microanalysis, Julian initiated a connection by gesturing towards Theresa as he sang 'my wife', to which Theresa smiled.

Evident again in the video clip were the efforts of Ray to connect lovingly to Kelly during their special song. To the words 'and if you really love me, come on and let it show', Ray leant back towards Kelly, singing to her with eye contact and smiles, and Kelly gave eye contact and smiled in return.

In the second interview with Daniel and Hazel, Hazel verbally affirmed Daniel, for example, when Daniel commented that he was 'old' and 'grizzly', Hazel replied: 'you're not old' and 'you're not grizzly'.

Despite the myriad challenges of living with advanced dementia, here are examples of all four people with dementia contributing in a nurturing way towards their couplehood, which in turn could strengthen feelings of attachment between the two. As well as being moments in the present, this also felt like a glimpse on how they may have interacted in the past, before dementia intruded. As dementia progresses, these moments must become increasingly valuable for the receiving spouse and the relationship overall.

1.2.6 Music Therapy upholding Couplehood – Examples from Microanalysis

Many of the video clips from the sixth MT sessions show examples of MT supporting and upholding relationships, but two in particular seemed relevant to couplehood. In both cases, the music also appeared to mirror elements of each couplehood.

These moments of music were selected by the caregivers and were analysed using Trondalen's method of microanalysis (Trondalen, 2007). For more information on this method, please see chapter four, p.79. I have included a description of the music here, along with a summary from the microanalysis.

Case One: Gordon and Lucy, 'Take Me Home, Country Roads' (John Denver)

Gordon chose this clip because the music reminded him of happy, family times together. This was a song they used to sing as a family, and reminded Gordon of travelling together through West Virginia whilst on holiday.

Description of the Context

This song comes towards the end of the MT session, 45 minutes in. Gordon, Lucy and Rhian (the Music Therapist) are sitting relatively closely in a semi-circle, with Lucy in the middle. Lucy had previously seemed sleepy, with her eyes closed, and Gordon gently asks if she remembers travelling through West Virginia, to which Lucy opens her eyes and softly replies: 'I know, yes I do'. Rhian gently gives Lucy two shakers, one under each hand. Gordon anticipates the music with humour, smiling as he says: 'We can see if we'll be in harmony, with your husband on the drums!' He plays the drum a little; Rhian strums her guitar.

Brief Description of the Music

Rhian plays the guitar and sings: 'Almost heaven, West Virginia...'. Gordon lightly taps the drum and sings along. He plays with the fingertips of both hands, lightly and at a lively pace, like a pitter-patter. Lucy seems to sing along a little too, mouthing some of the words but (to begin with) with no audible sound.

This familiar song is sung in G major, a bright major key, and at a moderate pace. The piece feels gentle but quite lively, and Rhian sings with a warm and full tone, perhaps to try to gain Lucy's engagement, but without being loud in dynamic. There is flexibility in the tempo, with pauses and rallentandos (a slowing in tempo) used to build anticipation of the returning choruses.

Lucy smiles and looks down at her tray and moves her fingers a little. Occasionally, Lucy forms the shape of words from the song. This becomes more frequent and obvious in the chorus, and towards the end of the song you can clearly hear Lucy singing the words 'Take me home'. At the end of the first chorus, Lucy says: 'All these things now'.

Gordon sings throughout; his singing is louder in the first verse and choruses, where he seems surer of the words. His voice is softer than Rhian's and sits lower in the texture of the piece, being lower in pitch, dynamic and intensity than Rhian's. He taps lightly on the drum all the way through, and often looks at Rhian as she plays and sings.

Overall, there is a feeling that the music is wrapping around this trio, holding them in warmth of sound and song. It feels as if the music would have filled the room, despite it not being loud in dynamic.

Discussion

Gordon chose this song because it had personal significance, reminding him of family holidays and driving through West Virginia. The music therefore relates to the couple's shared past, upholding their identity as a couple. It is also an opportunity for shared interaction, something they can experience together, bringing them together in time. This seems in contrast to our conversations during the interviews, where Lucy often seemed dislocated in time; perhaps in a different time within her mind.

In the interviews, Gordon stressed how important it was for Lucy to have stimulation and interaction; he believed this would aid her cognitive and physical processes, and could even improve dementia symptoms. The music provided this opportunity and Rhian paced the music to encourage optimum interaction from Lucy, whilst also attuning to Gordon.

The lyrics of the song seemed significant. This song is about place, home, a journey, and belonging. There is also a sense of time in the song, with the word 'yesterday' pulled out in time with a pause, before a return to the chorus. Dwelling and pausing on the word 'yesterday' is possibly a technique used by Rhian to hook Lucy and Gordon back into the chorus of the song.

It also seems to have further significance; the song represents time in the past where the couple experienced travelling and adventure together, in contrast to the present moment, where they are unable to leave the house due to Lucy's mobility difficulties. The song reminds Gordon of happy, family times, and it feels as if those memories are being stretched into the present moment, dwelling on 'yesterday'.

At the end of the first chorus, Lucy clearly says: 'All these things now'. It is impossible to know exactly what Lucy meant by this, but I wonder if in some way this was referring to a memory of the past, or a comment about the music they were sharing.

The music is centred on Lucy; Rhian uses therapeutic techniques to encourage her engagement (see Appendix 20, p.410). Gordon is a gentle presence in the music throughout, following Rhian's lead, very present but in a quieter, supportive manner. I wonder if this mirrors how Gordon has been in their lives together; alongside, supporting, letting Lucy lead but being beside her all the way. It could also describe the couple's present circumstances, with everything centred on Lucy, and Gordon providing a supporting role.

In this case, the MT addresses all of Kitwood's suggested psychological needs (Kitwood, 1997):

Attachment: Through the MT, there is a shared interaction, nurturing the couple's connection and relationship together. The music appears to mirror the couple's relationship.

Comfort: There is a feeling of warmth in the music that encompasses the trio. Remembering happy family times could be comforting for Lucy and Gordon.

Identity: The couple used to sing this song while travelling through West Virginia on holiday as a family. This reinforces memories and their identity as a couple.

Occupation: The couple are sharing in a meaningful interaction. Gordon believes that social interaction is important to help maintain Lucy's cognitive ability.

Inclusion: The therapist uses techniques to best engage and include Lucy, as well as attuning to Gordon. See Therapist Techniques, Appendix 20, p.410.

Love: Elements of love are indicated by the person-centred approach to therapy, and the humanistic stance of the therapist, being open and available for the clients, underpinned by Roger's three core qualities of empathy, unconditional positive regard and congruence (Rogers, 1957). The connection and love between Gordon and Lucy are also evident in the gentle way that Gordon connects with Lucy, for example, in asking her if she remembers travelling through West Virginia.

Case Five: Ray and Kelly, 'Love is All Around' (The Troggs / Wet, Wet, Wet)
Kelly chose this piece because the song was special to the couple: 'that's mine and Ray's song'.

Description of Context

This clip is from the end of the sixth session of MT, at one hour and sixteen minutes in. Ray and Kelly are sitting together on the sofa. Ray looks bright and happy, smiling. Kelly looks a little tired, rubbing her hand and her eyes. The Music Therapist, Neil, is kneeling in front of them with a ukelele, and the lyrics and chord sheet on the floor. He puts a lyric sheet on the table in front of Kelly and Ray. Neil starts by playing the ukulele, and Ray reads the lyric sheet, commenting on the title of the song and expressing 'ohhh!' Neil begins singing at quite a steady pace, and both Kelly and Ray join in straight away, singing, and Kelly playing the shaker gently.

Brief Description of the Music

This well-known pop song is played in the bright key of D major at a steady tempo. Neil starts singing the song slowly, inviting Kelly and Ray to join, and then settles into a steady tempo once they are all singing. Kelly plays the shaker to the beat of the song and sings gently, with a louder flourish of 'ohhh!' at the end (as Wet, Wet, Wet do in their recording of the song). Ray's singing is gentle but his laptop snare playing is lively and playful. He plays on the beat, but also adds flourishes of rhythm at appropriate moments in the song.

Throughout, Ray taps his feet, smiles, and points to his toes on the corresponding lyric ('I feel it in my toes'). He sometimes looks up lovingly at Kelly and smiles, leaning in closely to her and she leans into him and they give each other eye contact.

Kelly starts the second line a little early but Neil and Ray join her. Kelly is tapping her feet to the music, playing the shaker and also looking at Ray at times. At the end of one phrase, Ray sings 'oh yeah' and indicates to Kelly, and Neil answers with an 'ah ha'. To the words 'and if you really love me, come on and let it show', Ray leans back and towards Kelly, singing to her with eye contact and smiles, and Kelly gives eye contact and smiles in return. Kelly points to the lyric sheet to help Ray find his place. Ray begins to tap the laptop snare; little snippets of lively sound, and not just the beat but other appropriate rhythms that fit with the music too.

Kelly looks at her watch a couple of times, perhaps seeming a little distracted, or tired? Ray looks again, smiling at Kelly and singing and she responds similarly. He says 'this is from' but then taps the laptop and continues to sing. Ray follows the words in the next part of the song but points to Kelly in the bit 'oh yes I do'. Kelly looks at Ray as she sings 'by the way that I feel'. On the 'oh' high bit at the end of the song, Kelly raises her shaker up and towards Ray and smiles as she sings. There follows this exchange:

Ray: That's a nice song.
Kelly: Yeah, that's our song.
Ray: That's Wet, Wet, Wet that sang that.
Kelly: Yep, that's our song
Ray: That's lovely.

Discussion

Ray and Kelly have taken ownership of this song; it's a love song that celebrates their love and closeness to each other. The lyrics seem to sum up the couple's relationship: 'love is all around'. In the second interview, Kelly comments on their relationship using a direct lyric from the song: 'there's no beginning, there'll be no end'; this sums up how she feels about their relationship, and she believes Ray feels this too.

Despite the challenges and fear about what the future might hold, their sense of couplehood, of existing together, is strong and epitomised in the music. Their playing and singing are quite equal in volume and intensity. Alongside this, aspects of their individual personalities are highlighted, with Ray's playing on the drum being playful and lively, and Kelly's singing and playing gentler.

This is an intimate trio, and I am struck by how relaxed and open Kelly and Ray are in their expressions towards each other, despite Neil being there. This is also reflected in a freedom of expression in their singing and playing. There is no sense of self-consciousness, and Ray seems comfortable enough to add moments of improvised rhythms and a vocal phrase.

Once again, the MT addresses each of Kitwood's suggested psychological needs (Kitwood, 1997):

Attachment: This song epitomises Kelly and Ray's love for each other, nurturing their relationship. The music seems to mirror elements of their couplehood.

Comfort: There is a feeling of warmth in the connection between Kelly and Ray, exemplified in moments of eye contact, smiles and gestures to each other.

Identity: The couple have adopted this song as their love song, and singing it together upholds their identity as a couple. Elements of individual personality also come to the fore through the music.

Occupation: The couple are sharing in a meaningful interaction together.

Inclusion: The therapist's position on the floor in front of the couple, placing the words close to them, invites them both to join in. The choice of this song, bright D major key and steady pace invites interaction.

Love: As well as the person-centred and humanistic approach adopted by the therapist, there are clear signs of love shared between Kelly and Ray, exemplified by their eye contact, gestures and leaning in towards each other.

1.2.7 Winnicott's Mirror in MT

These examples remind me of Music Therapist Darnley-Smith's account of her experiences of working with people with dementia, and how music within the therapeutic process can have the effect of a mirror: reflecting something of the person back to themselves, in the shared experience (Darnley-Smith, 2020). Darnley-Smith is talking of Winnicott's mirror, where, in healthy early developmental stages, a baby looks at her/his mother, the mother looks, sees and acknowledges the baby, and the baby sees something of himself/herself in the mother's face, in return. This helps develop the baby's sense of self and understanding of her/his thoughts and feelings (Winnicott, 1971).

In a moving case study, Darnley-Smith describes interactions with a lady with advanced dementia; the lady's intense interactions, her own looking and seeing as therapist, and created music as a response. Darnley-Smith suggests this provided an opportunity for a 'cathartic experience of self, mirrored in the artwork itself' as well as the experience of being seen and heard (Darnley-Smith, 2020, p.153).

In this study, the music seemed to mirror elements of couplehood, the nature of the relationships between each couple. In video one, Gordon played a supportive role, not only in that he was ever-present in the music, but that he provided a continuous, gentle tapping on the drum, and gentle singing. As in life, he was focused on Lucy's experience, providing a gentle and supportive presence. From his comments in interview, this could reflect the nature of their relationship as it always had been: 'She's always been the social one, I've been the quiet, reserved one.'

Kelly and Ray's relationship seemed centred around love, honesty and openness, and again this feels evident in the music, where Ray openly expressed love for Kelly as he addressed her, singing: 'and if you really love me, come on and let it show'. Kelly responded with eye contact and smiles. This is the couple's special song, the music they first went to bed to. There is a feeling of intimacy, not only despite the therapist but including the therapist, who facilitated this moment that reflects how Kelly and Ray were as a couple.

1.3: Symbiosis in the relationship between person with dementia and caregiver

I have already mentioned that the relationships between the caregiver and the person with dementia in this study were all close. However, there were some moments in our interviews where this relationship seemed so intertwined and interdependent, there felt an element of symbiosis at play. By symbiosis, I mean a close and intimate relationship where partners depend on each other, and where one person's state is deeply affected by the other's. The closest definition I can find to this is from the Oxford Learner's Dictionary, which is as follows:

> 'The relationship between two different living creatures that live close together and depend on each other in particular ways, each getting particular benefits from the other' (Oxford Learner's Dictionary, 2023).

Research suggests that elements of symbiosis in long-term relationships is not unusual; that older couples who have been in a relationship together for a long time often experience an interdependency: 'spouse's symptoms wax and wane closely with those of their partners' (Balfour, 2020, p.125, citing Hoppmann, Gerstorf and Hibbert, 2011).

In case one, Gordon often referred to his and Lucy's personalities within a dyadic frame: the red and white roses of Tudor history; their contrasting personalities that together seem to make a whole: 'she's always been the social one, I've been the quiet, reserved one'. To Gordon, they were two halves of one whole; the whole being their couplehood. But there felt an element of symbiosis in the way that Gordon experienced Lucy's losses caused by dementia; that her losses were also his. For example, Lucy's loss in mobility also affected Gordon's ability to leave the house, as he had to stay in to care for her. Her loss of social interaction was also his loss. There was a sense of shared sadness as he talked about the things they used to do: 'We used to...' The wellbeing of one partner in the couplehood was intrinsically affecting that of the other.

This element of symbiosis in the relationship is perhaps corroborated by the way Gordon spoke in our interviews. When discussing Lucy, his speech was fluent, but when I asked him about his own feelings or experiences, this seemed more difficult to express, and he used an increased number of filler words, like 'um' and 'er'. Perhaps speaking about his own feelings had always been more difficult, but I also wonder if this reflected the fact that in that moment, his life was centred around caring for Lucy; there was little time for him, and accessing his own feelings was perhaps not possible for him at that time.

Much research details how all-encompassing and overwhelming caring for someone with dementia can be (Daley *et al.*, 2019; Farina *et al.*, 2017), and Gordon and Lucy's case illustrates this point. Gordon's care for Lucy was constant, taking up all his time and energy. It is possible that this caring role was eroding a sense of self for Gordon, as he responded to questions about himself by referring to Lucy's experiences:

> Interviewer: What was that like for you, that interaction there?
>
> Gordon: Um, it's good, it's good to see Lucy, you know when she does sing, participating. Er, but I mean, the other thing is it's good to see her happy, er, which, you know, you've seen today she's happy, most of the time, and she's happy when she's interacting.

Again, this is not uncommon. In her writing on dignity and couplehood in dementia, Hellstrom comments:

> Just as people with dementia are at great risk of being seen as having lost their selves (Basting 2003) so too the spouse loses his or her spousal identity and is transformed to a caregiver (Hellstrom, p.55, 2014).

However, in this case, it was not Gordon's spousal identity but his individual identity that felt diminished. His identity in couplehood with Lucy still felt strong; he maintained his quiet, supportive role that ever was in their relationship, but his own thoughts, feelings and needs seemed elusive. Elements of his individual personality came through in the interview, but a sense of Lucy's personality seemed dominant, despite the challenges in communication that she was experiencing.

The erosion of a sense of self because of the caring role was also present for Theresa (case four), who explicitly expressed this fear: 'I don't think I can carry on much longer really, and still be me'. Balfour explores a loss of sense of self in a moving case study (2020). Here, there were similar feelings of the spousal caregiver being lost: 'He was immersed in her world of dementia… Now he felt as though he didn't exist anymore' (Balfour, 2020, p.127). Dynamics of the pre-existing relationship interact with the challenges of dementia to create this loss. Balfour speaks of the concept of 'projective identification', where a person projects unmanageable, frightening thoughts and feelings onto another, in a form of self-defence. Through therapy, the caregiver was able to identify thoughts and feelings from projection that had come into his mind from his partner's, and with containment from the therapist, was able to start to recognise his own feelings, becoming 'more anchored in his own, separate mind' (Balfour, 2020, p.128).

In this study, the feeling of symbiosis in a relationship was not limited to spousal couples. In case two, Maria and her mother, Louisa, had always been close and Maria was fearful about what would happen to her when her mother dies: 'Mum is my life; she is my world…when there's nothing...I don't know how I'm going to cope then.' Maria could not bring herself to say 'when Mum dies' and instead used the words 'when there's nothing' indicating how hard this was for Maria to contemplate. It seemed that Louisa's health was intrinsically linked with Maria's mental health and stability; Maria recounted that on a recent occasion when her mother was unwell in hospital, Maria found herself unable to cope and attempted suicide. The element of symbiosis was again shown in Maria's response to the MT sessions, where she commented: 'We love it, don't we! It makes me happy because it makes Mum happy.'

It is clear that upholding the significant relationships during the journey of dementia can strengthen that bond and attachment, whether this is in couplehood or in a parent-child/grandchild relationship. Furthermore, this can improve wellbeing for both partners, but perhaps crucially important is the emotional and psychological health of the caregiver. It is so often they who go unnoticed, yet acutely need emotional and psychological support themselves, not only to keep themselves well, but also to provide the containment and security needed for the person living with dementia.

1.4: Relationships reconfigured by Dementia

1.4.1 Relationship between Caregiver and Person with Dementia

As dementia progresses and caregivers take on more of a caring role, it is inevitable that relationships shift and change in response. Theresa (case four) gave an insight into how challenging this can be, at first commenting on the couple's continuing love for each other: 'we been good friends, as well as been in love with each other all these years', but then acknowledging how things have changed: 'I feel that I'm a carer, and not a wife'. As we talked, I could feel the internal struggle this must create; Theresa spoke earnestly, with eye contact and an intensity in her communication. They had been a married, loving couple for over 60 years, and Theresa was very proud of this. Shifting from wife to caregiver felt significant, and Theresa continued to explain how this led to complications and perhaps a mismatch in their couplehood, as her own desire for sexual intimacy had changed: 'I don't know if there's something in you that just can't go back into that bit. I don't think I could cope at all really'.

Kelly and Ray (case five) also expressed tension around sexual intimacy, with Kelly describing an increase in Ray's need for sexual intimacy that she found challenging. This presented a mismatch in their relationship, and once again, they discussed this openly. In terms of how

they coped with this, Kelly commented with a positive outlook: 'I think that's probably affected him more that it has me, but I'm sure we'll come through it, most things we sort out!'

As relationships change, it is perhaps not surprising that feelings towards sexual intimacy fluctuate. Hypersexuality in the person with dementia could be a dementia symptom. This is most common in Frontotemporal dementia (Evrensel, Tarhan and Ceylan, 2015) but may also affect people with Vascular dementia, Ray's diagnosis, if that particular area of the brain has been damaged.

Seeking closeness through sexual intimacy could also be an expression of a need to feel secure and close to one's significant other, in response to the confusion and insecurities that may be experienced as dementia progresses. This again links to attachment; if a person is feeling unsafe, they may seek closer attachment with their partner, and this may take the form of seeking sexual intimacy (White, 2019).

Lack of feelings of sexual intimacy from a caregiver could be due to a number of reasons, including the change in role from an equal partner to a caregiver (this reflecting Theresa's comment, 'I feel that I'm a carer and not a wife') to caregiver exhaustion, and other complicated feelings towards sexual intimacy (Marriott, 2003; Albert, Martinelli and Pessoa, 2022).

Perren *et al*. (2007) conducted a study looking at the attachment styles of individuals within married couples where one person had dementia, the effect of their attachment styles on wellbeing for both, and in particular, on presentations such as anxiety, depression, agitation and aggression (Perren *et al*., 2007, p.163). Those couples who both had a secure attachment style had higher levels of wellbeing, and a lower occurrence of anxiety, depression, agitation and aggression.

The attachment style of each person in a dyad affects how they will react to each other and to the challenges of dementia. For example, if a person with dementia seeks security through sexual intimacy, but the caregiver partner has an insecure attachment, the caregiver may avoid such closeness and feel unable to respond in this way. The person with dementia is then left with an unmet need that they may be unable to verbalise. Perren *et al.* (2007) found that higher levels of avoidance from a caregiver resulted in higher levels of agitation and aggression from the person with dementia.

Whatever the reason for this mismatch in Kelly and Ray's relationship, their openness and Ray's continued capacity to express his feelings and process most conversations meant they were able to talk this through together, however difficult this might have felt. In Theresa's case, Julian's dementia had affected much of his communication and processing abilities, which made having a conversation together about this difficult topic impossible and perhaps also unethical. Theresa was also protecting Julian's feelings, hiding her own feelings about sexual intimacy: 'I try not to show that side, because it's negative and I don't want to be negative if I can help.'

This represented another shift in their relationship. Theresa was constantly trying to uphold Julian's wellbeing and had taken on the responsibility for his feelings: 'I try to keep him cheery… and keep him as happy as I can'. As well as feeling a sense of responsibility for Julian's feelings, she was also mindful of her daughters' and tried not to lean on them too much: 'I'll have a cry with them, not very often, because… at the end of the day, I also realise that he's their dad and they love him to bits'.

Difficult experiences due to dementia significantly reconfigured relationships for Maria, Leo and Louisa (case two). At times of stress, Louisa would sometimes physically project her feelings, kicking and hitting both Maria and Leo. Louisa also experienced moments where she confused Maria with other members of the family that Maria bore resemblance to. Louisa projected relationships and experiences from the past onto Maria: 'Sometimes she sees me, I'm all of her sisters, I'm her mother...I'm Mrs Black when she's in a rage.' The name 'Mrs Black' portrays how dark and frightening these moments must have felt, for both Maria and Louisa. Past conflicts were interacting with the present for Louisa, and Maria bore the brunt of this: 'I am the focus of all her memories, her life. Because I look like her sister.' Both Maria and Leo commented on the 'hard life' Louisa had experienced: 'she wouldn't get treated nicely' and understood that these experiences were interacting with her dementia symptoms: 'we all know that she can't help it'. Maria and Leo expressed how hard this was: 'When she's screaming and shouting and hitting you and you know, it's really hard…it is full on and it does break you.' The word 'break' here indicates how close Maria and Leo were to the point of not being able to cope anymore.

This example relates to another aspect of attachment. Research suggests that the attachment style we develop in early childhood is often carried throughout our lives and affects our relationships and interactions with others (McConnell and Moss, 2011). Both Maria and Leo commented that Louisa experienced 'a hard life' and this led me to wonder what type of

attachment relationship Louisa had with her own parents, and how this might have interacted in her relationships with her daughter and grandson when she was feeling overwhelmed and not recognising them. Of course, Maria and Leo's own attachment styles would also interact with Louisa's in return, and this may have affected how they coped with these challenging moments, and their own levels of emotional resilience (Perren *et al.*, 2007; McConnell and Moss, 2011).

In addition, Maria and Leo's comment that 'she wouldn't get treated nicely' indicated there may well have been incidences of trauma in Louisa's past, perhaps in her relationship with her sister, or in other relationships. Overwhelming feelings from past traumas may be triggered in dementia (Lewington, Berragan and Kuruvilla, 2024), and the person with dementia, who is possibly already experiencing feelings of a lack of safety due to their dementia symptoms (for example, not recognising their home or family members), relives the moment as if it were the present. Both of these elements: a possible insecure attachment and past traumas being revisited, become very present for the person with dementia, and are extremely challenging for a caregiver to contain and manage. Maria admitted: 'it's heartbreaking'.

It is very relevant to include trauma-informed thinking within dementia care. A traumatic event is a personalised experience, and what may be traumatic to one person may not be to another. In response to this, 'trauma' is being redefined to encompass any experience where a person feels overwhelmed and unable to cope (Lewington, Berragan and Kuruvilla, 2024). Previous studies have identified that between 69% and 89% of older adults have experienced a traumatic event in their lifetime (de Vries and Olff, 2009; Benjet *et al.* 2016), and in a recent feasibility study, 90% of participants with mild cognitive impairment reported that they had experienced at least one psychological trauma in their lifetime (Bell and Devlin, 2024). Therefore, the prevalence of an experience of trauma for the general population is high, and the fact that memories and feelings of past traumas can be retriggered in dementia, makes trauma-informed dementia care essential.

In contrast to the negative effects dementia had on the relationships in these three cases, Nia and her father, SJ (case three), became closer because of his illness. Nia described an overall feeling of softening from SJ, exemplified in that he now seemed to understand her need for creativity, but also manifesting more generally, for example, in SJ's new-found love of Nia's dog:

> He's completely in love with my dog...I'm not allowed to visit him without [name of dog]…and Dad talks to him all the time. Dad was never a dog person before.

There is much published research about the challenges of looking after someone with dementia, but over the last ten years this has been balanced somewhat by an increase in research looking at the positive aspects this caring role can bring. A systematic literature review by Yu, Cheng and Wang (2018) found that caring for someone with dementia can result in feelings of satisfaction and personal growth, as well as strengthening relationships between the caregiver and cared-for. Quinn *et al.* (2022) corroborates the strengthening and continuation of relationships, whilst also describing individual benefits for caregiver and person with dementia, including increased wellbeing. An enriching in relationship due to circumstances brought about by dementia is therefore not uncommon, and for Nia was a significant unforeseen benefit.

1.4.2 Other relationships reconfigured by dementia

Sadly, a recurring theme throughout the cases in this study was one of increased social isolation, both for the person with dementia and caregiver. Stories of other family members and friends stepping away was common. This was a significant source of stress for Nia (case three), who felt the lack of support from other members of the family acutely:

> [Support] In terms of my family, little bit up from zero *[laughs]*…I'm quite angry with my brothers, because, especially one of them has, um, the one who lives really nearby, they've just chosen to totally withdraw from him, for their own reasons, but, um, they're, they're, it's so unacceptable, so I've spent quite a lot of time being quite angry about that, and now I just don't bother…so I don't understand that, that's what I found difficult.

The hesitation in Nia's speech, which was mostly fluent otherwise, along with the use of 'um' and repetition of 'they're' indicate how difficult this was for Nia. Nia also described upsetting interactions with her brother, as she tried to encourage him to visit her father, resulting in a breakdown in their relationship: 'I've been slapped on the wrist for being mean and nasty *[laughs]…*we don't talk to each other anymore.' The onomatopoeic effect of the word 'slapped' indicates how hard and sharp these upsetting interactions felt to Nia, and the words 'mean' and 'nasty' portray how extreme her brother's reaction felt. Nia's laughter following this and the comment about the lack of family support seemed to express how shocking and unbelievable this was for Nia.

Similarly, SJ's friends had also given up on their relationship: 'he's very lonely...lots of his friends have dropped away.' The term 'dropped away' gives an almost visual image of friends gradually and quietly stepping away from SJ. Nia used this term twice in this context, reinforcing the sadness related to this loss, which was also sad for Nia herself: 'he gets very few visitors which is really sad'.

Theresa (case four) also recognised this loss for Julian, as she described his friends attempting to communicate: 'they didn't connect with him like they normally have in the past…I think they think they're deaf and blind and dumb, just because they're quiet.'

Maria and Leo (case two) also spoke of losing relationships with family members who had found the dementia-related experiences too much: 'my uncle...was going down the same road as my mum and so he's really distanced himself because I don't think he can cope with going through the rawness of it.' Leo described the loss of his brother: 'he's been my rock, he's been my best friend my whole life...and he's just like, washed his hands of her.'

These losses in relationships are sad to see and difficult to bear in themselves, but also represent how lonely and alone both a person with dementia and caregiver can feel, at a time in which they are in increased need of friendship and support. Sadly, it is not uncommon for people to retreat from engaging with a person with dementia, especially as dementia progresses (Brodaty and Donkin, 2009; Alzheimer's Society, 2016). This can be for numerous reasons, including the withdrawal of the person with dementia from social situations, finding communicating with the person with dementia more difficult as dementia progresses, and finding it hard to see changes in a person with whom there has been a previous relationship (Sabat and Lee, 2012; Fortune, Whyte and Genoe, 2021). The stigma and negative stereotyping that still surrounds dementia also has a role to play (Sabat, 2018; Cheston, 2022; Christopher, 2023), with a lack of understanding and fear of dementia itself putting people off visiting a person living with dementia. Social isolation and loneliness become real concerns and are compounded if the person with dementia is also physically frail, where getting out into the community becomes limited and sometimes impossible (as in case one with Gordon and Lucy).

6.6 Superordinate theme 1: Relationships - Conclusion

This superordinate theme has highlighted the importance of the relationship between the person with dementia and caregiver. The relationships within this study were all close; this was consistent despite the different familial connections. As dementia intrudes on these intimate

relationships, the ensuing losses for the person with dementia are also acutely felt by the caregiver. Research suggests that a close, loving relationship in this context may enhance attachment bonds for both partners and provide protective factors against stress, anxiety and depression. This theory was supported by the experiences recounted by the participants in this study.

Holding and exploring therapeutic work in this context within the framework of Attachment theory may bring a deeper understanding of both the perspective of the person with dementia and the caregiver, and their relationship together. A trauma-informed approach is also recommended for any therapeutic work in this context.

The examples from microanalysis presented within this superordinate theme exemplify how MT can provide opportunities for shared, intimate interactions, enabling emotional connection and strengthening the relationship and attachment between the person with dementia and caregiver. The created music can act as a mirror, bringing aspects of the relationship and the way the couple interact with each other into focus. This may be helpful in therapy, to illuminate and support aspects of the relationship. However, it is crucial that in upholding the relationship, the therapist also pays equal attention to the needs of each individual partner, and is particularly vigilant to signs that the caregiver may be feeling overburdened, stressed, or losing a sense of self.

Chapter 7: Findings: Superordinate Theme 2

Experiences of Dementia

7.1 Introduction

In this chapter I present the findings relating to superordinate theme 2: 'Experiences of Dementia'. As with the previous superordinate theme, I have included two examples from microanalysis that resonate particularly with this theme.

7.2 Superordinate Theme 2: Experiences of Dementia

Table 5: Superordinate Theme 2: Experiences of Dementia

	Superordinate Theme 2: Experiences of Dementia
Subordinate themes:	**2.1: The Caring Role** 2.1.1 An all-encompassing role 2.1.2 Emotional Toll 2.1.3 Challenging Experiences due to dementia 2.1.4 Examples from Microanalysis
	2.2: Fear 2.2.1 Fear of diagnosis and of progressive symptoms 2.2.2 Traumatic Experiences
	2.3: Views of the Care System
	2.4: What helps?

Within the loving relationships between the people with dementia and caregivers in this study, there was acknowledgement that dementia had significantly impacted the lives of both. This superordinate theme explores experiences due to dementia, particularly focusing on the caregivers' experiences of their caring role.

7.3 Exploration of Themes

2.1: The Caring Role

2.1.1 An All-Encompassing and Relentless Role

Six of the seven caregivers commented that the caring role had taken over their lives, and this had significantly detrimental effects. Taking on the majority of care for his grandmother, Leo (case two) commented: 'I've completely lost my life', and Theresa (case four) admitted: 'It's completely taken over…I haven't got my own life anymore, not at all, not in any way.' Leo's words are dramatic but accurately describe the significant sacrifice he had made to look after his grandmother. Theresa's use of the short, impactful phrases: 'not at all, not in any way' communicated with a firmness of tone and intense eye contact, indicated the heaviness of this impact. Daniel (case six) seemed to have accepted that he was Hazel's 'full time carer…[we just] get on with it' and for Gordon (case one), the caring role took up all his time: 'it doesn't leave a lot of time to do anything.' Kelly (case five) also made significant sacrifices: 'I used to go out…I can't do that anymore because he can't be left on his own', and was vigilant in her care for Ray: 'I'm constantly keeping an ear out'.

For these caregivers, the role was relentless and all-encompassing. Sadly, this is not unusual. The demands of caring for someone with dementia are well-documented and acknowledge the significant sacrifice that caregivers make, giving up their own lives to focus on the care for their loved one (Lindeza *et al.*, 2020; Farina *et al.*, 2017; Daley *et al.*, 2019).

In contrast, although Nia (case three) oversaw her father's care and provided much of it, she did not feel the same level of intensity: 'I don't feel overwhelmed by it.' Nia lived separately to SJ, and was able to hire live-in carers to help: 'they're amazing, and so the team around him are fantastic, and I love them, and we get on really well.' Nia recognised that this took some of the strain, and that she was able to engage professional carers because SJ could afford to do so: 'So support wise, in that way, amazing. But, I mean, you know, he's a well-off man, so, there isn't a problem with money and finances.'

In a recent systematic review, Lindeza *et al.* (2020) acknowledge how important good quality, professional support can be in caring for someone with dementia, helping the caregiver by 'reducing the burden and negative impact of their daily routine' (Lindeza *et al.*, 2020, p.e45). Perhaps Nia's case is an example of how this can work well; she was still very involved in her father's care and spent much time with him, but balanced this with consistent, high-quality and reliable professional care that enabled her to step back and not feel overwhelmed. It is

interesting to note that it was Nia that commented positively on changes in their relationship as a result of dementia: 'we have a relationship we would never have had if it wasn't for Alzheimer's, and I'm much, much, much closer to him now.'

Ideally, all caregivers should have access to good, supportive professional care. In a qualitative study, Oliveira, Sousa and Aubeeluck (2018) asked 150 caregivers: 'What would most help improve your quality of life as a carer?' Having more time to themselves and access to alternative, good quality care were the two most common replies given.

2.1.2 Emotional Toll

As well as giving up their own lives to care for their partner, parent or grandparent, the caring role exerted a deep emotional toll on the caregivers. In his interviews with me, Gordon (caregiver, case one), seemed to find it difficult to talk about how he felt, but the way he used language, and his body language, gave clear indications. Gordon alluded to the malevolent nature of dementia, saying 'it's, it's kind of crept up on us, um' The hesitation and use of 'um' suggest that this was difficult to talk about, and the word 'crept' implies an unknown, dangerous and frightening element, quite accurately reflecting causes of dementia which gradually erode the brain.

Gordon spoke of the experience sometimes being 'disheartening', 'disappointing' and unpredictable: 'there's no kind of constant thing'. He used an analogy of the sea: '[going] through the troughs and get back on the crest of the wave again', indicating a struggle and perhaps a risk of going under. The movement of the sea suggests a lack of control, and the couple had coped with unforeseen challenges, such as Lucy's sudden loss of mobility. In our third interview, Gordon used the metaphor of a 'rollercoaster' to describe their life, resonating with the analogy of the sea, again suggesting sudden changes and a lack of control over their situation, which must have felt quite frightening. Gordon also used the word 'plunge' to describe how sudden and dramatic Lucy's deterioration could be, highlighting how challenging this must have been to experience.

It seemed difficult for Gordon to talk about challenging times; there were pauses and hesitations in his speech and he used filler words ('um, er'). This was also reflected in his body language, for example, when talking of Lucy not recognising her children, Gordon crossed his arms and held them up to his face, as if trying to physically stop the words from coming out, or protecting himself, perhaps from an emotional response, in a defensive position.

Both Gordon and Daniel (case six) used language synonymous with fighting and battling in their descriptions of their caring role. Daniel referred to coping with Hazel's dementia as 'a trial' and he 'battles on', and Gordon used the phrases: 'trying to claw back', 'fight the decline' and 'combat', indicating that he was fighting hard for Lucy. It is perhaps interesting that this use of battle language came from two of the male caregivers in the study (although not the third), and was not present in the language used by female caregivers.

This use of battle and fighting language can also be found in relation to cancer care, with both patients and oncologists commonly using 'war metaphors' to describe their efforts to overcome the disease (McEachern, 2022). Although very different diseases, there are perhaps similarities between cancer and causes of dementia in the way they are experienced. Both can invade a person's being silently, with a slow onset of symptoms, and here I am reminded of Gordon's use of the phrase 'it's kind of crept up on us'. Throughout the world, a diagnosis of either disease is feared with dread (Christopher, 2023; Watson *et al*., 2023). Most significantly, both are life-changing diseases that can be aggressive and consuming. Conversely, although some cancers are curable, at present, diseases that cause dementia are not.

In her article, 'Illness as a Metaphor', Sontag (1991) explores the use of metaphors in relation to cancer and tuberculosis. Sontag concludes that whilst metaphors may be powerful in describing the disease and how this may feel to the person experiencing it, they can also be detrimental, and make the person feel responsible for any failure. Perhaps an obvious example of this is in the use of battle language; when someone talks of 'fighting' their disease, they seem to assume a degree of responsibility for winning, and could feel as if it is their own fault if they succumb, when in fact, it is the voracity of the disease itself, and perhaps the failure of treatment, that lies behind the defeat (McEachern, 2022).

Semino *et al.* (2017) and McEachern (2022) acknowledge this unhelpful use of war metaphors, but also argue for their usefulness in inspiring feelings of hope and motivation. In addition, Semino *et al.* (2017) argue that battle language may unite people in similar situations, as they share the same feelings about fighting a disease.

Gordon and Daniel used this language instinctively, revealing their feelings of fear, challenge and perhaps exhaustion in relation to their caring roles. These two caregivers were giving all they could in their care for their partners. As Sontag (1991) suggests, perhaps there is a risk here that feelings of failure may follow as dementia, inevitably, progresses.

The caring role had a significant emotional toll on Leo (case two), who made considerable sacrifices at a time in his life when he was just starting to make an independent living:

> Leo: I have no life; my whole life has gone…I've gone from starting a new business this year, completely retraining everything to having this and having to drop it… and, leave, leave everything, um, leave business partners, and just have everything go.

The repetition of the words 'gone' and 'leave,' in addition to the phrase 'drop it', emphasise the size of the loss for Leo. His losses were not limited to his career or financial security, but also affected his social life: 'I can't stay, friends...I haven't had a girlfriend in how long...I've completely lost my life.' This was distressing for Leo and he expressed these comments with tears and his head in his hands. He expressed fear about not knowing a path for the future: 'I'm terrified.'

Maria (case two) described her experience of caring as 'heartbreaking', particularly when Louisa's personality seemed to change from the 'beautiful, wonderful lady' when, towards the end of the day 'the devil comes in.' Maria recounted extremely challenging times relating to personal care:

> but come 7 o clock, and it's, you know, it's time to start thinking about going upstairs…having a lovely shower, time to clean, um, if she's not in the right space she will get angry, violent, um, she'll beat me with her granddad stick, she'll pinch me, she'll punch me. *[Maria starts crying a little]* She'll kick me in the head, um, if I'm on the floor helping, taking her pants off, her incontinence pants, and she's maybe had an accident and she feels shamed, she'll then get angry with me because *[gesturing with hands]* you know, she deflects her shame…

There was a flow and intensity in Maria's speech as she shared this very upsetting experience with me. Maria cried too, and I could not help but feel compassion and sadness for this family. This was a vivid insight into how hard these experiences were to bear, and how heartbreaking it was for Maria to see her Mum in this way: 'She's a beautiful, beautiful, wonderful lady. And she can't help it, we all know that she can't help it.'

Theresa (case four) had given up doing the things she loved in order to care for Julian, including her choir, for which she was 'very, very broken hearted,' and seeing her friends: 'it would have been lovely to have stayed with them and chatted a bit'. Emotionally, the impact of caring was overwhelming: 'it's just heartbreaking. Heart-wrenching' and Theresa admitted finding it hard to carry on: 'I'm finding it very difficult to always be cheery…I'm crumping a bit now. And um, finding it emotionally harder as well…I just burst into tears.' The use of the word

'crumping' suggests feelings of defeat, being similar to 'crumbling', and also a feeling of exhaustion, in that it is not quite the right word.

There were also impacts on Theresa's physical health: 'I get this awful anxiety ache, deep in my tummy' and sometimes she had difficulty sleeping, resulting in taking sleeping pills from the doctor: '[it was] the only way I could switch my head off'.

Kelly (case five) found Ray's mood swings upsetting: 'they're not such fun, as you can imagine' and admitted that she also felt low at times: 'I was really down…I hadn't slept for the past two nights and I really was down in the dump and I just wanted to go to sleep and not wake up.' Kelly broke down in our interview when thinking of the future:

> Kelly: It affects me *[crying and gesturing downwards movement with hand]* because I don't want to think about it because I know what the future's gonna be and obviously it's going to be hard, but I know I will cope.

Like Gordon, Daniel (case six) held his emotions back, but occasionally indicated how difficult the role was:

> Daniel: Sometimes, I'm extremely stressed out…um, so I drink red wine, probably too much…you know like, just, I can't get anywhere…I get annoyed and upset sometimes, but I think it's better to be annoyed and upset than to bottle it up.

Frustration was evident here, as well as an acknowledgement that the role can feel overwhelming. In our second interview when Hazel became anxious, Daniel held her and sang to her. He looked at me and commented: 'I need all the help I can get', and his emotions felt close to the surface as he stopped singing and his eyes were welling with tears.

Nia's emotional toll came not from her caring role but from other members of the family and their reaction to her father's dementia (case three; see p.128). Nia also felt sadness relating to her father's losses. The impact of dementia for SJ had been all encompassing, affecting every aspect of his life 'in every way it could do'. Nia described how SJ was an intelligent business man, living a high-paced life, well-travelled, with important job roles and a thriving social life. She suggested that perhaps the impact was greater for him because he was 'a very clever man, and sadly, you know, a long way, a further way to fall.' Describing dementia as a 'fall' indicates the cognitive decline but also a sense of suddenness and shock, and, as with Gordon and Lucy

in case one, a feeling of being out of control. This also indicates the significant change Nia saw in her father, which must have been challenging to come to terms with in itself.

The emotional toll resulting from the caring role and the changes dementia brings to the person being cared for, as well as to the relationship, plays no small part in a caregiver's experience, and it felt to me as if some of the caregivers in this study were only just coping. Of course, any emotional toll is felt in combination with the exhaustion of this relentless role, and alongside, the loss of time for themselves. Research reports that feelings of worry, stress, guilt and anger are common, along with ongoing feelings of grief as changes in the person with dementia and in their relationship continue with the progression of dementia (Blandin and Peppin, 2017; Lindeza *et al.*, 2020; Christopher, 2023). Not surprisingly, there are consequences to psychological health, with higher levels of anxiety and depression in caregivers of people with dementia than the general population (Huang, 2022; Christopher, 2023; García-Alberca, Lara and Berthier, 2011).

2.1.3 Challenging Experiences due to Dementia

I have already described some of the most challenging moments due to dementia recounted by the participants, including some upsetting and violent episodes for Louisa, Maria and Leo (case two), and sudden mood swings affecting Ray and Kelly (case five). In this section, further experiences are highlighted, in order to give insight into the participants' particular circumstances.

Case One - Gordon and Lucy

Gordon described Lucy as an independent and sociable person, and the losses she had experienced in dementia directly affected these two elements of her identity. He recounted losing her driving licence as 'a big blow'; the use of this language alludes to a physical hit, and this affected Lucy physically as it limited her ability to move around independently. The alliteration in 'big blow', emphases the impact this had on Lucy's independence.

Gordon suggested the loss of social interaction as instrumental to Lucy's cognitive decline, and that the COVID-19 lockdowns had a significant negative influence on this:

> And sadly, I would think, both the lockdowns, kind of mentally, [decline of] capabilities and so, kind of accelerated, I think it's the lack, the lack of interaction with people, cos she's a very sociable individual and you know, had a lot of interactions and things.

Lucy's sudden loss of mobility increased the loss of social interaction, as getting out of the house was, at that moment, not possible. Physical and cognitive ability were inextricably linked, with one directly influencing the other.

This loss affected Gordon too as he spoke of being 'tied' to the house, suggesting a feeling of being stuck inside. This contrasted with earlier life experiences where he described himself as a 'very active person'. Gordon believed that being able to go outside held opportunities and possibilities: 'I think at the moment what would help is getting Lucy to be able to go outside again'.

'Outside' seemed to hold enjoyment for Gordon; he spoke of moments when he could get out into the garden, describing it as a 'jungle', which indicates that perhaps there was a lot to do, but that it was a rich environment for Gordon: 'which I enjoy'.

Gordon suggested that the timescales within which changes due to dementia took place seemed to affect how they were experienced. Decline that had 'evolved' over time seemed easier to cope with than the 'sudden' change that happened when Lucy lost her mobility. Gordon referred to some changes, saying 'at least it's not been a very sudden impact', indicating that sudden change was more difficult to manage. This links with Gordon's use of metaphors of the sea and rollercoaster; sudden changes and decline could understandably result in feelings of being out of control.

Gordon seemed to suggest that perhaps Lucy was out of synchrony with the present time in her mind. In interview two, as we watched Lucy's interactions and conversations on the video, he commented: 'a lot of other interactions here *[gesturing towards the video]* are…obviously not relevant, but not er, directly, kind of related to what's going on'. In support of this, during our interviews Lucy often appeared to be remembering or existing in a different time; a time in the past, or perhaps a fantasised time due to confusion about the present moment. From Lucy's conversations and exchanges with Gordon, it was clear there was often a mismatch in time between them, which sometimes led to puzzlement for Gordon.

This is not an uncommon scenario, as damage in the brain caused by dementia can affect how people perceive and experience time (El Haj and Kapogiannis, 2016; Liu, Bulley and Irish, 2021). In Alzheimer's disease (Lucy's diagnosis), time perception, mental time travel (the ability to think backwards and forwards in time) and autobiographical memory can particularly become distorted (Liu, Bulley and Irish, 2021). Liu, Bulley and Irish (2021) write: 'the subjective

perception of time, along with the ability to navigate mentally through time…gives rise to a sense of self-continuity across past, present and future contexts' (Liu, Bulley and Irish, 2021, p.1). Initially, I thought that Lucy's apparent dislocations in time within her mind were due to cognitive deterioration from dementia; that her apparent time-travel was perhaps triggered by something heard or felt in the moment, and that dementia had affected her ability to stay rooted in the present. But reflecting on Liu, Bulley and Irish's (2021) comment above along with Gordon's comments, I wonder if, in remembering significant events from the past, Lucy was, perhaps subconsciously, attempting to reinforce her sense of self and self-continuity.

Lucy spoke about 'time' at different points in our interviews:

> Lucy: And I was a bit worried then, because, because when I realised that um, I didn't think about the time. It was just a thing at the time, that we were going down.
>
> Lucy: What time is it? Gordon: 10 past 12. Lucy: What time do you think we'll get home? Gordon: We are at home.
>
> Lucy: And then the other thing we had yesterday night, was it yesterday, or was it, I don't know when it was yesterday, where were we yesterday?

These comments felt unrelated to the moment and could perhaps be easily disregarded, but on further reflection, I wondered if Lucy was commenting to us that keeping a hold on time was challenging for her, or if she was trying to locate herself in time.

As music can bring back memories, it is possible that the music in therapy sessions heightened time distortion for Lucy, transporting her to moments in the past, and this may not have been helpful in her interactions with Gordon. But there were also signs that the music engaged and united Gordon and Lucy in the present moment, especially when they engaged in singing a song together (see microanalysis for case one, p.115).

This is a fascinating but complex area and one that requires deeper investigation than this study allows, however, the couple's mismatch in experiences of time remained a source of bewilderment for Gordon.

Case Two – Maria, Leo and Louisa

I have already mentioned some upsetting experiences this family endured as a consequence of dementia. Louisa's intensified expressions and sometimes violent responses must have been frightening and distressing both for herself and for her family. Maria commented that this was why the caring role was shared between herself and Leo: '[we're] dual caring, because we, the

strain is too much, one person cannot deal with it all.' Maria admitted that the tension and intensity was significant: 'we're all walking on a razor's edge'.

Maria and Leo comment that Louisa's heightened feelings and reactions seemed to occur most often in anticipation of personal care, or towards the end of the day. There could be many reasons why Louisa had a strong reaction to personal care. Louisa may have had physical pain aggravated by personal care, but was unable to communicate this. It is also possible that Louisa's understanding of what was happening in the moment was challenged, and perhaps she felt under threat and was trying to defend herself, hitting out verbally and physically as a coping strategy (James, *et al.,* 2024).

Maria also commented that Louisa sometimes did not recognise her as her daughter, but confused her with her sister, with whom Louisa had a difficult relationship. If this confusion occurred whilst Maria was helping Louisa with personal care, previous relationship dynamics and possible past traumas may also have been triggered, provoking feelings of insecurity and anger (see pp. 126 and 135). In these moments, Louisa's feelings of secure attachment may have been undermined, and her responses may have been communicating an unmet need in terms of feeling emotionally safe (Balfour, 2020; Cheston, 2022; James, *et al.,* 2024). Feelings of embarrassment and shame may also have been present; Maria suggested that during these episodes, Louisa may have been projecting her own difficult feelings, as she 'deflects her shame' at having to be helped in this intimate way (see p.135).

Louisa also became more distressed towards the end of the day. 'Sundowning' is an expression given where some dementia symptoms, or reactions to these, are experienced with greater intensity towards the end of the day, from late afternoon into the evening. This may include increased anxiety, confusion, and a tendency to walk around and feel unsettled (Valletta *et al.*, 2021; Christopher, 2023). Also common within sundowning experiences are requests for a parent's presence, or asking to go home, even though the person may already be at home (Miesen, 1992).

In a blog about his own experiences of living with dementia, Norman McNamara reflects on what he means when he says 'I want to go home' (McNamara, 2021). For McNamara, this is not a request to move physically to a different place, but to move in emotional feeling to a place of security: '"Home" is a place of safety, home is a place of reassurance and home is a peaceful place with no worries, no confusion and no troubles.' (McNamara, 2021).

McNamara continues by describing how his wife provides comfort and reassurance for him in these moments of anxiety and uncertainty (McNamara, 2021).

This clearly links to attachment theory, and from McNamara's experiences and insight it is feasible to suggest that in moments where a person expresses a wish to go home or to see their parents, there is a strong possibility that they are communicating a need to feel emotionally and psychologically rooted in their secure base; their secure attachment relationship with another person. Sundowning can therefore be clearly linked to an underlying need for secure attachment; to feel safe, reassured and comforted. This explanation may also be relevant for Louisa.

Case Three – Nia and SJ

Dementia had affected every aspect of SJ's life, and Nia commented on the most upsetting aspects. Nia described SJ's loneliness and confusion due to dementia, and how this impacted his wellbeing: 'He's lonely, he doesn't know where he is, all the time he's confused about where he is...sometimes he's OK about that but mostly he's upset.'

Nia recalled her father's earlier reactions to his dementia: 'he fought it for quite a long time...he's fought it really hard.' This internal battle with dementia indicates how difficult it must have been to accept the diagnosis. There seemed a feeling of determination and tenacity within this fight, in that SJ continued to fight 'long' and 'hard'. This description of SJ 'battling' dementia is reminiscent of Gordon and Daniel's fight as they cared for Lucy and Hazel, respectively. In SJ's battle, Nia particularly mentioned giving up driving: 'he stopped driving which he really fought against too'; this seemed a significant moment, perhaps symbolising the start of an erosion of independence.

In a recent literature review, Holden and Pusey (2021) acknowledge the significant emotional impact that can accompany the loss of a driving licence. They comment on this moment representing a significant 'life transition', resulting in many negative feelings, such as sadness, grief, anger, powerlessness, humiliation and embarrassment (Holden and Pusey, 2020). For SJ, who for many years was a powerful businessman, this must have been difficult, and brings back to mind Nia's comment that his decline had perhaps been 'a further way to fall'. This may well have been difficult for Nia too; Holden and Pusey (2021) comment that caregivers often feel guilt at having to enforce this life changing event.

Dementia had affected SJ's mobility too, which Nia found difficult: 'he's very shuffly and immobile, so um, spends a lot of time in bed, which is sad, for me.' One of the most challenging experiences for Nia seemed to be that, due to SJ's confusion and declining mobility, it was difficult to leave the house, or to engage SJ in interactions. Nia recounted a time when she planned to take him out:

> Nia: I had a great big plan to get him to [name of local place], I'd hired a wheelchair, hadn't told him about that, but anyway, you know…I couldn't even get him out of bed, I had to cancel it.
>
> But he's really lonely. *[Nodding]* And his caregivers are lovely but they don't really do, they don't, they can't take him out and do things, you know. He could really do with that, but it's difficult, he's not an easy man, so trying to get him to, I seem to be the only person who can get him out to do anything *[laughs]*

The phrase 'great big plan' indicates how much thought and effort went into this event, and how hard it was to organise a simple trip out. The underlying sense of responsibility is also present, as Nia recognised that SJ only responded to her requests to engage in leaving the house. As well as resonating with Gordon and Lucy's experience, the difficulties here for SJ and Nia highlight how challenging it can be for someone with advanced dementia to leave the house.

Case Four – Theresa and Julian

Dementia seemed to have altered aspects of Julian's personality, making him more easily stressed:

> He started to get very, um aggressive, almost as if he wanted to argue…one little word that you say, that he will take it the wrong way, um, he'll be angry and throws things down, and he stamps off like a naughty boy.

Theresa spoke fluently, and during this communication, the addition of a pause and use of 'um' indicated how difficult these changes in Julian were for her. Julian's memory and cognition were also affected: 'It's gone down and down, less and less is now being able to be done. There's still the sympathy, it's still there, although of course, two moments later it's gone.'

Dementia seemed to have affected long term as well as short term memory: 'No memory. Not of anything, anybody, anywhere, there's nothing.' Again, there is use of repetition here, portraying the extreme effects of dementia for Julian. The alliteration adds to the significance

of this, and there was an intensity in Theresa's speech and firm, direct eye contact as she spoke these words.

Despite these difficult experiences, it seemed to be the relentlessness of the role that caused Theresa the most stress: 'It's non-stop, it's incessant…you're like a Mum with a new baby'. Theresa recognised the strength and values needed to keep going: 'You need endless patience and of course lots of love…Got to be a strong person to do it.'

Case Five – Kelly and Ray

Mindsong's inclusion criteria for the MT@H service is 'advanced dementia or dementia with complex symptoms' (Mindsong, 2020). However, both Ray and Kelly described Ray as experiencing the earlier stages of dementia: 'I'm still in early stages.' Yet Ray's recent Mini-Mental State Examination score (Folstein, Folstein and McHugh, 1975) indicated a sharp decline in cognitive abilities: 'When [name of doctor] came this last, he scored 10 out of 30, in a year, which is a big…'. Kelly missed out the final word of her sentence, which could be 'decline' or 'drop', and I wonder if this was because emotionally it felt too difficult to say out loud.

Ray was dependent on Kelly for all his care needs, with the exception of showering and dressing, for which professional caregivers came in for half an hour each day. Kelly explained: 'I do everything else' and that Ray 'can't be left on his own.' The high degree of care needs and fact that Kelly needed to be with Ray indicated that he was perhaps further along in the dementia progression. It could be that Ray's continued ability to hold conversations and to express himself clearly was masking the fact that the dementia was already quite advanced.

This mismatch also seemed apparent in the individual experiences the dementia created for Ray and Kelly. Ray felt unchanged: 'I don't feel that I am different in any way', but for Kelly, there were lots of changes, including restrictions on her own life: 'it has affected things, obviously, because like, I used to go out…I can't do that anymore because he can't be left on his own.' Caring for Ray meant Kelly had to give up going out to see her friends and sharing music with them, which had been a significant sacrifice for her: 'cos that was my love.'

Other areas of change which were difficult included Ray's increased sex drive and mood swings, which created arguments: 'He gets frustrated and I get frustrated and we shout at each other…you have to fall out to make up, don't you!' Kelly commented on how low Ray had been, particularly during the time of his diagnosis:

> A few weeks ago, he was talking about going into the woods and not bothering to come back, but I think it was because, I mean, we're still waiting for a full assessment for his care plan, and there was just so much going on, different assessments, and I think it was just all too much.

'Not bothering to come back' resonated with Kelly's own feelings at times; as recounted earlier, where she talked about feeling low and wanting to 'go to sleep and not wake up' (p.136). These thoughts, hinting at suicide, indicate how difficult life may feel; how much of a struggle coming to terms with dementia and living with the disease can be. Sadly, there is research to corroborate, with studies including both people with dementia and caregivers experiencing suicidal ideation (Joling *et al.*, 2018). Research suggests this is more common for people who are also experiencing depressive symptoms, or who experience high levels of agitation, anxiety or caregiver burden (Joling *et al.*, 2018; Koyama *et al.*, 2015). Once again, this highlights the importance of emotional and psychological care for both the person with dementia and caregiver.

Case Six – Daniel and Hazel

Although Parkinson's Disease is not a form of dementia, Lewy Body Dementia is often experienced alongside (Savica *et al.,* 2013), and the symptoms Hazel experienced were a result of the combination of these two diseases interacting with each other. The challenges of living with Parkinson's and Lewy Body Dementia, as a person with the illness and as a caregiver, came through strongly in my interviews with Daniel and Hazel. One of the most frightening symptoms for Hazel were the hallucinations she experienced. These came without warning and Hazel would see a 'nasty man' that came into the house.

Hallucinations are a common occurrence in Lewy Body Dementia (Yumoto and Suwa, 2021; Christopher, 2023), as Lewy Body protein deposits damage certain areas of the brain that can then cause hallucinations (Sacks, 2012). Sleep disturbance and Parkinson's medication have also been identified as possible causes for hallucinations (Sacks, 2012; Christopher, 2023). Visual hallucinations are most common, and can be pleasant, or not, as in Hazel's case. Whatever the form, the hallucination can arrive suddenly, feel very real, and is generally uncontrollable for the person with dementia (Sacks, 2012).

On the video recording of the sixth MT session, Hazel and the therapist talked about her hallucinations, which Hazel linked to previous frightening dreams. From her words, I wondered if these were from childhood, but Hazel only specified that these were from a time 'when I was

little'. The dreams that Hazel remembered seemed to have a direct link with the frightening hallucinations she experienced in the present: 'It was when I was little…I was much bigger than I am now, but was little…and I saw these people… in my dreams. And they made me scared.'

The 'nasty man' that frequently came into Hazel and Daniel's house in the form of hallucinations was clearly real to Hazel. When reflecting on the experiences Hazel endured, I wondered about an alternative or additional explanation; that perhaps the nasty man represented Parkinson's and dementia to Hazel; an intruding presence that had come unwelcomed into her life, her home and her relationship with Daniel. In the MT intervention, the Music Therapist worked with Hazel and Daniel to find a way of singing and playing Hazel's hallucinations away (see p.147), giving her some control over her hallucinations; a successful tool the couple continued to use.

Hazel was aware of her condition and the challenges it was creating. Early in the interview, she commented: 'I might be a little bit funny, because I do have a problem…and if it gets out of control, I may have to go to my bed.' Through her awareness, Hazel gave insight into how she felt, commenting that when she was anxious, she felt: 'lots of wobbly'. Hazel was also aware that going to bed was a safe space for her: 'it's much nicer than going anywhere else, to go to bed'.

I wondered if Hazel's self-awareness was upsetting for her; she communicated an understanding that things had changed, and twice appeared to refer to herself as different before the illness began, saying: 'I was this person,' and 'before I went…'. Hazel was also aware of her moments of anxiety and confusion. In a humorous way, Hazel reflected on one episode of anxiety with a smile, commenting that it was 'just a little bit of an issue'; her smile belied an understatement as well as her self-awareness. Hazel realised how challenging her dementia was for Daniel and apologised to him, saying: 'yes, I'm sorry…I can't help it'.

Hazel was quite self-critical throughout and I wondered whether this, along with the level of awareness she had of her condition, created feelings of low mood and self-esteem for Hazel. When Daniel talked about her anxiety, Hazel referred to herself as a 'silly person'. She was also critical of her own singing, commenting on the video: 'Oh I sound awful! Listen to me!' and later in the video: 'I'm no good…at singing.' Despite this, Hazel sang often in the MT sessions, and also asked me if we could sing during our interviews: 'What are we going to sing?'

Hazel experienced unpredictable episodes of disturbance in her mood which were difficult for the couple. There was even a difficulty in naming these episodes. Hazel referred to these as 'anxiety' or a 'funny turn', and Daniel 'a meltdown', 'she goes off on one', 'got one on her' or 'anxiety meltdown'. The language used indicates the high level of challenge these moments presented. The unpredictability and extremes Hazel experienced intensified the challenges, as Daniel described:

> Hazel, at times, is perfectly happy and lucid and so on, and then, I don't know what you call it, whether it's a meltdown, or she goes off on one.
>
> Parkinsons is strange because it varies from Hazel being able to walk around perfectly ok, to not being able to walk at all…She is so variable.

These sudden changes applied to mobility, as well as emotional state of mind, and this was a significant concern, limiting what they could do together. Hazel would fall many times a day, and had 'bashed' and 'damaged' herself on many occasions. The couple stopped going swimming together because of the risk of slipping when walking around the pool: 'her balance is so poor.'

Hazel's difficulties with mobility and balance resonate with Gordon and Lucy and Nia and SJ's challenges around mobility, and again highlight how difficult it can be to leave the house. However, despite these physical challenges, Daniel explained that it was the sudden emotional changes that were the most difficult: 'I can cope with the physical Parkinsons side, but the mental side, is very tricky' and Daniel admitted that 'sometimes, I'm extremely stressed out.'

2.1.4 Music Therapy: using music as a tool to ease dementia experiences

Examples from Microanalysis

Many of the video clips from the sixth MT sessions show examples of MT easing difficult dementia experiences. I have chosen two clips that seem relevant to two of the most challenging experiences presented: Hazel's hallucinations, and Louisa's interactions with Maria, which can be undermining to their relationship. I have included a description of the music here, along with a summary from the microanalysis.

Case Six: Daniel and Hazel, Improvisation

This clip of music was chosen by the Music Therapist for microanalysis. Daniel and Hazel agreed this would be a good clip to use at the start of our second interview (see p.74 for further explanation).

Description of Context

This clip is taken from 17 minutes into the sixth MT session. Hazel had been talking about the nasty man in her hallucinations, and the therapist (Neil) suggests playing the nasty man away. Daniel sits to Hazel's left, and watches the interaction. Hazel chooses to play the djembe drum. The conversation prior to the music is as follows:

Neil: Could we try a theme in our playing?

Hazel: Mm hm.

Neil: In our playing, we're just gonna play, nasty man, go away.

Hazel: Mm hm. I don't know how…it just happens.

Neil: It just happens. I'll start playing.

Brief Description of the Music

Neil plays the ukelele in a minor key, in three time. Hazel quickly joins in on the djembe and Neil follows her pace. The tempo is steady at first, then Hazel increases the tempo and Neil matches this, supporting Hazel's sounds in rhythm and intensity. Hazel's movements are fluid and controlled; she seems embodied in the music as her whole body moves as she plays.

There is a moment where Hazel gives Neil eye contact, and smiles. The music becomes faster, louder and feels more intense. Neil sings to 'ah', a tune over the top of their playing. Hazel quietly sings the words: 'go away, go away'; Neil sings this too, reflecting and validating Hazel's singing. Hazel gives moments of eye contact to Daniel and Neil.

Hazel changes her drum playing from rhythmical tapping to smoothing across the drum's surface, and Neil changes his playing to match. The music calms to a softer and slower pace. Hazel ends the music with a clear and loud single tap, using both hands. Neil stops too. Daniel claps and gives praise. Hazel comments:

Hazel: He's gone.

Daniel: He's gone!

Hazel: He was here but now he's gone.

Daniel: He's gone, fantastic.

Hazel: He stays away now.

Neil: How do you, how do you feel, Hazel?

Hazel: Tired. Tired. But happy. I'm connecting with my world.

Neil: *[nodding]* Connecting with your world.

Hazel: Yes. Feeling more like me again. It's nice. *[Neil nods]*

Discussion

This section of music seems very significant for Hazel. Her Parkinson's and Lewy Body Dementia symptoms frequently cause episodes leaving Hazel out of control of her movements and her mood, with accompanying feelings of confusion, anxiety and disconnection. Her hallucinations are also very frightening for her. In this music, Hazel is very much in control; firstly, of the music itself, as Neil follows her changes in tempo, rhythm and intensity, and secondly, of her body, as she makes purposeful movements that engage her whole body. By the end of the improvisation, she also seems in control of her hallucinations, as she comments: 'He's gone.'

The 6/8 tempo that the piece settles into gives a sense of energy and drive to the music, and the E minor/D major tonality gives a folk feel, with Neil's free, improvised melody seeming to dance over the top. This sense of momentum seems to come from Hazel but also supports Hazel in her continuing playing. The music finishes in G major, a strong, bright key, reflecting the strong and clear ending from Hazel, with a whole-body movement. This feels like a real resolution. Hazel's words afterwards are significant; there is a feeling of empowerment, and a sense that Hazel has been strongly present in the music, driving it forward and leading the changes throughout.

The couple continue to use music to 'sing away' Hazel's hallucinations, and Daniel reminds Hazel of this when she thinks of them:

Daniel: Yeah, I know, but we can sing him away.

Hazel: Yes. We can sing him away.

Once again, the MT addresses all of Kitwood's psychological needs (Kitwood, 1997):

Attachment: There feels a sense of trust between Hazel and the therapist, as she freely expresses herself and seems to know that he will go with her; he will follow and support her.

Comfort: Hazel is in control of this interaction; she changes the pace and intensity of playing. Hazel is the centre of attention and is being listened to and supported.

Identity: Hazel expresses herself freely throughout the music; she is not held back by her Parkinson's or dementia symptoms. Hazel is the focus of the interaction.

Occupation: This is a very meaningful and significant interaction and Hazel is leading. Hazel is successful at playing away her hallucination.

Inclusion: Hazel leads this interaction and the therapist facilitates the safe space for her to do this, using specific techniques to support and attune. See Appendix 20, p.410 Therapist Techniques.

Love: The MT is completely person-centred; Hazel is leading the interaction and the therapist is attentive and supportive in his playing and communications with Hazel.

Case Two: Louisa and Maria, 'Danny Boy' trad. English / Irish folk song

Maria and Leo chose this song for analysis because of the cognitive ability Louisa shows in her singing and playing, and its emotional importance for them as a family: Louisa used to sing it to Maria as a child, and Maria named her eldest son after this song.

Description of the Context

This song comes near the start of the MT session, at 15 minutes in. Louisa is sat at the table, with a glockenspiel in front of her and a beater in her hand. Maria is sitting in the chair behind her, and Sally (the Music Therapist), sits opposite Louisa with her guitar, out of the picture captured by the video camera. Louisa had just been playing the glockenspiel with Sally accompanying on guitar. When Louisa stops playing, Sally suggests they have a song, mentioning 'Danny Boy'. Louisa begins to play it on glockenspiel, mouthing the words, and then begins to sing.

Brief Description of the Music

Louisa begins to sing 'Oh Danny Boy', matching the key that Sally is gently playing on guitar. She also plays the glockenspiel, picking out the rhythm of the melody. Louisa hesitates after the first line, looking at the glockenspiel and seeming to not know what to play. Sally suggests: 'shall we start it together?' and begins to sing. Louisa looks up at Sally, then joins in, singing with her and playing the glockenspiel, again picking out the rhythm of the melody.

The music is gentle and there is a warmth of sound throughout. The bright G major key and consistent rhythmic picking from Sally's guitar hold the song at a steady pace, but there is also flexibility in pacing, with some rallentandos (slowing up), especially when Louisa appears to need more time to rest or to take a breath. Sally's guitar playing and singing is gentle and warm, and Louisa's singing and playing sits over the top of this, being slightly louder in dynamic. Maria occasionally joins in; her singing is also gentle. There is a thread of musical connection between Louisa, Maria and Sally which feels fragile but beautiful.

Louisa is aware of Maria's presence throughout, despite Maria sitting behind her, out of her sight and also mostly out of sight on the video. At two points, Louisa verbally calls to Maria, saying 'Come on [name]' to encourage Maria to join in, and then later to both Sally and Maria: 'Come on girls!' At moments, the music brings out Louisa's sense of humour. She changes the words in the last line of verse one, singing 'you can't use up!' then looks up at Sally and laughs a little, and Sally laughs too. Louisa turns to Maria as well, as if trying to bring her in on the joke. She offers the glockenspiel to Sally: 'do you want to have a go?' and Maria encourages her to continue singing. Following a clearing of her throat, Lousia says 'pardon me for being rude, it was not me, it was my food!' and then continues to join in, singing and playing.

Towards the end of the song, Louisa seems tired and says 'I can't', and this seems to reflect her physical frailty and vulnerability. Maria encourages her: 'Come on Mum, I don't know the words', and Louisa joins in, singing again with Sally to the end of the song.

Discussion

This song is part of the family's shared identity and history, and hence, engaging in the moment together provides opportunities to uphold and strengthen the relationship between mother and daughter. The MT brings Louisa into the present moment to share in an experience with her daughter; Louisa is lucid and present, recognising Maria as her daughter, and inviting her to play with her. This resonates with Maria's belief that music connects them: 'It brings her back to me...Mummy again'. This is highly significant in their relationship, especially in the light of other contrasting, upsetting experiences where Louisa confuses Maria for other people, or reacts with aggression to personal care.

The music brings out aspects of Louisa's identity; there is a warmth to the whole experience, a willingness to engage with others and encourage them, a sense of humour, and an expressive musicality. This echoes Maria's comment in the interview: 'I see all of my Mum again and it's precious.' The music also reflects how physically frail and vulnerable Louisa is at present (and this is true for Maria too).

Cognitively, Louisa is engaging in the present moment, and uses many different skills at once to interact, including singing, playing, interacting with Sally and Maria, initiating the song and moments of humour and joint interaction. Louisa recognises Maria as her daughter and responds to her in a loving and inclusive way. As Maria says in our interview, there are not many times when her mother can engage in so many different cognitive processes all at once:

> ...this is a real breakthrough. Because there is a complete ability to understand and put different processes together, singing the words, playing in tune, and obviously, being with Sally as well...to see Mum use all those different skills, I haven't seen that for a long time.

Sally's singing and playing is beautiful, warm and inviting, sitting underneath Louisa's music in a holding and supporting manner, with pacing focused on enabling Louisa to interact. Again, the music seems to act as a mirror; the person-centredness in this interaction is reflective of how the family are focused on providing the best care they can for Louisa, which is often at great personal cost.

The MT addresses all of Kitwood's psychological needs (Kitwood, 1997):

Attachment: Louisa recognises Maria as her daughter and is aware she is with her throughout, despite Maria sitting behind her. Louisa has a trusting relationship with the therapist, engaging with her and allowing her support.

Comfort: There is a warmth in the music, in the therapist's singing and guitar playing, but in Louisa's too. The therapist plays at Louisa's pace, pausing for her at times, facilitating her interaction.

Identity: This is a family song; Louisa sang it to Maria when she was young and Maria named her first son 'Danny' after this song. Louisa's sense of humour comes out in the song.

Occupation: This is a meaningful moment of connection; Louisa is singing and playing, using more cognitive skills than Maria sees at any other time.

Inclusion: The therapist uses techniques to best engage and include Louisa, most significantly in her pacing (see Appendix 20, p.410).

Love: There is love expressed as Louisa calls for Maria to join in. The fragile thread of musical connection between Louisa, Maria and Sally seems to express a feeling of warmth and love between the trio.

2.2: Fear

2.2.1 Fear of diagnosis and of progressive symptoms

It is perhaps not surprising that there were many references to fear in relation to dementia throughout the interviews. Theresa (case four) experienced fear in relation to Julian's diagnosis. Even though the symptoms were there, it was '[a] shock': 'We were just stunned. We knew that life was never going to be the same again…It was very scary.' Theresa also had a fear of receiving a dementia diagnosis herself, despite having no symptoms: 'that's the last thing in the world you would want to have.' Having lived through the changes Julian had experienced, Theresa had first-hand insight into the deterioration dementia brings. It is, therefore, perhaps not surprising that she feared this for herself. A diagnosis would have also undermined Theresa's ability to care for Julian, and not being able to cope was a significant concern for Theresa: 'that it's not going to overwhelm me, so I can't do my job to look after him.'

Following on from a diagnosis is the knowledge that dementia is a progressive condition with no current cure. Kelly and Ray expressed fears for the future. In their conversations with me, they left out words that could name their fears, for example: increased symptoms such as memory loss, cognitive decline, and eventually, death. These thoughts were unthinkable, but by not naming them the fear seemed to loom larger:

> Kelly: It's the knowing in what's going to come in the future, I think he doesn't want to think about that, do you?
>
> Ray: I suppose not.
>
> Kelly: …I don't want to think about it because I know what the future's gonna be and obviously it's going to be hard.

Theresa expressed similar fears: 'there's no end to it really, and I know the worst is to come, I know the worst is to come, which is frightening.' One of Theresa's biggest fears was that Julian would not recognise her: 'He sometimes forgets who I am, which is a bit scary. It's gonna happen, I know it's gonna happen, yeah.' Theresa's repetition here emphasised her depth of feeling and apprehension about this happening.

2.2.2 Traumatic Experiences

Just as past traumatic experiences and feelings can be re-triggered for people with dementia, so they may also interact with current experiences for caregivers, and create further fears for the future.

Kelly and Ray (case five) recounted significant incidents that had dramatic effects on their lives. These were retold with urgency and fluency, with a sense of a need to tell. The first was an accident where Ray fell off his rollator into the street and bumped his head. This event seemed to have had significant consequences, as the couple wonder if this was the original cause of the damage that started his dementia symptoms. The use of the words 'nasty' and 'somersault' to describe what happened to Ray, as well as 'black' to describe his bruising, indicate how dramatic and frightening this episode was for them both.

A second experience concerned Ray's mother, whilst she was in hospital following breaking her hip in a fall. Ray began telling the story: 'I had this phone call from the hospital…she was isolated, she was, she'd been attacking people' and Kelly took over: 'like something out of a horror movie'. Again, there was a strong visual memory presented: 'this little old lady in this bed that had been pulled away from the wall surrounded by blood on the floor.' The inclusion of dramatic words such as 'isolated', 'attacking', 'horror' and 'blood' indicate that this was a

shocking and frightening experience for Ray and Kelly, and an image that had stayed with them.

There was fear surrounding the idea of being in hospital, and that being admitted to hospital should be avoided if at all possible. This related back to the rollator accident, where a friend's presence influenced the decision not to go to hospital: 'if it had been anyone else, there's no doubt, he'd have gone to hospital.' Ray also clearly stated that he didn't want to go: 'Fortunately, I said, "No, I 'm not going to hospital!"' At another point in the interview, Ray spoke of a time when he was in hospital: 'I didn't enjoy my hospitalisation, I really didn't.'

The strong negative feelings about hospital may not be surprising when thinking about the past traumatic experiences that had been related. I wondered whether Ray's mother's experience of dementia and how Ray and Kelly experienced visiting her in hospital, might be adding to the couple's fear of what dementia might bring for Ray. Were they frightened that this might be a repeated experience for Ray? There was another indication in the interview that may corroborate this view, with Kelly making a clear connection between Ray and his mother: 'Towards the end, she started speaking Welsh…well, just recently, [Ray] has developed a love for Welsh music…which I think is quite interesting.' There is a possibility that there was an implicit connection in Kelly's mind between Ray's mother's experience and what might happen for Ray.

During our third interview, Theresa (case four) spoke of a recent traumatic experience when Julian had been admitted to hospital. The urgency of her speech, intensity of eye contact, and lengthy account of the experience communicated that this was an extremely challenging event and one that she needed to tell me about. The experience had negative repercussions for Theresa's physical and mental health:

> And so, I had two days in hospital with him, and he stayed in, I didn't leave until 12,… he'd just fallen asleep on a trolley. No beds…I was absolutely done up, and I came home, I went to bed, I didn't really sleep, I cried a lot.

Theresa recounted a time during this admission where she noticed a lady choking, and called to nurses who attended her, and that no one acknowledged or thanked Theresa for bringing the incident to their attention. Theresa found the experience frightening, and this on top of the 'dreadful experience' that Julian had been through left her exhausted, with serious consequences:

> I was feeling really ill myself…and I had a bit of a breakdown at the end of the next week, 'cos I'd looked after him night and day. I didn't have any rest, snatching a, half hour here or there, frightened he was gonna fall out of bed.
>
> I wasn't fine of course. And I'd had a physical and mental breakdown. I had like a *[circles on top of her head with her hand]* the top of my head was like a cloud, I couldn't think straight, I couldn't make decisions. I've never been like it in my whole life, I completely lost the plot. So stress, I suppose, and lack of sleep, anyway, the combination put me down, for the first time.

One of Theresa's worst fears, of not coping, had become a reality. Her words 'put me down' emphasise the collapse Theresa felt, both physically and mentally.

Within this experience Theresa also made reference to feelings of abandonment, particularly with regards to being a caregiver: 'because very often, as the carer, you're left to your own devices'. This particular hospital experience, which was frightening for Theresa and where she felt out of control and abandoned, may well have triggered Theresa's own attachment needs. Theresa stresses her feelings of abandonment:

> Nobody…if we hadn't been with him…nobody offered him, or indeed us, a glass of water or a drink. Nobody came to us and told us why we were sitting there and what we were waiting for.

On Theresa's return to the hospital the next morning:

> I could see him sat, outside this little room where they put us, which was off the main ward, in a chair, in his underpants and his shirt that he was wearing the day before, and he was wet, he hadn't been washed or shaved, nothing, nothing at all. He looked absolutely lost.
>
> I didn't know what to do because, what do you do, when nobody tells you what's happening?

The repetition of the word 'nobody', 'nothing' and description of Julian looking 'absolutely lost' emphasises the strength of feelings of being abandoned, left alone, with no one to help. Due to his advanced dementia, Julian depended on Theresa in every aspect, including for feelings of security and attachment. But who was there for Theresa in this moment where she seemed to feel both her own and Julian's sense of abandonment? Theresa's use of the word 'us' again indicates how strongly she identified as a couple with Julian in this incidence, how they were one, and his experiences had a direct and deep effect on her, to a symbiotic extent.

Reflecting on the experience, Theresa felt that the passing of time helped her to feel more like herself: 'It's taken, it's 8 weeks ago now, um, and I've adjusted again.' This 'adjustment' felt a significant shift and change in experience for Theresa, illustrating how dramatically and suddenly things can change, and how external factors can influence the experience as dementia progresses.

Hazel and Daniel also endured a challenging hospital stay during the course of the MT intervention, when Hazel became very unwell:

> Daniel: Hazel was in hospital, because she was very poorly, and just lying there, not moving, unfortunately no stimulus, and very often you [*addressing Hazel and hand lightly on her arm]* were sleepy, weren't you…physically going downhill quite badly.

Daniel praised the medical staff, acknowledging that they were doing everything they could for Hazel's physical health, but noted that her emotional wellbeing was deteriorating:

> I mean they're working on the medical front, but it's not quite the same as the emotional front…in hospital, there was no stimulation…Literally just be laying there 24 hours a day, awful … so hospital's not a good environment…There was no other stimulus.
>
> You can understand providing that sort of close care and attention would be impossible for the NHS, because they basically have to have someone like me sitting next to the bed all day…they can't afford that. So, I understand that, but I'm glad to get her out.

It was music that helped her regain consciousness:

> Interviewer: Is that what happened in hospital?
>
> Daniel: absolutely, the nurses were absolutely amazed, would come and look, or tell their friends 'come and have a look at this', because they'd see Hazel laying there going 'ahh, ahh', and then I'd come along and play a Spotify, Elvis Presley, or something, and 'ahh ahh' would turn into *[sings a tune to ah],* in time with the music… well then, she would sing the words. And they were all amazed. And in fact, I know that one, two of the nurses went and sang to her, cos they picked up on it.
>
> Interviewer: And nothing else would bring that kind of response?
>
> Daniel: No, no, talking, shaking her, nothing you know
>
> Interviewer: Gosh
>
> Daniel: It's the only thing that got through.

It is widely acknowledged that for people with dementia, a hospital admission can be a frightening, confusing and distressing experience (NICE, 2024; NIHR, 2020). Dislocating a person with dementia from their home, routine and family into a busy, noisy and unfamiliar environment can also cause dementia symptoms to progress (Abbott *et al.*, 2022; NIHR,2020). Sadly, people with dementia are twice as likely to need an emergency hospital admission than those of a similar age without dementia, and emergency admissions remain high across the UK (Abbott *et al.*, 2022). As is evident in this study throughout, the experiences of the person with dementia directly affect caregivers too; Theresa's case epitomises this.

2.3: Views of the Care System

In addition to challenging hospital experiences, some caregivers had strong views about the care system as a whole.

Maria and Leo (case two) were passionate in their discussions about this topic. They spoke with intensity and pace, often speaking over each other. I felt as if they really needed to have someone listen to their experiences. They both used strong language to communicate disappointment and anger at the lack of support in the system and the way they and Louisa had been treated, including the words: 'diabolical…despicable…abandoned…terrible'. Their experiences led them to believe that the whole care system is 'systemically broken'.

Their experience as a family, and for Louisa as a person dependent for all care needs, had been negative and they believed had at times resulted in Louisa becoming ill with UTI infections, due to lack of care. An example of this was given where professional caregivers failed to check Louisa's urine for possible dehydration: 'disgusted and horrified…it's abuse…how easy is it to pick up a white commode, to tip it to the side and check the colour of the pee.'

There was a definite feel of 'them and us', with the family believing that because they had stepped in to provide care, they were no longer a priority in the system. Maria spoke of wanting to hold someone to account for the 'huge failures' but not knowing how to do this. The family had a set of cameras around the house so that they could monitor Louisa when they were not there, and felt that this added to the 'them and us' dynamic: 'we are the enemy, because we are the only ones who care, because we have cameras.' Again, the use of the word 'enemy' indicates how strongly Maria felt about the situation.

Maria and Leo believed that being in hospital, and particularly in a care home, would be damaging to Louisa's health: 'abandoned in a care home…they'll just dose her up'. The word

'abandoned' has emotional connotations and portrays Maria's strength of feeling against her mother moving into a care home. This view seemed to come from Louisa's own wish not to go into a care home, which 'she is vehemently against', and also views of some of the professional caregivers; Maria recounted them saying to her: 'the second you put her into a home...we don't even give her 12 weeks.'

Theresa (case four) also recognised issues with the care system, commenting on how difficult it was to navigate, and feelings of dismay when hearing that if she offered to pay for any day care, the three hours respite a week she had been awarded would stop: 'I was shocked, honestly, I was shocked.'

The care system left her with a sense of hopelessness, and another added pressure of having to carry the load herself: 'I know times are tough…I can see what's happening with the care sector…the hospitals, everywhere. But it doesn't make it any easier to bear...you're going to have to carry on.'

In contrast, Gordon (case one) and Daniel (case six) received good support from local, specialised NHS teams:

> Gordon: I mean there's a team, a unit, locally in the NHS called the complex care at home…And they've been very good, very helpful, um, setting things up, you know they've done this chair and other things, and again, talking about ways of getting access for Lucy to go outside, so it's kind of still in the development stage, I mean they only got involved about a month or so ago, but um, you know so far they've been very supportive.
>
> Daniel: They're very good, we get excellent support from everybody…and the doctor, I know a lot of people complain about their GPs, we think the [name of surgery] where we go is fantastic. You know, very, very responsive, and they have a frailty team who come round and check up on us, and you can phone anytime, you know, so all good.

Whilst there are regional differences across the country with regards to dementia care and support, and every person's experience may be different, there are documented experiences of the challenges in navigating the care system. Resonating with Maria's view, a case study from the Alzheimer's Society reports 'a broken system of care' (Alzheimer's Society, 2019). A UK study in 2014 report caregivers finding accessing dementia support services 'challenging and stressful' (Peel and Harding, 2014). From my personal experience of working in the context of dementia care in Gloucestershire for the last 17 years, I see how passionate our dementia professionals are about providing high-quality, supportive and accessible services, and the

improvements that have been made over time. However, as Maria, Leo and Theresa exemplified, navigating the system is still challenging and can be a stressful experience in itself, in addition to the existing demands of the caring role.

2.4: What Helps?

Despite the significant challenges and emotional toll caused by dementia, there was recognition of supportive local services, family relationships and friendships that had been helpful.

For Nia and Theresa, support from friends and family was invaluable:

> Nia: my kids are supportive and everybody knows, everyone I know always says 'how's your dad?', so people know how involved I am.
>
> Theresa: My girls are wonderfully supportive, especially emotionally.

Theresa expressed how important it was to connect with others in a similar situation, to share experiences and support each other:

> People that have already done it and been through it, they're the ones that give you all your guidelines if you like, because they've done it, and they know, they know exactly how you're feeling, they know exactly what to say and how to say it.

Theresa is a naturally warm and open person, and seemed to find it easy to connect with others. This was evident in the manner Theresa communicated with myself in our interviews, but she also commented that this was one of her coping strategies: 'I do tend to share; I think it's a way forward…I know quite a few people who don't share...they struggle. And very often a breakdown happens.' Theresa continued, commenting: 'we help each other and we hold each other up.' There was a sense of shared understanding here, camaraderie and supportiveness. The words 'hold each other up' indicate how easy it might be to fall under the weight of the caring role, and that others felt this too.

When asked what else would help, three caregivers mentioned respite time:

> Theresa: I would like to think that he would be happy if he would be away from me for a while.
>
> Kelly: For me, it would be for him, either somebody to come and look after him, well basically I suppose so I could have a couple of days off a week. I, and maybe, a Saturday night, so I can just go and know that I don't have to worry about him, so I know he's looked after, yeah.

> Daniel: someone to be here *[pause]* and to go shopping. Because Hazel is different with other people. Just having someone else here, for some reason…improves the behaviour. Or I could go and do things when I wanted to do things.

Maria was clear regarding what would help: 'proper, tailored, specialist care' and Leo reinforced this: 'educated care'. They believed that at present the care system is based on monetary gain: 'care is commercial, it's all about the money' and that this needed to change to a system based on respect and dignity: 'there's no care given to her feelings, her dignity, what she would like'.

These findings resonate with Oliveria, Souza and Aubeeluck's (2018) qualitative study, where 'time for themselves' and 'appropriate care alternatives in place' were most commonly identified by caregivers of people with dementia as factors that would improve their quality of life. 'Support from family and friends' also ranked highly amongst helpful suggestions (Oliveria, Sousa and Aubeeluck, 2018, p.5).

7.4 Superordinate theme 2: Experiences of Dementia - Conclusion

The experiences of dementia across the six cases were individualised and diverse, with variations in symptoms and how these were experienced depending on many different factors, including different causes of dementia, previous life and relationship dynamics and interacting attachment styles. However, in five of the six cases, the role of the caregiver was all-encompassing and extremely demanding. There was significant emotional toll, and six caregivers in this study put their own lives on hold in order to care for their family member.

The caregivers described some extremely challenging experiences that significantly impacted physical and mental health, as well as the relationship with the person with dementia. There was an element of fear surrounding diagnosis and what may be to come as dementia progressed. Previous traumatic experiences for both the person with dementia and caregiver interacted and compounded fearful feelings about the future.

There were some particularly upsetting experiences relating to hospital stays, which fuelled an ongoing fear of being admitted, and resulted in one caregiver's breakdown. Views about the care system as a whole were varied, with some experiencing good support from local services, and others enduring very difficult, negative experiences with care services, and feelings of hopelessness when trying to navigate the system.

Two examples from microanalysis exemplified how MT can ease difficult dementia experiences; in these instances, relating to chasing away hallucinations, engaging cognitive processes and upholding significant relationships. These benefits were particularly significant when considered within the context of these experiences of dementia, and for case two, in the context of that relationship, which had withstood incredibly upsetting interactions on a regular basis.

The caregivers identified three key aspects that would improve their experiences of caring: having more time for themselves, access to good, professional care, and support from family and friends. These do not seem unreasonable requests, especially considering the significant demands and emotional toll caregivers experience.

There are an estimated 540,000 caregivers for people with dementia in the UK, saving the UK around £13.9 billion a year (NHS England, 2018; Public Health England, 2022). Caregivers are at increased risk of mental and physical ill health because of their caring role. Surely, society has a duty to pre-empt this risk and address the current lack of support given to caregivers, implementing policies and services that ensure regular respite with good quality, accessible care available where needed.

Chapter 8: Findings: Superordinate Theme 3

Experiences of Music Therapy

8.1 Introduction

In this chapter, I present the findings relating to the superordinate theme, 'Experiences of Music Therapy'. All six examples from microanalysis resonate with this theme, but I have chosen to include two that relate particularly to two subordinate themes in this section: the Impact of MT in relation to Kitwood's Flower (Kitwood, 1997) and Aspects of Self, and Creativity and Magic (see table 7, p.165).

As with the findings for the superordinate theme, 'Relationships' presented in chapter 6, new theories became useful to engage with in developing my understanding and interpretation of the data for this superordinate theme. I introduce these here, before presenting the exploration of themes.

8.2 Theories of Self

Cheston and Christopher (2019) argue that receiving a diagnosis of dementia is an existential threat; that it affects every aspect of being: our sense of self, our self-esteem, how we function in the world and our relationships with others. In addition to this threat (as we have seen in chapter seven), the experience of dementia can have acute consequences for caregivers, including significant emotional toll, changes in identity and relationship, and a threatened sense of self. Compounding this, whilst caregivers may not have a progressive dementia that erodes their cognitive and physical functioning, aspects of a caregiver's daily functioning can be significantly impacted by stress and exhaustion from the unrelenting nature of the caring role, as was exemplified in Theresa's case (see p.155).

Identified within Cheston and Christopher's research are key psychological aspects of self that, if supported, can provide a protective element against the negative experiences of dementia (Cheston and Christopher, 2019). These include a sense of self and self-continuity, self-esteem, the feeling of having a meaningful life, and social connectedness (Cheston and Christopher, 2019). Strengthened, supportive relationships can also increase emotional resilience for people with dementia and their caregivers (Sabat, 2018; Cheston and Christopher, 2019), and, as already discussed, help to strengthen feelings of a secure attachment (White, 2019; Balfour 2020; Cheston, 2022).

These vital components of self resonate with Kitwood's flower (Kitwood, 1997) representing his five fundamental psychological needs. Parallels can be seen as follows: identity relating to a sense of self and self-continuity; comfort, attachment and love being of vital importance to relationships; inclusion relating to social connectedness and self-esteem, and occupation again resonating with self-esteem but also with the feeling of meaning in a person's life.

The concept of 'self' is complicated, but essentially, our sense of self can be defined as: 'the essence of who we are and how we see ourselves' (Christopher, 2023 p.128). Steven Sabat suggests three aspects of selfhood, and I have summarised these and how they may be affected by dementia in the table below (Sabat, 2018).

Sabat's framework highlights the importance of relationship and how interactions with others can help to build or undermine aspects of selfhood. This resonates with Kitwood's concept of personhood, which emphasises the need for value and respect for the person with dementia in relationship with another (Kitwood, 1997; Kitwood and Brooker, 2019).

It is easy to see how these aspects of self were at risk of being undermined for the participants in this study. One obvious example of a threat to self 2 and self 3 (see table 7, below) is the loss of job roles, positions in society and relationship changes due to decline in cognitive functioning, as experienced by SJ (see p.136). Arguably this threat to self is easily extended to the caregiver, who may have to give up work to look after someone with dementia, as in Leo's case (see p.135). For the caregivers in this study, there was also a potential threat to self 1 (see table 7, below), the loss of a sense of individual identity, because of the overwhelming role of caring (as may have been the case for Theresa and Gordon, see p.123).

Table 6: Aspects of Selfhood (Sabat, 2018)

Aspect of Selfhood	Explanation	How this may be affected by dementia
Self 1	The experience of being a unique individual, the feeling of 'I', 'me', 'my' 'we' (you and I) and 'us' (you and me), (Sabat, 2018, p.138). This refers to our sense of self and self-continuity, that we are essentially the same person we were before, are now and will be in the future (Christopher, 2023).	Sabat suggests that this aspect of self is preserved throughout advanced stages of dementia, evidenced by people in these stages referring to themselves as a person, even if that takes the form of pointing to themselves rather than verbally referring to themselves as 'I', 'me' or 'my' (Sabat, 2018).
Self 2	This aspect of selfhood relates to our physical and mental attributes, e.g. our height, age, hair colour, state of health, beliefs, personality, achievements and abilities (Sabat, 2018).	Dementia may impact on some of our abilities but despite this, Sabat suggests that many aspects of a person's sense of self 2 can be retained in dementia. The preservation of these attributes is significantly affected by interactions with others, and this may become under threat if the person with dementia is seen by others as 'someone with dementia', or someone with memory problems, instead of being seen as a whole person with a myriad of attributes. Sabat comments that this can have a 'tremendous assault' on feelings of self-worth, and undermine this aspect of selfhood (Sabat, 2018, p.143).
Self 3	This relates to how we present ourselves to others. Our presentation will differ depending on who we are interacting with and within which occasion we find ourselves, e.g. how I present myself as a mother is different to how I present whilst teaching, and different again to how I present myself as a therapist. This aspect requires the presence of at least one other person; the relational aspect of selfhood (Sabat, 2018).	Sabat believes this aspect of self is the most vulnerable to being undermined in dementia, as so much of the presentation of self depends on the responses from other people (Sabat, 2018). Positive interactions and supportive relationships that acknowledge and validate an individual's personhood can help to preserve a person's sense of self 3.

I will now present the third superordinate theme, 'Experiences of Music Therapy.'

8.3 Superordinate Theme 3: Experiences of Music Therapy

Table 7: Superordinate Theme 3: Experiences of Music Therapy

	Superordinate Theme 3: Experiences of Music Therapy
Subordinate themes:	**3.1: Impact of MT** 3.1.1 In relation to Kitwood's Flower, Aspects of Self, and Relationships. 3.1.2 Music as a Tool 3.1.3 Considering the use of Nostalgia in MT 3.1.4 Example from Microanalysis 3.1.5 Joy and Hope
	3.2: Creativity and Magic 3.2.1 Example from Microanalysis
	3.3: The Therapist 3.3.1 Skills of the Therapist 3.3.2 Therapist or Friend?
	3.4: MT at End of Life

8.4 Exploration of Themes

3.1: Impact of Music Therapy

3.1.1: The Impact of MT in Relation to Kitwood's Flower, Aspects of Self, and Relationships

Identity: A sense of self and self-continuity

I believe there is evidence of MT upholding all three aspects of self in every musical moment chosen for microanalysis presented in this thesis. As exemplified in the musical moments, the therapist listens, hears, attends to and values the expressions from both the person with dementia and caregiver, thereby acknowledging the individual self 1 of both in the dyad. The therapist uses specific techniques to connect and engage with both, facilitating musical moments that bring the person with dementia and caregiver to the fore (see Appendix 20, p.410, Therapist Techniques).

A clear example of this is exemplified in case two, where the therapist played at a steady, gentle pace to enable Louisa's participation, and gave pauses in order for her to rest or breathe. The musical intensity provided by the therapist was warm and supportive, gently encouraging Louisa to continue, and allowing her to be the focus of the interaction. As a result,

Louisa sang and played and at the same time interacted with the therapist and Maria, whom she recognised in this moment as her daughter. As Maria commented, Louisa was engaging in many different cognitive processes at once, and in this moment, MT was upholding her personality, her skills and attributes; strengthening a sense of selves 1 and 2. In Louisa's recognition of Maria as her daughter, the therapy was also upholding her sense of self 3, as she presented to Maria as her mother. In turn, Maria responded as her daughter, upholding her own sense of self 3 (see p.149).

In every case, the MT created a safe space where participants could express themselves freely, and through this, the music elicited aspects of personality. This seemed especially pertinent for the participants with dementia: as I watched the video clips for microanalysis, there felt a strengthened presence of the person with dementia, which gave deeper insights into who they were and glimpses into how they interacted with their family member. These aspects were brought out through the music more clearly than when I met the participants in-person for our interviews. The caregivers also commented on this, seeming to see more of their loved one again through the music. In turn, this strengthened their relationships, and provided opportunities to reinforce a sense of self 3 for both:

> Gordon: Lucy loves to communicate...I'm not the most communicative of people so you know, communicating with other people is a beneficial, beneficial thing.
>
> Maria: It brings her back to me...Mummy again…[it's] a gift...I see all of my Mum again and it's precious.
>
> Nia: They were having a laugh and…he's still got his sense of humour and I really hold onto that, it's really precious.
>
> Julian: Tickle Mary *[singing along to 'It's a long way to Tipperary']*
>
> Theresa: You're doing 'Tickle Mary' again…You were making [therapist's name] laugh!
>
> Julian: Was I? How's that? Better than making you cry, innit!

For Maria (case two), the music also connected with her biographical identity, reminding her of memories from childhood, including intimate moments with her mother: 'she sang it to me when I was a little girl'. This relates to self-continuity (self 1), but also to relationships past and present (self 3). Music had been important in Maria's life story; she named her first child 'Danny' because Louisa used to sing 'Danny Boy' to her: 'That's why I named Danny, Danny. Mum used to sing it to me every morning.'

Biographical identity also seemed strengthened for Theresa (case four). As we watched the video of the sixth session of MT together, the music elicited moments of reminiscence,

bringing back fond memories. This strengthened Theresa and Julian's individual identities as well as their couplehood, as Theresa remembered Julian's past for him. There were memories of Julian as a young man working on a farm, and of Theresa's father singing as she walked with her family from her grandmother's house as a young girl: 'Dad would sing all the way home'.

Difficult feelings in MT

The majority of comments from participants were about how uplifting their experiences of MT had been. However, there were some difficult feelings recounted, expressed particularly by caregivers Theresa and Gordon. Whilst listening to these experiences, and again whilst analysing the data, I was aware of feelings of conflict within myself. I realised I was interpreting these comments as a Music Therapist, and perhaps diminishing the extent of negative emotions this had created for Theresa and Gordon. I needed to pause and engage in reflexive thinking in order to ensure that I was thinking about their comments from their perspectives. In the analysis stage, I worked hard to bracket-off my thinking as a therapist, and looked again at the text with a more objective stance. I hope, in my reporting of these difficult moments, that I have presented them from a perspective that resonates more clearly with Theresa and Gordon's experiences, as well as giving an explanation of how these difficult moments might still be therapeutic within MT.

Theresa (case four), spoke of upsetting times elicited by the music: 'When [name of therapist] plays, he [Julian] remembers them [songs], and he gets a bit, um, emotional, seems to…It was quite upsetting for me, to see him getting emotional.' The music brought moments of sadness for Julian, expressed with tears, and this was very difficult for Theresa to endure:

> Theresa: He was quite emotional…it would stir a memory, I presume, and that would make him upset, you know…and he'd cry.
>
> Interviewer: Was that difficult for you?
>
> Theresa: It was quite, because I've not, obviously he does get emotional now, and worrying, but he never cried, never. But he did get very emotional, and I would say to [name of therapist] just carry on, carry on, and he'd *[moving gesture with hands]*
>
> Interviewer: Work through it?
>
> Theresa: Yeah, work through it.

These were clearly difficult moments for Theresa and Julian, and reminded me of the findings from my literature review, where, in a home-based MT study, three dyads dropped out due to

stress caused by the intervention (Holden *et al.,* 2019). However, Theresa and Julian continued with the therapy, and seemed to work through the difficult feelings.

MT aims to connect with people in their genuine state, however they might be feeling. This is one of the central tenets of therapy, to provide an experience for the client of 'being fully seen and fully understood' (Yalom, 2001, p.18). From a therapist's perspective, supporting Julian to access these feelings and providing a safe and held space for him to express them could be a cathartic experience for him. Julian's feelings were being acknowledged and validated; demonstrating an acceptance that it was natural to grieve for things past. In this way, Julian's sense of self and self-worth were being supported. If these moments of sadness were disregarded or not allowed, we would be denying Julian access to the natural range of human emotions; at risk of infantilising him by making the decision for him that these feelings were too difficult or in some way unacceptable.

Theresa recognised that supporting feelings of sadness had benefits over time:
'But now…six weeks in, he's enjoying it more. The actual process of doing it has definitely helped. Helped [Julian] to control the emotions a bit more, yeah.' Theresa became more comfortable with Julian's range of feelings: 'It's quite nice to see the emotions playing on his face too, you know, not just always emotionally upset, but also emotionally enjoying it.'

Watching the video of the sixth MT session also brought sadness for Gordon, as he reflected that music from their shared past did not seem to elicit relevant memories for Lucy that they could share together in the present:

> Interviewer: Can I ask what's it like to reminisce like that?
>
> Gordon: Er, yeah, it is kind of sad in a way, in that Lucy doesn't remember any of these things, very few, I mean, you get the impression that a lot of people remember, not the near past, but the distant past, and um, sadly with Lucy, she doesn't remember much of that at all.

Here, the music seemed to highlight the couple's mismatch in time and the decline in Lucy's ability to engage in reminiscence and communication with Gordon. Despite this, Lucy did seem to remember the music, as seen in the video clip for microanalysis, where Lucy joined in, singing some of the words to 'Take Me Home, Country Roads.' This gave the couple a shared interaction in the present moment, and Gordon seemed to feel comfort from this:

> Interviewer: How does it feel for you to, um, share the music with Lucy?

> Gordon: Um, well it's nice cos it brings back, it brings back memories, er, in that particular instance, um, again, it's always good to see Lucy actually singing the words or mouthing the words, you know, because it kind of shows that there's something there, kind of thing.

Inclusion and Occupation: Self-esteem

'Self-esteem' is another complex concept, but can basically be defined as the value we give ourselves; our sense of self-worth (Jordan, Ziegler-Hill and Cameron, 2020). Again, it is easy to imagine scenarios in which self-esteem comes under threat, for example, as dementia symptoms increase, the ability to complete basic functioning tasks becomes more challenging, creating potential feelings of defeat and helplessness. I couldn't help wonder about Hazel's self-esteem as she criticised her singing and apologised to Daniel for her moments of anxiety (see p.145).

In MT, interactions are attuned to an individualised level; paced so that the person with dementia can participate. The emphasis is on what a person can do, rather than what a person can no longer do. Being successful in a meaningful interaction with others, that celebrates a person's ability, clearly has the potential to increase feelings of self-esteem, but also upholds aspects of identity through self 2 and self 3. These feelings of self-worth may spread to the caregiver as well, as they are part of this meaningful interaction. For some cases in this study, the MT facilitated levels of engagement to a surprising degree that seemed to go against the decline experienced in dementia:

> Leo: Nanna's singing and her ability to remember those things are trending in the opposite direction.
>
> Maria: ...this is a real breakthrough. Because there is a complete ability to understand and put different processes together, singing the words, playing in tune, and obviously, being with [therapist's name] as well...to see Mum use all those different skills, I haven't seen that for a long time.
>
> Nia: being able to do something that he could actually do…he could keep playing even though he could barely write.

Not only was the person with dementia engaged in something they could access, but they excelled in the music-making, which may have led to feelings of self-worth and empowerment:

> Maria: [*to Louisa*]: You're the star there, love, you're the star.
>
> Maria: Joy! Now this bit fills me with pride *[wipes away a tear]*, it's overwhelmingly beautiful.
>
> Leo: She can still keep up.

> Nia: It was watching something extraordinary…unbelievably special. I think it just gave him something really special, and that gave me relief.
>
> Kelly: It's like he [Ray] was the star.

Inclusion: Social connectedness

As exemplified in chapter six, friends and family may step away from people with dementia, leaving both the person with dementia and the caregiver at increased risk of social isolation, and therefore decreased social connectedness. This is heightened when a person with dementia's mobility is challenged (as with Gordon and Lucy, see p.138). In this study, the MT provided opportunities to support connection between the person with dementia and caregiver, as well as with the therapist. This was appreciated by the caregivers, who enjoyed sharing a positive interaction together:

> Nia: It's really nice to have that time, you know, to be able to do that with him…It would be really nice to see if we could play it a bit more together.
>
> Theresa: It's something nice to do together.

In some cases, social connection through music was extended to include others. Theresa (case four) asked if her granddaughter could join in, and this created connection within the wider family:

> Theresa: She sat with me, she was a little bit shy for a minute, and then she started singing, woah! What an experience that was! And she wasn't singing quietly and nervously, she's singing *[gesture with elbow]* and she was singing all the old ones, you know, that I didn't even know she knew! It was amazing, it was amazing!…It was really, really good. And one day [name of daughter] came, she came and sat with us, and so that was a bit more of a family thing.

Ray started attending a day centre and took his instruments with him, joining in with the singing there: 'It's lovely, we have a singing session, and a big screen, so we got all the words, and we can join in the singing and we sing all the stuff.'

Attachment, Comfort, Love: Relationships

I have already discussed the importance of the relationship between the person with dementia and caregiver, and the reconfiguration that can occur because of dementia (see p.124).

A strong sense of attachment and containment in relationships are crucial for both in the dyad, and in all cases the MT provided opportunities for shared interaction and supported emotional connection, which seemed to strengthen the relationship between the person with dementia and caregiver. Examples of MT upholding couplehood were given in chapter six (see p.115 and p.118). The MT also seemed to strengthen Maria and Louisa's relationship, as through music, aspects of Louisa's personality shone through; not only did Maria see her Mum as 'Mummy again', but also, Louisa recognised Maria as her daughter (see p.149). This is particularly significant when considered within the context of their experiences of dementia, which included some upsetting experiences, where Louisa confused her daughter for other family members.

In addition, Ray believed the MT helped to support his relationship with Kelly:

> Ray: We've been through some pretty rough patches, haven't we?
>
> Kelly: Yeah, we have.
>
> Ray: But there's it's helped [the MT]…we, we, well, I can't help, I've got a smile on my face when I talk about it.

In case six, Daniel used physical touch and music to comfort and reassure Hazel in her times of anxiety, epitomising his love and care for her. Music became a vital part of their relationship, facilitating their physical and emotional closeness.

This intervention, which involves working with the caregiver alongside the person with dementia, as clients of equal importance, holds particular significance in the potential to support these important relationships, and I am reminded of White's recommendation for the need of supportive interventions that 'involve both carer and cared for together by offering the possibility of lasting relational change' (White, 2019, p.31, see p.101).

Occupation: Finding meaning in life

In progressing dementia, as cognitive ability declines and skills are lost, feelings of being able to contribute to life in a meaningful way may become threatened. Whilst the caregiver may feel great meaning in their life in providing care, this might not be what they would have chosen to do, had dementia not intruded on their lives.

Potentially, the MT sessions provided a way of finding meaning through music; meaningful connection with each other, something positive to share in the midst of challenging dementia

experiences, and for caregivers, discovering that music can be used as a tool beyond therapy sessions to support daily care and wellbeing (see below, section 3.1.2).

Section Summary

In all six cases of microanalysis, the moments from MT addressed all five of Kitwood's psychological needs (Kitwood, 1997), and supported key aspects of self, often for both the person with dementia and the caregiver (see p.117, 120, 149, 152, 179 and 184). This seems significant, especially as the musical moments analysed were brief, ranging from the shortest clip being only 40 seconds long (case four), to the longest at just under four minutes (case two).

In addition, the MT provided moments of shared interaction and supported emotional connection between the dyads, strengthening these important relationships.

3.1.2: Music as a Tool

In every case the caregivers described using music more frequently in daily life following the MT intervention. For Theresa, the MT 'brought it [music] more to the forefront'. For Ray and Kelly, music became a feature in their daily lives. Kelly bought Ray some of his own percussion instruments, so they could continue to sing and play together.

In some cases, the MT gave caregivers musical strategies to help in daily care, and the therapist helped to develop the caregiver's confidence to use these at times of need. This was particularly significant in two cases, where music became the main coping strategy in times of challenge.

For Maria and Leo (case two), the MT sessions encouraged them to 'think outside the box' in their care for Louisa: not only using music as a tool, but also in their thinking about Louisa's wellbeing, the triggers that upset her, and how she appeared physically. Maria commented:

> We've learnt so much through the Music Therapy. This is the tool that Mindsong has given us...so that we now have the music to be able to use as a positive tool, to deflect situations if we can see a trigger. It's given us the tools to be able to cope as a family.

There was a sense that, through the experience of MT, the family came to know Louisa more deeply as she was at that moment in time, gaining a heightened awareness of when Louisa was physically unwell:

> Maria: It's given us ideas, and it's shown us where her triggers truly are…and it also means that we're far more aware when there is something medically wrong as opposed to just mood, or you know, overheating, dehydration, we can really tell so much easier, what it is going on.

The family spent much time and energy focused on Louisa's happiness, and Leo commented that it was as if his grandmother was 'in a Disney movie', as they controlled the environment to remove as many triggers as possible and used music to calm, to motivate, and to help Louisa to move: 'whistle while you work!' Leo developed an understanding that the music used needed to be right for Louisa in that moment: 'the right, appropriate music. And when Nan's in the headspace and she's in a happy, controlled environment, she's happy as Larry.'

Leo and Maria's responses regarding the MT were extremely positive, expressed with smiles, tears and words such as: 'overwhelmingly beautiful', 'pride', 'breakthrough', 'lovely', 'enjoying', 'gorgeous', 'vital', 'blew me away', 'amazing', 'remarkable'. This was in stark contrast to the negative language used to express the family's experiences of the care system, dementia symptoms and the caring role. It felt as if Maria and Leo were expressing at the two extreme ends of the emotional spectrum, and were equally passionate and intense at both extremes. This magnified their emotions and gave a clear indication of the significant positive impact MT brought for this family.

The MT also brought important change for Daniel and Hazel (case six). As a result of the MT, the couple used music to chase away Hazel's hallucinations (see p.147), giving Hazel some control over these frightening moments. Daniel also continued to use music to calm Hazel when she became anxious. I witnessed a moving moment where Daniel calmed Hazel from a moment of anxiety. Daniel sang along to Spotify and the song 'Make You Feel My Love', with his arm around Hazel, looking down at her and holding her hand. This loving, intimate moment calmed Hazel. The words from the song 'go to the ends of the earth for you, to make you feel my love', seemed to resonate with the moment as Daniel sang them. It felt to me that this is what he was doing: going to the ends of the earth in his care for Hazel; his whole life being centred around her care and wellbeing.

Daniel acknowledged that music is a tool he continued to use: 'it gives me something I can do, whereas before, I couldn't think of anything to do, when Hazel's having a bit of an anxiety attack or something.'

Music became a crucial coping strategy for Daniel when Hazel was unresponsive in hospital (see p.156), bringing her back to a conscious state when nothing else worked: 'it's the only thing that got through.' Daniel describes how the music connected:

> Daniel: Hazel's making a, sort of a groaning noise a lot of the time…and that shifts to being in tune with whatever song, and then possibly the words too. Well, that, that's you know, she's tuning in
>
> Interviewer: she's tuning into the music
>
> Daniel: she's tuning in.

Daniel commented on how important the MT was for them:

> When it first started, I didn't think it would make any difference, and then as it's gone along, I've realised how it does make a big difference. And, it's the one real thing that we've got now that works.

Skill-sharing; enabling caregivers to use music as a tool beyond therapy session times was identified as an important aspect in this study's literature review, being a key feature of eight of the studies included in the review. This study supports the importance of skill-sharing, and also exemplifies some successful cases where this has enabled the caregiver to use music as a tool to support the couple to a significant effect.

3.1.3: Considering the use of Nostalgia in MT

Mindsong Music Therapists often use songs that are well-known and have meaning for the people they are working with; these familiar songs can help to facilitate a quick connection between therapist, person with dementia and caregiver. Similarly, there are examples in literature of Music Therapists employing 'reminiscence', which has been helpful in supporting communication, levels of engagement, feelings of wellbeing, and relationships for people living with dementia (Ashida, 2000; Dassa and Amir, 2014; Tamplin *et al.,* 2018; Kelly and Ahessy, 2021). In the examples chosen by participants for microanalysis, four of the six musical moments were songs that were well-known and held emotional significance for the participants. As well as offering comfort through familiarity and a quick connection, by singing these songs together, aspects of identity, personality and relationship were also strengthened (see p.115, 119, 149 and 177).

This resonates with research regarding interventions that use 'nostalgia' to increase psychological resources for people with dementia. The term 'nostalgia' differs from 'reminiscence' in that whilst 'reminiscence' is concerned with remembering experiences from

the past, 'nostalgia' refers more specifically to positive memories that have deep personal meaning, and may involve an embodied experience with sensory elements, including memories of smell, sight, touch and sound (Christopher, 2023). Research evidences that engaging in nostalgic memories can provide a 'psychological buffer' against distressing situations for people with or without dementia (Wildschut *et al.* 2006; Ismail *et al.* 2018). Nostalgic memories can create feelings of improved mood, increased self-esteem, a sense of social-connectedness, self-continuity and an increased feeling of meaning in life (Wildschut *et al.,* 2006; Christopher, 2023). These are exactly the psychological domains that dementia can erode (Cheston and Christopher, 2019); therefore, the use of nostalgia is of significance when considering interventions to support people with dementia. This is also important in supporting caregivers, whom, as we have seen in chapters six and seven, are often enveloped into negative experiences of dementia.

The fact that four of the six musical moments chosen by caregivers for microanalysis in this study related to significant personal memories of the past supports how important nostalgic memories can be in caring for someone with dementia. For the caregivers in this study, the music brought back times when perhaps they felt more connected to their loved one; precious memories from the past. For Gordon (case one), 'Take Me Home, Country Roads' represented treasured family holidays and a time when life was adventurous. For Maria (case two), the music reminded her of precious moments when her mother sang to her, when she was 'mummy' again, in stark contrast to moments affected by distress and confusion (see p.149).

Dodd *et al.* (2022) developed a home-based nostalgic intervention for people with mild to moderate dementia and their spouses. Their study involved six couples (person with dementia and their spouse) identifying nostalgic memories from their life together, and objects that might help them to remember these, for example, photos, souvenirs or music. The nostalgic memories were captured in a personalised workbook which the couples were encouraged to use together to facilitate daily nostalgic conversations. The couples were supported at home or over the phone by 'nostalgic coaches' and results showed improvements in a range of outcomes, including self-esteem, self-growth, meaning in life and social connectedness (Dodd *et al.* 2022). There are similarities in this intervention to Mindsong's MT@H intervention, in that both are home-based, include both caregiver and person with dementia, and the element of skill-sharing.

Perhaps by including nostalgia more explicitly in MT, we could take the benefits a step further. Although a person with advanced or complex dementia may not be able to engage in nostalgic

conversation, they may still be able to be involved in music-making, as is exemplified in the musical examples in this study. Skills of the therapist are crucial as the music is taken at a pace within which the person with advanced dementia can also access. Techniques such as body positioning, pauses, slowing up, tailored use of intensity of sound are employed to encourage inclusion and engagement of the person with dementia (see Appendix 20, p.410). In this way, both the person with dementia and caregiver can join together in this shared interaction, bringing them into the present moment, strengthening their relationship whilst also potentially experiencing the individual psychological benefits of engaging in nostalgic memories together.

It would be interesting to see if and how 'nostalgia' could be employed more explicitly in MT. Perhaps the Music Therapists could dwell for longer with their clients in moments that relate to personal memories, exploring these memories, the feelings they elicit, and the possibilities of embodied experiences that may result. Research in this area would be beneficial, to explore if and how nostalgia might be employed in MT, and to what effect.

3.1.4 Music Therapy providing empowerment and strengthening a sense of identity - An Example from Microanalysis

Four of the six clips chosen for microanalysis include well-known songs that relate to memories from the past. This clip from case four shows the therapy facilitating a moment where the person with dementia's personality comes through, strengthening a sense of identity. It also shows a moment of empowerment for the person with dementia, as Julian initiates a well-loved song from his past, and leads the music throughout the interaction. I have included a description of the music here, along with a summary from the microanalysis.

Case Four: Theresa and Julian: 'A little ditty'

This clip was chosen by Theresa. It's a song Julian often initiates during the MT sessions, which Theresa refers to as 'A little ditty'. Theresa explains why she chose this moment: 'Because I think that's showing his confidence. To others, I mean, he's sharing with others, he remembers, and I think it's very special.'

Description of the Context

This is from the sixth session of MT, 11 minutes in. Theresa, Julian and Bethan (the therapist) are sitting in the couple's lounge, quite far from each other, in different chairs. They had been listening to a recording of 'Do Not Forsake Me, Oh My Darling'; playing along, with Theresa playing shaker, Bethan playing the caterpillar (a wooden, slatted instrument that gives a rippled wooden sound) and Julian playing the drum. All three play a strong beat, and Julian sings a little at times too. There is a strong sense of connection, with eye contact shared at moments across the trio. At the end of the song, there is the following exchange:

> Bethan: 'That's a good one, that one'
> Theresa: 'Yeah, yeah, it's nice.'
> Bethan: 'From the film High Noon.'
> Theresa: 'Before my time'

As Theresa speaks this last comment, Julian starts singing.

Brief Description of the Music

Julian initiates this song, first by tapping the drum lightly on his lap and then singing. Theresa and the therapist were talking, and Julian starts as they are talking. They both stop and turn to him and join in, playing their instruments to the beat of the song.

The song is in D major and has a very steady beat to it, with a crotchet, quaver rhythm, which gives the music a rocking, jaunty feel. Julian continues to sing on his own, with Theresa and Bethan playing the shaker and caterpillar, emphasising the beat and bringing out some of the jaunty rhythms. The dynamic level changes slightly, with Julian singing a little louder once Theresa and Bethan have joined him, and dipping in volume as he laughs towards the end of the song.

A cheeky 'tum tum tum' rhythm after the end of one line is emphasised by Julian and Bethan on their instruments. When Julian sings about 'my wife' he points to Theresa and she smiles. Theresa is smiling and plays more strongly as the song goes on, then moving her feet to the music as well, and a fun, dramatic movement upwards with her arms at the end, emphasising the end of the song with a flourish (pom-pom). The music is very rhythmical with a strong beat. There is a sense of togetherness and fun, and the attention is most definitely on Julian as he leads the song.

Discussion

This is a short clip of music but communicates a great deal. Julian is clearly comfortable in the therapeutic process, feeling safe enough to initiate this song, and continuing to lead the trio as the song progresses. Therapeutically, this could give Julian a sense of empowerment, perhaps increasing his self-confidence. It has brought him into the present moment, and his efforts to connect with others are successful. The focus is very much on Julian and the music seems to be celebrating something that he can do well. It allows aspects of his personality, namely his sense of humour and sociable nature, to come to the fore, strengthening his presence in the room and the relationships within it.

The music gives Julian the opportunity to initiate connection with Theresa, to whom he gestures towards as he sings 'my wife'. This feels significant; in my experiences with Julian, it's mostly Theresa that initiates interactions between the two of them. However, here, Julian initiates and continues with confidence. Despite significant damage from dementia to Julian's memory and cognitive skills, he still recognises Theresa as his wife and wants to interact with her. Theresa smiles back in return, and continues to play with him. Unlike in our second interview, Theresa is sitting quite a way away from Julian and her sounds are mostly gentle. I wondered if this was communicating a sense of tiredness from Theresa. Nevertheless, she joins him throughout the song and celebrates at the end by raising the shaker and giving stronger sounds for the last 'pom-pom'.

The MT addresses all of Kitwood's psychological needs (Kitwood, 1997):

Attachment: Julian clearly feels safe enough in his relationship with Theresa and the therapist to initiate this song. There is a sense that he knows they will join in with him.

Comfort: Julian is being listened and attended to; the therapist and Theresa join him with smiles and eye contact, engaging in the song with him.

Identity: This song brings out an element of fun in Julian's personality. His voice is heard throughout; it seems significant that Theresa and Bethan refrain from singing – it is Julian's voice that is heard.

Occupation: Julian has initiated this interaction and Theresa and the therapist have joined in with him. It feels a meaningful, shared interaction.

Inclusion: Julian is being supported in his singing and playing; both Theresa and the therapist join in, but not overwhelming Julian in sound. He is the centre of the interaction.

Love: There is a clear moment when Julian gestures towards Theresa as he sings 'my wife' and Theresa smiles in return. This feels like an expression of love. Once again, the therapist attunes and attends to the couple with an open and person-centred approach.

3.1.5: Joy and Hope

It is clear that for many of the participants in this study, the MT facilitated shared moments of joy together, upholding a general sense of wellbeing and improved mood, for both the person with dementia and caregiver. This in turn communicated a sense of hope, that in the face of extremely challenging and upsetting experiences due to dementia, there was something celebratory and joyful that participants could share in together. All caregivers expressed an enjoyment or appreciation of MT. In some cases, their enjoyment was directly linked to feelings portrayed by the person with dementia:

> Maria: We love it, don't we…It makes me happy because it makes Mum happy.
>
> Leo: More than anything it's good to see her smile.
>
> Nia: …seeing the joy that it, and seeing Dad brought out of his illness, and you know, being able to do something that he could actually do, that gave him great pleasure, was you know, unbelievably special. He loves this…and it fills me with pleasure, pleasure for him.
>
> Daniel: I think it's fantastic that Hazel has been introduced to live music like that, um, she obviously loves it.

Some of the participants with dementia were able to corroborate their feelings of enjoyment. In a moment of lucidity, Lucy (case one) commented how much she had enjoyed the MT and the social contact, reinforcing her sociable personality:

> Interviewer: Have you enjoyed the music?
>
> Lucy: I've enjoyed the music and things, yes...It's been fantastic, it's really good … And I did enjoy it with people around who were actually singing with me.

Ray (case five) described feeling 'refreshed' and 'reborn…it was amazing therapy', and Hazel (case six) replied 'yes' when asked if she enjoyed the music.

In some cases, music was the only thing that connected for the person with dementia, and enhanced their wellbeing:

> Nia: It's the thing that makes his life good really, music, the piano … it takes him away from all that other stuff…So the times when he was playing music, um, were, times when he wasn't fighting his Alzheimer's, and so, it was lovely.
>
> Maria: The only real connection that she's had.
>
> Daniel: It's the only thing that got through.

For some, the MT had a transformative effect on mood:

> Theresa (case four): He was quite grumpy, but the minute we started, it just lifts, you know it just lifts the mood and we enjoy it, we just enjoy it…it's been an uplifting experience.
>
> Kelly (case five): the music and the singing, it just lifted us…I mean, when [name of therapist] got here, he [indicating Ray] was really [*pulls a grumpy face]* but by the time he left, he was more and more happy, and a few weeks after, I can't remember why I was down in the dumps but I was, and the same thing happened, by the time he [the therapist] left I was…It wasn't until that that I realized how much it was helping me as well.
>
> Ray: It's just lightened our life really.

Maria described the impact Louisa's improved wellbeing had on her caring role:

> You know, it makes life so much easier you know, just, cause somebody that's happy is easy, and when somebody's upset and angry then life is very fractious and it makes life so much harder.

Three caregivers directly expressed their own enjoyment:

> Gordon: I joined in and I enjoyed it.
>
> Theresa: We loved it, absolutely loved it!…it was nice for me too. It's just the most brilliant, I thoroughly enjoyed it, I'd quite like to do it again.
>
> Kelly: Oh I really do enjoy it, yeah…Lovely, really, really, yeah.

Maria described a significant impact on Leo's mental health: 'Well, that's positive for your mental health, isn't it, because you're getting back into music again yourself.' Leo acknowledged this had physical benefits too: 'It's also been helping my arthritis in my hand as well.'

3.2: Creativity and Magic

I use the word 'magic' in this subordinate theme because this seemed an important element of the MT for Nia, caregiver in case three. Nia referred to the MT sessions being 'magical' and the Music Therapist as a 'magician'. In this context, the word 'magic' seemed linked to the creativity that the MT facilitated; Nia expressed a sense of wonderment as she watched her father improvise with the Music Therapist:

> Nia: I mean it was sort of miraculous. And um, watching him, watching [name of therapist] getting him to improvise was extraordinary, so it made me feel like there was something, really, um, magical about it.

The way that music connected for SJ, in such a deep, absorbing and positive manner, was in direct contrast to SJ's experiences of his ongoing dementia, and Nia experienced this as music taking SJ to a different place: 'it takes him away from all that other stuff…he was just absorbed in what she [the therapist] was doing.'

The magical feeling was not just related to the creativity within SJ and the therapist's improvisations, but also in reference to the skills of the therapist: 'It was a bit like magic, you know, sometimes that, she could find a way to get him accessing something'. Nia commented that SJ also felt this magical element: 'He really, really loves it, I mean he honestly thinks it's magic. We both think she's a magician!' It feels fitting here, to present the microanalysis for this case, which offers an insight into this magical world that the MT seemed to facilitate.

3.2.1 Music Therapy - Creativity and Magic - An Example from Microanalysis

Case Three: SJ and Nia, 'Messing Around'

Chosen by Nia because she felt that something was happening; the therapist (Penny) had introduced a new idea and SJ 'wasn't fazed by it'. SJ and Penny coined the phrase 'messing around' to describe their improvisations.

Description of the Context

SJ and Penny are sitting together at the piano; SJ sits at the treble end, slightly turned in towards Penny. Nia sits some way away, filming the session on her phone.

Brief Description of the Music

Penny had been playing Beethoven's 'Moonlight Sonata' (but in A minor). She slows as she comes to the end of a phrase and turns towards SJ and he responds with two staccato chords; A minor triads, high up on the piano, loud and energetic. SJ has matched Penny's key, but with very different sounds, and Penny responds in return, matching SJ's pace and energy, and continuing his idea, developing it a little as she moves to F major and then back to A minor. SJ watches her playing, nodding and raising his eyes a little as she moves to F major, as if acknowledging this change. In the return to A minor, SJ joins in with a B minor chord; it doesn't quite fit and his playing is a little hesitant. He changes to a single note, G, more firmly and repeatedly, and Penny changes her chord to G major to match.

The music is lively and SJ and Penny are very connected and in their own musical bubble, as they look at each other and respond to each other's playing. SJ plays on, developing his tune which has a feel of Beethoven's 'Ode to Joy' about it, although not exactly this tune. Penny responds with more staccato chords and quaver movement. She moves again to an F major chord and SJ looks at her, continuing with single crotchet notes to the pace of the piece and again with a similar tune to 'Ode to Joy'. SJ looks again at Penny as he plays, moving lower down the keyboard and slowing up. Penny matches and their music becomes slower and gentler. As the music slows to an almost stop, Penny plays an F major chord with a GAA tune in the right hand which feels like an invitation, or a question. SJ responds with Bach's Prelude in C major, gently playing the broken-chord melody. Penny mirrors this. SJ looks at Penny, then suddenly returns to staccato chords and they stop together and look at each other. Penny laughs a little. SJ plays a loud C major chord – Penny answers – pause – SJ plays a slightly gentler chord – Penny responds – two chords from SJ – two from Penny. There is a real sense of fun, playfulness and connection.

SJ returns to the Bach, playing gently and expressively with an intensity of tone. Penny supports with similar playing underneath. SJ speeds up and plays more of the piece and Penny changes her harmony underneath to match the tune. There is flow and evenness to their playing, which continues for a while. SJ slows and plays some notes higher up and Penny introduces a new idea, the Brahms lullaby; just the tune in C major. SJ joins in, playing a harmony line to the tune, a compound 6^{th} above. There is a gentleness and togetherness and SJ shapes his phrases very musically. As Penny plays the second part of the tune, SJ copies the quaver, quaver, crotchet rhythm. He follows the shape, gentleness and phrasing, then returns to snippets of 'Ode to Joy' and the Bach, but following the rhythm of the Brahms. As Penny returns to the tonic chord (C major), SJ plays the Bach tune again, this time more fully, turning to look at Penny, and they stop together. He says something (indiscernible) and Penny laughs. Nia comments: 'So nice, love it!' and Penny: 'It's like a beautiful conversation'.

Discussion

SJ seeks interaction with Penny in a playful and communicative manner. He is completely absorbed in the interaction, sitting next to her at the piano, turned in towards her, watching her playing and giving eye contact. He initiates playful communication with sudden and unexpected staccato chords, repeating this later in the music. This feels like a challenge from SJ for Penny: 'What about this? Will you still come with me?'

SJ must have had interesting, creative interactions with others both in his personal and professional life, being a very successful banker and also a father and husband. He had a particularly deep connection with his last wife, and some of this was through music. I wondered if there was a resonance of that deep connection in this music; SJ and Penny are deeply engaged together and in the corresponding interview, Nia speaks of 'their own world' with magical properties. There is a deep attachment shown between SJ and Penny, and it feels as if there is trust; that when SJ changes what he does, he knows Penny will go with him. They are in their own 'bubble', a magical space in the music, where new, creative, playfulness and deep connection can take place.

This clip shows moments of creative flow, where SJ and Penny are successfully connecting in a meaningful, communicative manner. SJ is both initiating ideas and responding to new ideas from Penny, being creative and playful in his free communication at a time when everything else is deteriorating due to dementia.

The music highlights aspects of SJ's personality: his humour, his ability to connect with people, to be creative, to challenge, and his love for music and the piano. The tunes he returns to perhaps bring comfort, but there is also new material, both initiated and responded to by SJ. This exemplifies what SJ can do, in a world where everything else is in decline.

Once again, the MT addresses all of Kitwood's psychological needs (Kitwood, 1997):

Attachment: There is clearly a safe and trusted relationship here, as SJ initiates interaction with the therapist and playfully introduces new ideas. There is a sense of trust that the therapist will go with him.

Comfort: In contrast to the decline due to dementia, SJ is thriving in this musical, creative context. He seems happy and absorbed in what he is doing.

Identity: The improvisation brings out SJ's sense of humour and creativity. SJ plays snippets of pieces that he often plays – it feels as if these are 'his' pieces.

Occupation: This feels a meaningful interaction; SJ is deeply connected to Penny in the music, they are having a musical conversation together. SJ brings in new musical ideas.

Inclusion: Penny replies to SJ's musical sounds, and supports him in his fluent playing. It feels as if they are sharing as equal partners.

Love: Once again, this is a person-centred approach where the therapist is completely open and available for the client, attuning to his communications and expressions.

As an artist herself, Nia had a deep belief in the power of art and creativity, and from her comments in our interviews, recognised that in SJ's experiences of MT, it was the process of creativity and making music together that was important, rather than a finished product: 'she wasn't trying to teach him anything, she just played with him, and you know, he played and she played…and in fact they coined a phrase, they called it 'messing around'.'

Despite all-encompassing deterioration due to dementia, SJ was able to participate in the music, initiating new ideas, responding in musically appropriate ways that required a high level of skill and cognitive ability. In the musical relationship with his therapist, SJ was able to take part in a musical flow; a shared, spontaneous creativity. Nia commented: 'he wasn't thinking when he was playing, he was just playing'. Music was the only place where this level of creativity was still possible for SJ, and so it was perhaps not surprising that this felt magical to Nia.

Much has been written about the value of creativity, that it is an essential part of human existence; key to our survival as a race and to our personal health and wellbeing (Winnicott, 1971; Kaufman and Sternberg, 2021). There is also much research suggesting the use of creativity as a tool to support mental and physical wellbeing (Cohen, 2006; Eschelman *et al.,* 2014; Conner, De Young and Silvia, 2016; Carson, Yang and Forgeard, 2021). For SJ, engaging creatively in MT transformed him in the moment and lifted him out of his dementia symptoms, engaging him in a shared, meaningful interaction at a deep level, with a sense of fun and playfulness, and a strengthening of identity. This positively impacted SJ's sense of self and

wellbeing, and provided opportunities for engaging in cognitive abilities that he was not able to access at any other time.

Hazel (case six) also engaged in musical improvisation in the selected moment for microanalysis (see p.147). What is common in both of these interactions is a sense of heightened connectedness between therapist and person with dementia, an absorption in the moment and sense of intensity in the communication between the two, and, as Nia describes, a feeling that the person with dementia and therapist had created 'their own world', within which this interaction took place.

Music Therapist, Carolyn Kenny, wrote about creating a 'musical space' or 'musical cocoon' in therapy sessions (Kenny, 2014). She believed that essential to this is being absolutely present in the moment, a concept that resonates with Yalom's teaching of the importance of 'The Here and Now' (Yalom, 2001, p.46). This is about 'being' - not just with the client, but being present and aware of the space itself:

> It is about giving our attention to the spaces we create in music therapy through an intense focus on being. And it is about the process of how we create the interplay between these spaces of creativity and wonder in the music therapy experience (Kenny, 2014).

The words 'spaces of creativity and wonder' certainly resonate with the descriptions from Nia of the 'magical…world' within which musical interactions took place between SJ and Penny. It also seemed to apply to the interactions of Hazel and Neil, as they created music that held the power to rid Hazel of her hallucinations (see p.147).

Kenny develops the idea of 'musical space' by describing it as a 'closed and intimate field', within which there is understanding and trust between client and therapist. This 'field of play' is the therapeutic safe space, in which the client feels able to be free in his/her/their expressions, in the knowledge that they will be heard, valued, supported and contained by the therapist: 'All at once, there is a new freedom and sometimes a joyful sense of discovery, experimentation, and a new energy in the play' (Kenny, 2014).

There certainly seemed a sense of joyful discovery and experimentation in the musical interactions between SJ and Penny. For Hazel, there was absolute freedom in her expressions and movements, which were usually bound by uncontrollable movements from Parkinson's disease. There was also discovery, as Hazel found a new way of being in control of her

hallucinations, and a sense of joy when she commented about how she felt afterwards: 'connecting with my world…More like me again.'

3.3: The Therapist

The five Music Therapists that facilitated MT for participants in this study all used similar methods of engagement, including well-known songs and improvisation. Within this, specific techniques were employed to elicit and support interaction with the participants (see Appendix 20, p.410). This was the limit of uniformity in the intervention, as the MT is always personalised and tailored to best meet and support the people the therapists are working with. The Music Therapist of course also brings themselves into the relationship, being genuine and authentic in their presence in the therapeutic space (Rogers, 1957). This again can influence what happens within MT sessions. In some cases, caregivers referred particularly to their relationship with their therapist, and acknowledged some of the skills they saw employed within the therapeutic process.

3.3.1 Skills of the Therapist

In case three, Nia sometimes sat back and watched the therapy happen between SJ and Penny. She expressed a sense of delighted surprise that SJ and Penny were able to make a relationship through music, despite her doubts that this would happen: 'he doesn't always respond really well to people'.

Nia commented on the therapist's skills, recognising that Penny enabled them both to play: 'She could find a way to get him accessing something…she just knew how to, she just kind of got how to deal with him…She's made me play too!'

Nia spoke of her pleasure in watching SJ and Penny engage in improvisation: 'watching Penny getting him to improvise…was extraordinary' and this brought out unexpected elements of creativity within SJ's personality:

> I mean, I was amazed by that because he was not that sort of man, you know, he wasn't a sort of improvising creator, although in business I guess he was, he was creative in different ways, yeah, I don't think it would have been something he'd have been able to even imagine him doing.

Within improvisation, Nia recognised the spontaneity of the music and that Penny facilitated a space where things could develop and change:

> Going with the flow…it was a time of allowing, of being able to mess around…she's introducing other…in a way that it didn't matter if it was the wrong key…it allowed [the music] to develop.

Therapist skills were not just apparent in the music but in the sessions overall: 'he was telling her his life story and she let him, I think he just had to say it and she let him and it was just part of the session.' This shows a deep level of trust within the therapeutic relationship, which also seemed to be mirrored within the music. Penny also managed a potentially challenging situation, diffusing in a skilful way with a game:

> There's one point where he puts his hand on her knee, and she doesn't, she doesn't make that awkward at all, and just makes gestures hand on hand that into a game too, I mean it's not weird but it could be weird, you know.

Kelly and Ray (case five) also recognised therapeutic skills in the process of the sessions:

> Ray: Neil wasn't just about music; he involved himself with what was going on.
>
> Kelly: He's just got that something, hasn't he, that draws you out.

And Ray was aware that he was an equal person in the trio: 'I think that we both attended, there was no differentiation at all.'

3.3.2 Therapist or Friend?

In two cases, the caregivers expressed a fondness for their therapist, that they appreciated their company and felt that their visits were like that of a friend. Theresa (case four) found the relationship between herself and the therapist helpful: 'she always asked how we were, she sometimes quite patiently listened to me waffling on.' The therapist's company was an important element of the MT:

> It's also nice to have somebody in your home doing something…because you spend so much time, you know, on your own…well, not literally on your own, of course not, but to have a conversation…I enjoyed her company very much.

For Kelly, the company provided by the therapist was perhaps felt more deeply; she commented: 'It just feels like, just sitting with friends, having a, enjoyment sort of session'. Kelly was moved when the therapist learnt their special song and would play it at the end of every session for them: 'I do remember, feeling very touched [name of therapist] had actually learnt that for us.'

There was some sadness expressed about the sessions coming to an end, and some of this seemed directly linked to the loss of the company of the therapist. Kelly explained: 'I think it was sad cos it felt like we were losing a friend.' Ray commented further: **'**When [therapist's name] left, we were both a bit, down-crest, down-fallen, and somebody [*looking at Kelly and pointing to her]* was shedding a few tears.'

In these two cases, it is perhaps interesting to think about what the therapist was representing for Theresa, Kelly and Ray. In Mindsong's communications with couples before therapy starts, it is made clear that it is a qualified therapist visiting, and that the work is for a limited amount of time. Theresa, Kelly and Ray were aware of this from the start of the intervention. However, one of the vital elements of therapy is that therapeutic relationships are formed, and during the 12 sessions of therapy, the therapist gets to know the people he/she is working with and vice versa. Because music can connect deeply on an emotional level for people, and because the participants in this study were enduring extremely difficult times, this knowledge and understanding of a person perhaps happened at a deeper level. The therapist is coming into the home and working with the couple as they are, providing personalised support at a challenging time. No wonder it is difficult to say goodbye.

In addition, Theresa and Kelly both expressed their love of social contact and that they greatly miss this element in their lives. Theresa recounted how sad she was when she had to give up her choir, and when she went to see a concert, was unable to stay to talk to her friends, because Julian was unsettled: 'and that was quite upsetting, because I would have loved to have stopped afterwards.' Kelly also missed her friends who were performers that she used to see often:

> They were great friends of mine…not cabaret, but just music, and they were great entertainers, and I was out, before [Ray] was ill, I was probably out well, 5, 6 days of the week with them…But that's my, cos that was my love.

Here are two very sociable people to whom social connection is important and a big part of their lives, and this has been significantly curtailed because of dementia. Perhaps the therapist, being kind and attentive, listening and getting to know them, represents this element of social connection and friendship that Theresa and Kelly so desperately missed.

I also wonder whether the fact that the therapy took place in the participants' homes, affected the way in which the therapist was seen by some participants. Both Theresa and Kelly mentioned this directly. Theresa commented: 'It's also nice to have somebody in your home',

and when asked why she thought the therapy worked so well, Kelly explained: 'I think that the fact that Neil was, *coming in* [Kelly's stress]' made a difference.

Mindsong's MT@H service works so well for people with advanced or complex dementia and their caregivers because the therapists go into the peoples' private homes. This makes the service accessible for people right through to end-of-life stages. However, stepping into someone's home is entering into a private space, with information all around about how someone lives and what is important to them. This is an intimate space and very different from conducting therapy in a clinic, hospital or day centre. The clients are perhaps already more vulnerable to the possibility of becoming close to their therapist. Mindsong Music Therapists have said that there feels a blurring of boundaries here, that often clients will ask them about their own lives. In a way, it feels genuine and reciprocal when building a relationship to share a little, but also important to hold therapeutic boundaries and to gently remind, where necessary, that this is a client-therapist relationship, with a clear ending to the therapy.

It is important to contemplate the particular ethical considerations that occur in the context of home-based therapy. Boland (2019) corroborates the blurring of boundaries that may be experienced when a therapist provides therapy in a person's home, suggesting that the client may view the therapist more as a friend or a 'family helper' (Boland, 2019). She also suggests that the relationship may take on a different feel to that of a more traditional client–therapist relationship, in that the client becomes the host of the situation, and may feel the need to provide the therapist with a comfortable space, refreshments and a warm welcome. In effect, the client is serving the therapist, rather than the therapist being there for the clients' needs (Boland, 2019). From my own clinical experiences and from conversations with Mindsong's Music Therapists, this certainly resonates with situations we find ourselves in during clinical visits to people's homes.

Another aspect to keep in mind is that people with advanced dementia may often be unable to withdraw from the therapy if they wish to, as the therapists are coming to the client, in their own home. A person with limited mobility, or without verbal communication, may be unable to walk away, or communicate that they do not wish to take part in the therapy (Sinason, 1992; Hughes and Cheston, 2021). If the therapist is viewed as a friend or guest, the person may also not feel emotionally able to refuse the therapy. It is therefore essential that therapists working in home environments remain sensitive to these possibilities, and consider the question of ongoing consent from clients, being alert to body language, vocal sounds, and facial expressions that might communicate a wish to stop the therapy.

3.4: Music at the end of life

In this study, two of the participants with dementia died during the research process. SJ (case three) passed away after the eighth session of MT, and Louisa (case two) died not long after the 12th session of MT. Both caregivers spoke of the importance of music during this time.

Maria and Leo provided palliative care for Louisa at home, and in her final days, Maria would lie beside Louisa and sing to her. This seemed to give Louisa moments of clarity, within which they were able to say goodbye to each other. The music seemed to have been a precious gift for this family, and Maria said in a phone call to me: 'You [Mindsong] were the brightness in a very dark time'.

The MT took place in the last few months of SJ's life, although this was not apparent until the last sessions SJ took part in. Nia described the whole experience as being: 'possibly the most positive thing in his life towards the end.'

Nia used music as a comforting presence in the last hours of SJ's life; music was something she could give to help her father and share in with him, in his final hours:

> When he was really dying, on the last day, I played music to him on my phone on the bed...I felt like that was, something calming, I suppose and take him into something different.

Hearing is thought to be the last sense retained, making sound and music potential mediums of connection right up to the point of death (Weber, 1999). Adrienne Freeman writes of her experiences of using MT to support people at the end of life on a hospital ward for people with advanced dementia (Freeman, 2020). She describes intimate moments of working at people's bedsides; the MT 'accompanying the dying person with dementia' (p.229). Freeman's clinical examples show MT connecting with patients in the days and moments before death, supporting spiritual needs, aspects of a person's identity, and providing moments of interaction and relaxation (Freeman, 2020). These moving examples also exemplify music as a comforting presence, and through therapy, a validation and valuing of the person's presence during this time of transition.

There is evidence from research conducted on near death experiences, that an element of consciousness is maintained in the moments before and during death, and perhaps even beyond death (Van Lommel, 2007). Consciousness in the liminal moments just before death

concurs with my own experience of my mother's recent death; she appeared completely unconscious for hours, but when I kissed her forehead and told her that we were with her, she groaned, moved her hand, smiled, and then died.

For Louisa and SJ, music provided an emotional connection and a comforting presence in that liminal space between the end of life and death itself. Nia's words echoed her reference to SJ and Penny's musical space: 'their own world' as she described taking SJ 'into something different' in his last hours. Perhaps it is helpful here to think of Kenny's 'musical cocoon' (Kenny, 2014); that Maria and Nia were creating a safe, musical space to aid Louisa and SJ's transition into death. We can never know exactly how music is experienced in death by an individual, but the thought that music could aid this transition is no doubt comforting, as this was for Maria and Nia.

Music continued to play an important role for Nia, influencing SJ's funeral service, and providing her with an ongoing connection to her father. The music at SJ's funeral reflected his playing in the MT sessions; Nia chose one of the pieces he would often play: 'the organist had a keyboard and he played the fugue that Dad played', bringing a sense of her father's musical identity into the service. Nia described singing 'rousing hymns' and this seemed to bring a sense of togetherness and perhaps even healing: 'everyone had a good sing…that felt great'.

Since SJ's death, Nia continued to play the piano, and this enhanced a sense of closeness and a way of remembering him: 'I love that I can just sit down at the piano…start playing that one piece that I play that reminds me of Dad, it takes me back to Dad I guess, and the lovely bit of Dad.'

8.5 Superordinate Theme 3: Experiences of MT - Conclusion

Essentially, MT was experienced as an important intervention that supported relationships between the person with dementia and caregiver at a time when they were steeped in challenges due to dementia and the caring role. The findings from this study resonate with the findings from my literature review, which suggested that home-based MT has the potential to support wellbeing, reduce caregiver stress, and provide opportunities for meaningful shared experiences and connection, upholding this important relationship between the person with dementia and caregiver.

All six examples of MT from microanalysis addressed all five of Kitwood's psychological needs represented in his flower (Kitwood, 1997), also supporting key aspects of self for both the person with dementia and the caregiver. This included upholding a sense of self, self-esteem, social connection, and a sense of meaning in life, which have been identified as key factors that may protect against the distressing experiences dementia can create (Cheston and Christopher, 2019). The MT also brought feelings of joy and hope for the participants, which was significant in the light of the significant challenges living with advanced dementia presented.

Through shared musical experiences, the MT provided opportunities for a strengthened sense of emotional connection between each dyad. As the music elicited aspects of personality, the presence and sense of each individual was more strongly felt through the music, and this enabled both the person with dementia and family caregiver to see each other and interact with each other within the framework of their existing relationship, again strengthening and upholding this important and treasured relationship.

The safe and trusted space facilitated by the therapist allowed freedom of expression and creativity to flourish, which, according to some caregivers, was not evident at any other time. In some cases, this allowed for the engagement of a greater number of cognitive processes, and greater control over communication (particularly evident in cases two, three and six). For Hazel (case six), creativity in music also gave her control over her physical movements and her frightening, intrusive hallucinations.

Through skill-sharing between therapist and caregiver, music continued to be used to support daily care and wellbeing and, in some cases, made a transformative difference to the caring role, and to these important relationships. Music also played a significant role at end of life, providing emotional connection and comfort for the person with dementia and caregiver.

Chapter 9: Final Reflections on the Findings

9.1 Introduction

In this chapter I present my final reflections on the findings, including a synthesis using an arts-based research approach in the form of visual representations.

9.2 Final Reflections

The overriding finding of this study is that family caregivers (caregivers) make sense of their experiences of MT within the context of the relationship with the person they are caring for, which in turn, is steeped in their experiences of dementia. Their interaction with MT is also inherently affected by what they bring to each encounter, both as an individual and as a couple (or as a trio, as in case two). This includes aspects such as the participants' personalities, life experiences, past traumas, attachment styles, and mental and physical health. Reflecting a relativist position and constructivist ontology, this is indeed a complex phenomenon, creating deeply personal experiences and understanding, which were captured in individual case summaries (see Appendix 3, p.268 for an example). Despite this, there was much common ground, with IPA and microanalysis eliciting some strong themes from the data. Following the completion of the analysis and synthesis of IPA and microanalysis, I found myself reflecting further on the three superordinate themes, and how they related to each other.

9.3 Visual Representation: The Relationship between the Three Superordinate Themes

Throughout the analysis and writing stages of this thesis, I was aware that the three superordinate themes (Relationships, Experiences of Dementia, and Experiences of MT) were closely related and continually interwove and influenced each other. As a dementia progresses and relationships change in reaction to this, so these three elements and their relation to each other also shift and change. Turning to an arts-based research approach, I created a visual representation to contribute towards the overall synthesis of the data, and to aid my reflection and understanding of how the themes related to each other. Initially, I worked with an artist to develop three images; one to represent each superordinate theme. We used paint on acetate to explore different shapes and colours.

9.3.1 Relationships

To represent the first theme, 'Relationships', I chose a circle, in bright yellow colour. Although there were challenges within the relationships between participants in this study, each had an

overriding feeling of closeness and love, and the gentle, rounded shape of a circle seemed to best represent this element of the participants' relationships. The definite, recognisable shape of the circle and thickness of paint also seemed to resonate with the longevity in the relationships; that they were all well-established. The bright yellow colour was chosen to reflect the love and positivity in the relationships, despite the challenges due to dementia.

Figure 3: Yellow circle representing 'Relationships'

9.3.2 Experiences of Dementia

After establishing this first image, I envisaged the images for the remaining two themes being placed within or on top of the first, rather than existing separately. The 'Experiences of Dementia' recounted by the participants in this study were often challenging and upsetting. Dementia intruded on these existing relationships, bringing complex circumstances, changing and sometimes, fracturing relationships. In contrast to the gentle, rounded shape that represented 'Relationships', I chose sharp, random shapes that might represent how these experiences may have felt within the participants' relationships. The artist I worked with painted a red circle on acetate, then created sharp shapes by removing some of the paint with a craft knife.

Figure 4: Red, sharp shapes to represent the theme 'Experiences of Dementia'

9.3.3 Experiences of Music Therapy

To represent the participants' experiences of MT, I chose a complimentary colour, something that would work with yellow and red. As a complementary colour, I hoped that orange could represent the person-centred nature of the therapy; the therapists' attention to the participants, their relationships and their circumstances due to dementia. Wavy orange lines represented phrases of music that provided connection between the couple/trio and the therapist. The MT also provided a containing framework, within which reconnection and new ways of communicating were explored. This was represented by the orange border outlining this circle.

Figure 5: Circle with orange wavy lines and border to represent MT

9.3.4 The Relationship between the Themes

The idea was that one image could be placed on top of the other, to show how dementia experiences might affect a relationship, and how MT can interweave and support the relationship and the particular circumstances of each couple/trio. The difficulty with this in practice was that when we placed the images on top of the other, they almost concealed the yellow circle representing relationships altogether; the very element that MT upheld and strengthened. Therefore, the three-layered image had the opposite effect of what I was trying to portray:

Figure 6: Images two and three on top of image one

It was clear that this was not going to work in this medium, so I attempted to reproduce the images using tools within Microsoft word, with some success. The bright, yellow circle was easy to create:

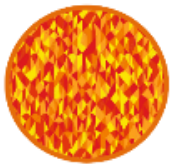
Figure 7: Bright yellow circle representing 'Relationships'

For 'Experiences of Dementia', I chose to place random, sharp red shapes within the yellow circle. I felt the resultant image was perhaps reminiscent of images from brain scans of the diseased brain due to dementia:

Figure 8: Yellow circle with red, sharp shapes, representing the 'Experiences of Dementia' as they intrude and interact with the existing 'Relationship'.

To illustrate 'Experiences of MT', I once again chose the colour orange, outlining the circle in orange to represent the containment that may be experienced through MT. At this point, I wondered if a kaleidoscope image might work well; with orange shapes interacting with red and yellow to represent the MT interweaving and connecting with the participants, their relationship and their circumstances due to dementia. The shifting nature of a kaleidoscope resonated with the shifts and changes brought to the participants' relationships by their ongoing experiences of dementia. I created this image by adapting an Adobe stock image, which I have permission to use:

Figure 9: The Kaleidoscope: circle with orange outline and yellow, red and orange shapes like a kaleidoscope.

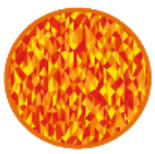


9.3.5 Reflections on the Images

Figure 8: 'Experiences of Dementia' as they interact with 'Relationships'.

I used sharp, random, red shapes to represent the participants' experiences of dementia as relayed to me, because I thought these particular shapes might represent the sudden changes and losses brought on by dementia, and how these might have been experienced by the participants. However, one of my supervisors reminded me that changes due to dementia can also be positive, as was the case for Nia in case three, who commented that a consequence of her father's dementia was that it had brought them closer together. My supervisor suggested that by representing the dementia experiences with sharp, random shapes I could be colluding with a disabling view of dementia that could feed into associated ongoing stigma, and that instead, the shapes and language used to describe them could be softened, to represent blood veins or vessels, signifying change, but not necessarily fracture or damage. For the final image in the kaleidoscope, (figure 9) I made the yellow, red and orange shapes softer and similar, to accommodate this view.

Figure 9: The Kaleidoscope



The kaleidoscope image is the closest I have come to something that reflects the relationship between these three themes, as I understand them in relation to these particular participants' experiences. However, I still think there should be more yellow in the image, as this colour

represents the participants' relationships, and was one of the key elements that the MT upheld and strengthened.

9.4 Conclusion

Exploring the relationship between the three superordinate themes using this arts-based approach has been an interesting experience. I feel I have not been able to produce an image that completely represents my understanding of the relationship between the three themes. However, the process of creating these images, reflecting on which colours and shapes to use, and how the images should fit together, has consolidated my understanding that supporting these important relationships between the person with dementia and caregiver is crucial, and perhaps the most important element that MT can offer in this context.

MT provides containment for both in the dyad, but can also bind from within, interacting with many different elements of the relationship, such as supporting emotional connection, finding new ways of communicating, sharing time together, and creating tools that support daily life. Through skill-sharing, the caregiver and person with dementia can continue to connect through music beyond the duration of therapy, and music can become a tool, supporting daily care and a continued source of strength for the relationship. Although things may shift and at times feel fractured, new patterns can be made; relationships can adapt and endure.

Chapter 10: Conclusions

10.1 Introduction

In this chapter I discuss the methods employed, the limitations of the study, and identify what I believe are the unique contributions this study has brought to existing research literature. Finally, implications for future research and recommendations for practice are presented.

10.2 Discussions Regarding Methodology and Method

10.2.1 Employing a Multimethod Approach

When I began work on this study, I envisaged using methods situated within the qualitative paradigm, as my position as a Music Therapist naturally resonates with a constructivist belief, and my interest lies in how people make sense of their experiences. As I have argued previously, the inclusion of music microanalysis can be seen as encompassing both qualitative and arts-based research approaches, and the creation of a visual representation of the three superordinate themes was rooted in arts-based research, therefore this study evolved into a 'multimethod' study, using a mix of qualitative and arts-based research approaches.

As mentioned previously, adopting a 'multimethod' approach has been employed in previous MT studies. In 2019, Music Therapist Claire Flower combined IPA with microanalysis for the first part of her PhD study. However, Flower developed a different output from her microanalysis of the MT; a graphic score, within which she was able to add verbal comments from IPA. This created a visual synthesis of the findings from these two methods. I initially explored creating a graphic score for this study, within which I was also hoping to synthesise findings from IPA and microanalysis. I was disappointed by my attempts to do so, feeling that the scores did not represent enough of the essence of the participants' presence or experiences, so instead, I turned to a narrative approach, synthesising the findings from both methods within individual case summaries, which I felt was more successful (see Appendix 3, p.268).

In another PhD study, Rebecca Lockett (2022) used a combination of qualitative and arts-based research approaches to explore participants' experiences of musical improvisation. Lockett employed semi-structured interviews, musical improvisation, microanalysis and the creation of graphic scores as a unique combination of research methods. Lockett's method of synthesis involved looking for themes across the different layers of analysis, resulting in a 'Meta-

Structure of Analysis' (Lockett, 2022). As I understand from her findings, the final synthesis across the whole dataset was created using IPA (Lockett, 2022).

These different approaches highlight the creativity in research design that can be elicited from using a 'multimethod' approach. I would also argue that the complexity involved in synthesising some of these approaches also indicates the challenges inherent in exploring a research topic with a combination of different research methods. I feel that the approach I adopted for this study has resulted in the creation of rich data sources, and perhaps different approaches to data synthesis, with varying degrees of success.

I feel that, in particular, the inclusion of microanalysis, concerned with both the music itself and the process of its creation, created different and deeper insights into the understanding of participants' experiences than the data from IPA alone. The microanalysis illuminated aspects of individual personality more clearly (particularly for the person with dementia, for example, see p.177, microanalysis for case four) and aspects of the relationship between the dyads (for example, see p.115, microanalysis for case one). This, alongside IPA, created rich insights into the participants' experiences, and perhaps allowed a deeper level of participation: again, particularly from the person with dementia (see microanalysis for case two, p.149).

The employment of an arts-based research method to explore the interaction of the three superordinate themes provided opportunities for further reflection, and the resultant concept of a kaleidoscope image representing how these three elements interact does capture something of the ongoing shifts and changes that dementia can create for an individual and for the particular relationships explored within this study. However, I feel this has a limited influence on the overall findings of the study, as these ongoing changes were already reflected within the findings from IPA and microanalysis.

Synthesising the results from IPA and microanalysis was challenging, and the development of the individual case summaries came from a desire to tell the stories of the participants; to do justice to the detailed and intimate experiences they relayed to me. Embedding the findings from microanalysis within the findings from IPA helped to illustrate these stories, and deepen the insights into the participants' experiences. However, one of the limitations of this approach has been that I have not been able to include the case summaries within this thesis, due to the limit on word count. So, although the synthesis feels successful from my point of view, it may feel less so for the reader.

10.2.2 Interpretative Phenomenological Analysis (IPA)

This study involved the exploration of a complex phenomenon: the experiences created through an intervention that interacted with individuals and dyads/triad within the context of long-term relationships and the complex circumstances that dementia can create. With its roots in phenomenology, hermeneutics and idiography, I anticipated that IPA would be an appropriate method to explore this topic.

Freedom in IPA

I would argue that, whilst IPA provides a systematic process with which to collect, analyse and synthesise data, there is also an element of freedom present, particularly during the interview process and within the stages of analysis. Following standard practice for IPA, I developed an interview schedule ahead of interviewing participants, with questions that aimed to explore the research question. However, within this structure, it is also acceptable in IPA for the interviewer to stray from the predetermined questions, and readjust to suit the personal situation of the participant, or to follow a particular line of thinking, allowing the participant to explore their experiences in perhaps a deeper way than if the schedule was adhered to (Smith, Flowers and Larkin, 2009). An example of this can be seen in interview three with Nia (caregiver from case three), which took place following her father's funeral. To be more sensitive to the situation, I changed the interview questions, which I believe showed respect to her context, and this allowed an open and reflective conversation to flow (see reflection on p.76).

This freedom at interview stage encourages the researcher to become more deeply engaged within the process, perhaps thinking more profoundly about the participant's experiences, and influencing the course of the interview by asking different questions; inviting a greater exploration of the topic being discussed. It also inspires a person-centred approach, as the researcher follows the thoughts and meanings expressed by the participant in that moment. This person-centred approach feels congruent with the MT intervention employed for this study, and, I would argue, to the study as a whole, which has been shaped and held with thoughts of the participants' wellbeing throughout (see chapter five, Ethical Considerations, p.85).

This person-centred approach; following the participants' understanding of their experiences, is also mirrored in the analysis stages, where the detailed examination of the use of the participants' language, pacing and body language reveals intimate details of their personalities, circumstances and relationships. Again, the researcher is intimately involved, as they analyse

the text using the hermeneutic circle, bringing their own interpretation to the participants' understanding of their experiences.

I initially found the nature in which the participants shared so openly with me, sometimes relating intimate experiences and feelings, both humbling and surprising. However, on reflection, I believe that the freedom within IPA that allows the researcher to be deeply connected with the participants at interview stage, and the person-centred nature of IPA, during interview and analysis stages, perhaps makes this a less surprising outcome.

Reflexivity in IPA

These two elements: the researcher being deeply within the research process, and the person-centred nature of IPA, resonate with earlier arguments in this thesis suggesting that the roles of qualitative researcher and therapist share some common ground (see p.52). During the course of this study, I felt the tension between these two roles. Primarily, I was, of course, a researcher and not a therapist, but at times I had to work hard to maintain this perspective, especially when participants were relating upsetting times (for example, Theresa's breakdown following Julian's hospital admission, see p.155, and Hazel's moments of anxiety where Daniel comforted her, p.173). There were times within the interviews when I responded as a therapist, and sometimes when I responded just as myself, for example, when I perhaps intervened too much in the conversation with Kelly and Ray (see p.113). This may reflect my relative inexperience in conducting IPA interviews, or perhaps I would be challenged in this way regardless of experience. I do not believe that these moments impacted negatively on the participants or on the data collected; conversely, I feel they have resulted in a deeper sharing from the participants. However, I was aware as I wrote the findings chapters, that some of the experiences related needed to be presented in a sensitive manner in order to protect an element of dignity for the participants (for example, regarding conversations around sexual intimacy, see p.125).

10.2.3 Microanalysis

The intervention for this study was musical and therefore it felt important to include music within the analysis stage. With my existing knowledge of MT, I knew the Music Therapists would tailor the therapy sessions to ensure that the person with dementia had the opportunity to be included and engaged as much as possible, and I expected the MT clips to bring a stronger presence of the participants with dementia into the research data. As mentioned previously, I believe the addition of microanalysis has allowed a rich source of data which has added depth to the findings that would not have been elicited from IPA alone. This relates

both to aspects of individual personality but also, most importantly, to the illumination of key aspects of the dyads' relationships and circumstances.

I have wondered whether the inclusion of music in the intervention also influenced the manner in which the participants engaged within the interview process. Research suggests that music can help people to access feelings more readily and share more freely (Ansdell, 1995; Clements-Cortes, 2004). Perhaps the inclusion of music, with the added element of the trusted relationship between the participants and their Music Therapists, also transferred in some way to their relationship with myself as researcher. The participants knew that I was linked to the intervention I was researching, and I made it clear in the Participation Information Sheet that I was also a Music Therapist. This could have affected the way the participants viewed me, perhaps resulting in a more open relationship. This is an interesting area which could benefit from further investigation.

Reflexivity in Microanalysis

Whilst preparing to watch each video clip of MT, I realised that I anticipated that the therapy would elicit benefits for both person with dementia and caregiver. On reflection, I recognised this was an assumption based on my clinical experience. During the microanalysis, I worked hard to bracket these assumptions, but at times I wonder how successful I was. I attempted to listen and view the recordings from the participants' perspectives, and I believe I have captured true elements of this. However, I know that at times I was also influenced by my experiences as a Music Therapist, and this is reflected in the inclusion of 'Therapist Techniques' that I identified from the video clips and have presented in Appendix 20 (p.410). However, the identification of these specific techniques may be helpful to other Music Therapists working in this context, so perhaps this is an example where the inclusion of different perspectives in the analysis process can be helpful.

10.2.4 Interview Two: Interpersonal Process Recall (IPR)

In order to encourage the participants' reflections of their experiences of MT, I used the technique of IPR (Kettley, Kettley and Bates, 2015) during the second set of interviews (see p.73). This involved the participants and myself watching the video recording of the sixth session of MT together. The participants were asked to pause the video when they wanted to comment on anything; for example, how they remembered feeling at a particular moment, or how they felt now about the session. This interview was also recorded, and the transcripts provided the data for IPA for the second set of interviews.

The advantage of IPR is that the participant is in control of the process; they choose when to stop the video and share their thoughts and feelings. This again resonates with a person-centred approach. However, in practice, this was more successful in some cases than others. Theresa (case four) frequently commented on the video as she watched with Julian, and we paused the video as she shared her recollections. Conversely, Gordon (case one), who generally seemed to find it difficult to talk about his own feelings, did not pause the video, despite a reminder that he could do so. As the video continued, I found myself intervening, pausing and asking Gordon directly: 'What was that moment like for you there?' This was another example where I was probably too direct, but this did result in some insights from Gordon (see p.123).

The participants' experiences of watching their MT session back were mixed. For the participants with dementia, watching the video brought moments of smiles, laughter and singing (as for Louisa, case two, and Julian, case four). In the moment, these felt like additional benefits for the participants as their mood seemed uplifted. Additionally, Lucy (case one) appeared generally more engaged during this interview, and I wondered if the music on the video had prompted this. Conversely, Hazel (case six) became anxious as we watched the video together, and I was concerned that it was the video itself that may have upset her (see my reflection, p.75). Neither Ray or SJ were present when I watched the videos back with Kelly and with Nia.

Most of the caregivers responded with delight in watching the video; for Theresa and Julian, this elicited further moments of shared interaction, with Julian singing along with Theresa. However, Kelly seemed to respond with mixed feelings. The video evidenced her levels of engagement, which she seemed pleased about: 'More so actually watching that back has made me realise that I enjoy it more than I thought I did.' However, as well as provoking laughter, Kelly also seemed self-conscious about her singing and glockenspiel playing, commenting: 'Oh God, that just sounds awful hearing that back!' I responded by asking another question: 'Oh! What was it like to play at the time, and sing?' and Kelly replied that this was a song she did not know so well: 'Yeah, it was OK, I didn't, didn't have the tune, cos I've never played one, so it's quite difficult.'

From my perspective as researcher, when the person with dementia was present and watched the videos back with the caregiver and myself, it gave me another opportunity to see the couples interacting in a musical situation (in addition to the videos themselves). This seemed to give a strengthened sense of the person with dementia in that moment and I saw aspects of

their personality that I did not witness during the other interviews. This was an additional layer of understanding that I was able to bring within the analysis stage.

10.3 Limitations

10.3.1 The Three Superordinate Themes

It could be argued that the superordinate theme that relates most closely to the research question is theme three, 'Experiences of Music Therapy', and that perhaps the exploration of this theme could have benefitted from more time and attention. However, superordinate themes one and two were generated from the data; during the analysis stage, these key areas emerged with a strong and consistent presence. It could be that my interview questions led to this outcome, some of which directly ask about the dyads' relationships and experiences of dementia. In addition to this, however, there seemed a clear need from the participants to talk about what they had been through, and how they were feeling in relation to this and their relationships. The three themes therefore, although perhaps being directed by the interview questions, were also drawn directly from the participants' data.

10.3.2 Limits of a Novice Researcher

As commented on throughout this thesis, I come to this study as a researcher, but with a strong clinical background as a Music Therapist working in this context. Throughout the study, I attempted to question my own thinking to try and determine from which perspective I was examining the data (see Appendix 5, p.285). As is consistent with IPA and microanalysis (Smith, Flowers and Larkin, 2009; Trondalen, 2007), during the analysis stages I systematically engaged in bracketing-off, in order to represent the data and findings from the participants' perspectives; to tell their stories and be as true to their phenomenological world as I could be.

My awareness of my own perspective and assumptions has grown throughout the research process, and I believe that as a result of undertaking this study, I now have a better understanding of my own pre-conceptions and how these may influence my interpretation of any data. I also feel that, from conducting IPA on 18 interviews and microanalysis on six clips of MT, I am now more able to recognise from which perspective I am examining the data, and more adept at stepping outside my own perspective to examine the data from the participant's perspective.

10.3.3 Limited Participant Representation

This study has been concerned with in-depth, idiomatic experiences, and including six dyads/triad in the research has produced six different sets of experiences, from which rich insights and understanding has developed. This sample size has felt right for this study; large enough to give a range of experiences, but small enough to be able to analyse at a deep level. Including more participants would have made this qualitative study unruly, and, as dementia is experienced in such a personal and individual way, it is impossible to contemplate the full range of experiences that might be encountered in this context. Despite this, I am aware that there are particular groups of people not represented in this study.

Types of dementia

The types of dementia experienced by the participants were limited to Alzheimer's Disease, Vascular Dementia, Mixed Dementia (Alzheimer's and Vascular) and Lewy Body Dementia. Although the following were not excluded, there was no one with a rarer type of dementia, such as Frontotemporal Dementia, Posterior Cortical Atrophy, Creutzfeldt–Jakob Disease or Korsakoff's Syndrome (Alzheimer's Society, 2024; Dementia UK, 2024). Similarly, no participant had Young Onset Dementia (YOD); a dementia diagnosed (or with symptoms) before the age of 65. These different causes of dementia bring varying symptoms, and living with dementia before the age of 65 can compound challenging experiences: for example, some people may still be working, or have young or teenage children at home. Including people with YOD, or rarer forms of dementia, will have produced very different sets of experience and understanding.

Participant Demographics

Although there was a range of social class represented in this study, there were no participants from ethnic minority groups. This is somewhat reflective of the county within which Mindsong works; in Gloucestershire, only 6.9% of the population describe themselves as of ethnic minority, a comparatively lower figure than the 19% given for England as a whole (Gloucestershire County Council, 2023). In addition to this, nationally, people with dementia from ethnic minority communities are underrepresented in accessing and receiving dementia services (Hussain, 2024; Race Equality Foundation, 2025). This is due to a range of reasons, including language barriers, cultural differences, an under representation of staff in dementia care from minority communities, a lack of understanding about dementia and a continued stigma around the illness (Hussain, 2024; Race Equality Foundation, 2025). Reflecting this national picture, at present, few people from ethnic minority communities in Gloucestershire

engage with Mindsong services, so it was unlikely that this study would be able to recruit participants from these communities.

Relationships

All the caregivers in this study were family members and described close, loving relationships with the person they were caring for. In my clinical experience, this is not always the case, and it may be that, because of the commitment requested in participating in this study, it was always going to attract caregivers that had a strong bond with the person with dementia. It would have been interesting to include caregivers where the relationship was not so close or experienced disruption, to see if these experiences differed greatly or not.

Response to MT

Every person in this study responded to the music and MT. Although most people who consent to Mindsong's MT@H intervention do respond positively to the therapy, there are a small minority of people for whom music does not seem to connect, or who cannot tolerate the therapy at this time in their lives. It would have been interesting if this study had included a participant that found it difficult to connect with music, although it is possible that these participants may have refused the therapy in the first instance.

10.3.4 Variations in the Duration of Intervention and Interviews

In some cases, there were variations in the duration of intervention length, time difference as to when interviews took place, and a resultant effect on the overall length of the research process. SJ and Nia (case three) were only able to participate in eight MT sessions, because sadly, SJ became unwell and died before the end of the intervention. Despite this, the MT seemed to have a transformative effect for SJ, who, when engaged in improvisation with the therapist, became absorbed in a shared, creative improvisation, which Nia saw as 'magical', and lifted him out of his ongoing fight with dementia (see p.181).

Conversely, Hazel and Daniel (case six), had sixteen sessions of MT before the final interview. Therapy was extended here, because Hazel became unwell and was admitted to hospital. During this stay, music was the only thing that connected with Hazel, bringing her out of an unresponsive state. Because music had such a transformative effect, Mindsong extended the therapy: Neil visited Hazel in hospital and then helped her transition back home, with four extra MT sessions. Although this was beyond the intervention set for this study, it felt more important to respond to the needs of the person with dementia above the requirements of the study, and so extra sessions were given. The MT had already brought significant benefits for

this couple, including a tool to chase away hallucinations, and a musical strategy to help calm Hazel at times when her anxiety became overwhelming. Although the extra four sessions provided additional support, I do not believe they had any significant effect on the findings relating to this couple.

Hazel's stay in hospital also delayed the last interview, and this was also the case with Julian and Theresa (case four). In this case, the MT was paused until Julian returned home, and then resumed. Delays in MT delivery within the MT@H service are common, and sometimes result in a disjointed delivery of the 12 sessions. This cannot usually be helped, as delays are most often due to illness, important appointments or hospital admissions. In this study, I do not believe that the delay in MT delivery, or in the event of the third interview, affected results in any significant way.

10.4 What New Understanding Does this Research Bring?

10.4.1 A Study Rooted in the Participants' Contexts

As far as I am aware, this is the first in-depth study exploring the experiences of MT for family caregivers of people with advanced/complex dementia that has considered their experiences so deeply within the context of their situation: their relationships and experiences of dementia. Despite my years of clinical work in this field, this study has, at times, surprised me, with how profoundly the effects of dementia are also experienced by the caregiver. It has felt as if the caregivers were enveloped into the experience of dementia, and this had significant consequences for every aspect of their lives. This has changed my understanding of this context, highlighting how vital it is that caregivers are supported, and bringing a new understanding that, wherever possible, focusing on supporting the relationship between the dyad is essential, and perhaps the most significant element MT can provide.

10.4.2 Additional insights and understanding of this particular context

This research also adds to existing literature that evidences how complex, challenging and changeable the experience of dementia can be for the caregiver, affecting their life almost as much as the person with dementia themselves. These insights could be helpful for professionals and organisations working to support a person with dementia being cared for by a family member, and I hope, will be particularly helpful for Music Therapists working in this context.

10.4.3 Exploring this particular Music Therapy Intervention

This is also the first comprehensive study of this particular intervention, which includes both the person with dementia and caregiver as equal clients, is home-based, time-limited, and explicitly includes elements of skill-sharing. From the findings from this study, I would argue that home-based MT that includes the caregiver alongside the person with dementia can work successfully, and that a 12-week intervention is long enough to support significant positive change for both in the dyad, on an individual and relationship level.

10.4.4. Theoretical Underpinning

This study considered a specific context: MT with a person with advanced or complex dementia and caregiver together, as equal clients, in a home-based environment. The findings from this study have highlighted that, holding MT in this context within particular theoretical frameworks, benefits the work in terms of bringing a deeper understanding of each individual's experience, as well as each dyadic relationship. Kitwood's flower (Kitwood, 1997) was already employed to underpin Mindsong's approach to MT, but the importance of holding the work in reference to Attachment theory and with an understanding of a trauma-informed approach, are aspects that that have emerged strongly as a result of this study.

10.4.5 Supporting skill-sharing between Music Therapist and Family Caregiver

This research adds to the emerging literature supporting skill-sharing in this context and echoes the findings from my literature review, suggesting that skill-sharing is embedded more successfully when the Music Therapist can work in-person, alongside the couple, modelling techniques and strategies, and encouraging the caregiver to employ these on a daily basis.

10.4.6 A Multimethod Approach

Employing microanalysis alongside IPA has worked successfully and allowed rich sources of data to interact to create in-depth accounts and understanding of the participants' experiences. The creation of individual case summaries was key to embedding the findings from microanalysis within those from IPA. Although this is not the first study to employ these two methods, it is one of few, and as far as I am aware, the way in which I have synthesised the two sets of analysis results is novel.

10.5 Implications for Research

10.5.1 Participant Demographics

As noted in the limitations section of this chapter, this research relates to a narrow band of participants. It would be interesting to discover more about caregivers' experiences, particularly when caring for people with rarer forms of dementia, including YOD. It would also be illuminating to see how effective the MT intervention might be for participants whose relationships are not so close, or are even in conflict. Another identified area is if and how MT can support people with dementia who find connecting with music a challenging experience. Other areas of research that need more attention include MT for people with dementia and caregivers from ethnic minority communities, and the experiences of grandchildren providing the majority of care for their grandparent with dementia.

10.5.2 MT Intervention

In terms of MT intervention, this study has suggested that the explicit inclusion of 'nostalgia' in MT sessions might be helpful in supporting significant aspects of self (see p.174). A research study exploring how nostalgia might be employed within MT, and the effects of this, would provide further investigation.

10.5.3 Methodology

Regarding methodology, it would be interesting to see more studies employing a multimethod approach, and in particular addressing different methods of synthesising findings from multiple research approaches. In addition, it would be interesting to see if microanalysis could be woven more extensively into IPA; to explore if these two methods could be more closely employed and to what effect.

Another area highlighted by this study is the exploration of IPA itself, and whether its person-centred nature leads to a deeper engagement with the research participants. It would also be interesting to see if the inclusion of a creative element, such as music, influences the extent of the engagement of participants, and how this in particular might influence their relationship with the researcher.

10.6 Recommendations for Practice

10.6.1 Including the Family Caregiver

This study has highlighted how profoundly experiences as a result of dementia can affect caregivers, and their relationship with the person they are caring for. I have argued that it is

vital that the caregiver is given emotional support and containment to help maintain their own psychological health, but also to continue to be able to provide containment and care for the person with dementia. Therefore, therapeutic interventions that aim to provide support for a person with dementia being cared for by a family member, should also seek to include the caregiver as an equal client alongside, wherever possible.

10.6.2 Focusing on the Relationship

Perhaps the most crucial element of support that the intervention in this study provided was the upholding and strengthening of the relationship itself, through shared, meaningful interaction that supported emotional connection between the dyads. In turn, this provided opportunities for enhancing feelings of attachment between couples, potentially leading to increased wellbeing for both and a reduction in challenging experiences that may have resulted from a person feeling unsafe. An explicit focus on the relationship, and exploring ways in which MT might support this in each dyadic situation could be practised more comprehensively within Mindsong's MT@H service, and is also a recommendation for other therapeutic interventions that may be employed within this context.

I must add a caveat to this recommendation, in that the findings from this study only related to people who had close and loving relationships. A focus on strengthening an existing relationship might not be beneficial if that relationship is in conflict, or where there has been a relationship breakdown. As there were no instances of this within this study, I cannot give this focus on relationships as a blanket recommendation, but suggest that this is left to the therapist's discretion, who should always take into consideration the personal situation of the couple they are working with.

10.6.3 Theoretical Underpinning

I would advocate for any therapeutic work undertaken in this particular context to be considered within the theoretical framework of Attachment theory. Viewing the work through this framework may bring a deeper understanding of both the person with dementia and caregiver's experiences, both as an individual and within their relationship. Therapists should also employ a trauma-informed approach, with an understanding that both clients with dementia and caregivers may have past traumatic experiences that may interplay with the present moment, affecting how they experience dementia and their relationships. Kitwood's flower (Kitwood, 1997) is also clearly a useful lens through which to view the work, both in evaluating the MT and in identifying aspects that might be helpful to focus on.

10.6.4 Home-based Interventions

People with advanced/complex dementia and their caregivers are at increased risk of social isolation, and often experience difficulties in accessing support outside the home, due to advancing dementia symptoms and mobility problems. These challenges were evident in four cases in this study (cases one, two, three and six). Services based in the home are generally more accessible and should be considered wherever possible. Despite concerns raised from my literature review about home-based studies potentially being too stressful for participants (Holden, 2019), the home-based intervention in this study worked well, and was successful in supporting both in the dyad.

10.6.5 Considering Therapeutic Boundaries when Working in People's Homes

Even though the intervention was successful, there were moments when the relationship with the Music Therapist became blurred for some participants, as they began to view their therapist more as a friend. In going into a person's own home, the therapist is stepping into an intimate, private space. As discussed in chapter eight (p.188), this has a different feel to conducting therapy in a clinic, day centre or hospital. Any therapist going into a person's home, especially if the therapy delivered focuses on providing emotional and psychological support, should carefully consider therapeutic boundaries, and be clear from the start that the therapy is time-limited. This would hopefully ease difficult endings and keep therapist-client relationships intimate but still professional, and not dipping into feelings of friendship. This is an element already considered by Music Therapists delivering Mindsong's MT@H intervention, but the findings from this study suggest that this should be an **essential consideration** for therapeutic work in this context.

10.6.6 Considering Ongoing Consent

Related to the point above, is the possibility that, when working in someone's home, that person may feel less able to withdraw from the therapy, as they cannot choose not to attend a session, or to walk out of the situation. People with advanced/complex dementia may not be able to verbally communicate that they wish the therapy to stop, or physically able to walk away. It is therefore essential that, as well as gaining consent for therapy at the start of an intervention, ongoing consent must be considered, and therapists should be vigilant to the communications from the person with dementia that might take the form of facial expressions or body language, in case there are indications that they wish to stop. I suggest this is another **essential consideration** for the therapist to hold in mind whilst working in this context.

10.6.7 Including the element of skill-sharing

The findings from this study echo the emerging research from my literature review that skill-sharing between the Music Therapist and caregiver can be successful and can extend the benefits of using music to support challenging situations, wellbeing and relationships. In this study, this was extended to include moments at the end of life, and even beyond, where in case three the caregiver continued to play music used in MT sessions to help her remember her father once he had died. Previous research suggests that skill-sharing is more successful when the Music Therapist supports the caregiver in-person, and this study also strengthens this suggestion. I would advocate for the inclusion of the element of skill-sharing in MT, supported by the therapist, when working in this context.

10.6.8 Considering using Nostalgia

Music Therapists often use well-known songs in MT when working with people with dementia (Melhuish, Grady and Holland, 2019; Thompson *et al.,* 2023), as was the case in this study. However, it may be useful to re-frame these moments and think of them as moments of 'musical nostalgia', explicitly bringing in the element of nostalgia and perhaps dwelling longer on the memories, thoughts and feelings evoked by the music, and seeing where this leads. When thinking of the evidenced benefits of nostalgia (see p.174), this may further increase the positive impact of MT on both an individual and relationship level.

10.7 Final Conclusion

This study aimed to explore the lived experiences of family caregivers when they engaged in MT alongside the person with dementia whom they were caring for. Using a multimethod approach, rich insights and understanding of personal experiences came to light. The findings of this study highlight how dementia experiences profoundly affect the lives of caregivers, as well as the person diagnosed, and how important the relationship between these two people is, in terms of emotional and psychological wellbeing for both.

In every case, the MT addressed all of Kitwood's suggested psychological needs (Kitwood, 1997), and supported vital aspects of self that have been identified as protective factors against negative experiences of dementia (Cheston and Christopher, 2019). The MT provided emotional containment for both the person with dementia and caregiver, and facilitated moments of meaningful shared interactions, strengthening the relationship and bringing moments of joy and hope in the face of complex circumstances due to dementia.

A recent report from the Commission on Dementia recognised the potential music has to support people living with dementia, and called for a range of appropriate music interventions, including MT, to be more widely available and accessible (Bamford and Bowell, 2018). The use of music and MT to support people living with dementia is also recommended in national guidance (NICE, 2019). The findings in this study support these recommendations, but crucially, advocate that support through MT should also be extended to include caregivers, especially where they are caring for a person with dementia at home.

Dementia brings a myriad of challenges and changes to these significant relationships and it is naïve to think that MT is the answer to this. However, in these six cases, MT played a significant role in supporting both the person with dementia and caregiver at an individual and relationship level. Through skill-sharing, music continued to make transformative differences in the caring role for some of the caregivers in this study. Music also played an important part at the end of life for two of the cases, providing a 'musical cocoon' (Kenny, 2014); a holding and comforting presence for the person with dementia and caregiver, in the transitional moments between life and death.

It is my hope that the findings from this study strengthen the voice of family caregivers of people with advanced/complex dementia within the research literature, and deepen any understanding of how MT might be experienced in this particular, complex and often challenging context. There are strong recommendations for practice which will inform Mindsong's MT@H service going forward. I also hope the blueprint of the MT@H service as described in this thesis, along with the recommendations from these findings, might be helpful in developing other MT services to support people living with advanced/complex dementia and caregivers, their relationships and circumstances.

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Appendix 1: Aligning Kitwood's Psychological Needs to Mindsong's Music Therapy Practice

Identified Need	Kitwood's Definition of the Need	Mindsong's interpretation of how this may align to MT practice
Attachment	The need for a secure attachment with a consistent, reliable and significant other person or people. To have trust and security in relationship with another person. First identified by John Bowlby (1979), attachment needs remain with us throughout life and are particularly important at times when we feel unsafe or uncertain. Attachment needs can therefore be intensified in dementia (Miesen, 1992; Kitwood, 1997).	The development of a safe and trusting therapeutic relationship between client and therapist is vital in therapy. This allows for the free expression of thoughts and feelings, whether these are presented musically or verbally expressed. Creating a safe space and relationship can also allow creativity to flourish. Crucially, attachment relates to the relationship between the person with dementia and family caregiver, which can be strengthened in moments of sharing music together.
Comfort	To provide comfort for a person: tenderness, closeness, reassurance in the face of the uncertainty, fear and losses that dementia may create: 'To comfort another person is to provide a kind of warmth and strength which might enable them to remain in one piece when they are in danger of falling apart' (Kitwood, 1997, p.81).	The feeling of being heard and validated, attended and attuned to. To be held within the music. There may be comfort and warmth within the relationships and perhaps within the music. A sense of security fostered by the familiarity of singing well-known songs together may be experienced. The music may bring back memories creating a sense of self-continuity, which may also inspire feelings of comfort.
Identity	'… to know who one is, in cognition and in feeling' (Kitwood, 1997, p.83). To have a sense of self, of who 'I' am, and a sense of self-continuity, in that I am the same person that was, is now and will be in the future. Kitwood acknowledges the influence of others in the formation and understanding of individual identity (Kitwood, 1997).	Singing and playing songs that have important significance in a person's life history can strengthen a sense of identity. Joint identity can also be strengthened as significant music from a couple's past is recreated together. Music in therapy can sometimes reach a person where other forms of communication no longer work. Family members talk of music bringing back a person: 'you found him!' (Mindsong Caregiver, 2016). New music created through improvisation or the recreation of well-known songs may bring out elements of personality, such as a sense of humour, or a sociable nature.

Identified Need	Kitwood's Definition of the Need	Mindsong's interpretation of how this may align to MT practice
Occupation	To engage in a meaningful and significant way, to use a person's abilities and attributes. This may be in interaction with others, or in solitary occupation. 'If people are deprived of occupation, their abilities begin to atrophy, and their self-esteem drains away' (Kitwood, 1997, p.83).	Engaging in music-making together is a meaningful occupation, giving opportunities for connection within the relationship of the person with dementia and caregiver. These moments also provide opportunities for stimulation and engagement, often involving multiple cognitive processes and perhaps working against the trend of decline and atrophy in dementia.
Inclusion	The human need to be included, to be part of a group is evolutionary, and is very present in the experience of dementia, where social life and opportunities for social-connection often 'dwindle away' (Kitwood, 1997, p.83).	The therapy is client-led: person-centred. The therapist attunes to both the person with dementia and caregiver, using skills such as sensitive pacing, body positioning, matching and mirroring within the music in order to engage and support both in the dyad.
Love	Kitwood suggests that the five identified needs overlap with each other, coming together in the 'central need for love' (Kitwood, 1997, p. 81).	MT inherently fosters love through shared musical experiences, emotional expression, and deepened connections. The therapist is open and available for the client, in accordance with Roger's three core qualities of empathy, unconditional positive regard and congruence (Rogers, 1957; Fromm, 1994).

Appendix 2: Systematic Literature Review

'What is the evidence of effectiveness of Music Therapy for improving wellbeing for carers of people with dementia?'

A Systematic Review

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ABSTRACT

Background

Family/informal carers of people with dementia are twice as likely to suffer poor health to non-carers of a similar age. Music Therapy (MT) is already a NICE recommended intervention to support wellbeing for people with dementia, with reported improvements in mood, wellbeing, and a strengthened sense of self. This review evaluates the evidence to date for the extension of MT to family carers of people with dementia, across quantitative, qualitative, and mixed methods studies.

Methods

Eleven electronic databases were searched between March – June 2021: AMED, Cinahl Plus, EBSCO ebook collection, Medline, APA Psycbooks, APA PsycInfo, PubMed, Scopus, Cochrane, BioMed and NICE. Searches for grey literature were also undertaken.

Study selection was performed independently by the first two authors; any discrepancies were discussed and resolved according to the inclusion criteria. Independent quality assessment using the EPHPP tool for quantitative studies used the same resolution process.

Study heterogeneity dictated a narrative synthesis, the results of which are presented here using the PRISMA reporting tool and structured by type of evidence (quantitative, qualitative).

Results

10 papers (8 studies) of various study design were included, representing 87 carers. Interventions found were all group-based MT, but varied from songwriting, group singing, to a more general application of MT.

Outcomes measured included depression, anxiety, burden and self-esteem; some studies reported positive effects, but these were often not at a significant level and were based on weak evidence. There was variation in scientific quality, with ratings from 'weak' to 'moderate'. Seven of the included studies were feasibility/pilot studies, with relatively small sample sizes for quantitative studies.

The specific use of music, the creative process and role of the therapist were identified from qualitative data as key mechanisms for inclusion and expression.

Conclusions

There was no strong evidence to suggest that MT supports wellbeing for family carers of people with dementia, underpinned by poor study quality, with key flaws in study design, including small sample sizes, high possibility of performance bias, and a lack of information in reporting. Promising results were found in the qualitative data, with the specific use of music, the creative process, and the role of the therapist facilitating a 'safe space' for carers to express, be heard, and develop strong, supportive relationships with their peers.

More research with larger sample sizes, better methodological quality and more comprehensive reporting is required to determine whether MT can have a positive influence on wellbeing for carers of people with dementia.

Funding

No application for funding was made for this systematic review.

Registration

A protocol was published in advance on Prospero (CRD42021243203, PROSPERO (york.ac.uk))

Keywords: Music Therapy; Family Carers; Dementia; Wellbeing

BACKGROUND

Globally, an estimated 50 million people live with dementia, a figure set to almost triple by 2050 (Alzheimer's Research UK, 2021). In the UK alone approximately 670,000 unpaid carers look after someone with dementia, saving the economy around £11 billion a year (Alzheimer's Society, 2014; Carer's Trust 2018).

The challenges of this complex role can create stress in every area of life, including social, financial, emotional, physical and psychological strain (Alzheimer's Society, 2016; Etters et al, 2008; Newbronner et al, 2013). This affects carers' health and ability to care, which may lead to an earlier admission to care home or hospital for the person with dementia (Etters et al, 2008). Family carers are recognised as a population group at risk, being "twice as likely" to suffer from poor health compared to non-carers of a similar age (NHS, 2019). There is often little support for this population group "as a carer you become invisible as a person" (Oliveira et al, 2018). Attending to their own needs is often difficult, yet if they are not supported, their mental and physical health, and that of the person they are caring for, are both at risk (Etters et al, 2008).

For couples, dementia intrudes on a pre-existing relationship and the changes and losses experienced can result in a "dementia grief" for both person with dementia and carer (Blandin and Peppin, 2017). Often, the carer finds themselves in a role supporting not only the physical but also the emotional needs of their partner, becoming a "container" for their feelings in attempts to comfort and reassure (Balfour, 2020). It is crucial, therefore, that the carer, as well as the person with dementia, is supported with interventions addressing both practical and emotional concerns.

Carer quality of life is linked to health (Li et al, 2012; Farina et al, 2017), so employing interventions that support quality of life may lead to improvements in mental and physical health.

A growing body of research suggests Music Therapy (MT) is an effective intervention to support quality of life for people with dementia (Hsu et al, 2015; McDermott et al, 2012; Ridder et al, 2013). This is reflected in the UK NICE Guidelines which recommend MT as an intervention to support people with dementia (NICE 2019). However, there is a paucity of research regarding the effects of MT for the people caring for, and often participating alongside, the person with dementia. Earlier research suggests positive outcomes, with Clair and Ebberts (1997) reporting that MT enhanced "purposeful joint participation" between couples where one person has dementia. More recently, Hsu et al (2015) and Melhuish et al (2017) report benefits for staff in care homes when engaging in MT alongside their clients.

For a person with dementia, the ability to engage with music seems preserved much longer than verbal communication (Baird and Samson, 2015) and music connects with emotional memories which can strengthen a sense of self, as well as stimulate interaction and self-expression (Jäncke, 2008). A recent systematic review found that MT positively affects cognitive function for people with dementia, with additional improvements suggested in quality of life and depression (Moreno-Morales et al, 2020).

For carers, MT has the potential to support in similar ways, encouraging self-expression and a focus on the individual, which may feel lost in the role of caring (Oliveira et al, 2018). Furthermore, as MT is an existing intervention already in place for people with dementia, it seems logical to explore its potential to improve the wellbeing of those caring for that person. Establishing an evidence base is also important for the MT profession, not only to discern *what* works through quantitative evaluation but also *how* interventions work with qualitative studies, in order to inform theory of change approaches and theoretically based outcome measures. To this end, this systematic review aimed to identify all relevant primary research studies reporting on the effects of MT on wellbeing for family carers of people with dementia and to assess the quality of research found, alongside an analysis of qualitative evidence to explore pathways of change for this population group.

METHODS

The Preferred Reporting Items for Systematic Review and Meta-Analysis guidelines were followed for this systematic review (PRISMA 2021). A protocol was also published in advance on Prospero (CRD42021243203, PROSPERO (york.ac.uk))

Definitions

The term 'informal carer' is used interchangeably with 'family carer', 'carer' or 'caregiver' and can be defined as any unpaid individual "who takes on a caring role to support someone with a diminishing physical ability, a debilitating cognitive condition or a chronic life-limiting illness" (IACO, 2021). For this review, the term 'carer' referred to an adult informal carer providing most of the care for a person with dementia.

MT is a clinical intervention, provided by qualified therapists that have completed an accredited course, usually at Masters level. In the UK, Music Therapists (MTs) are considered Allied Health Professionals and need to be registered with the Health and Care Professions Council to practice. A growing profession, many countries across the world have similar standards of practice for MTs

(Kern et al, 2017). Therefore, only research reporting on interventions provided by MTs was included.

For this review, wellbeing was viewed as synonymous with 'quality of life' and study outcomes included 'wellbeing', 'quality of life', mood, depression, and anxiety.

Search Strategy

These definitions informed the search terms used to identify relevant papers. The search string used for electronic database searches was as follows:

Carers OR "Carergivers" OR "Informal" OR "Family" AND "Music Therap*" AND "Wellbeing" OR "Well-being" OR "Well being" OR "Quality of Life" OR "Mood" OR "Depression" OR "Anxiety" OR "qol". (See supplementary material, appendix 1 for full search terms.)

The search process took place between March – June 2021. Eleven electronic databases were searched: AMED, Cinahl Plus, EBSCO ebook collection, Medline, APA Psycbooks, APA PsycInfo, PubMed, Scopus, Cochrane, BioMed and NICE. Zetoc and EThOS were also searched for any Grey Literature.

Authors were contacted directly to request full papers or English translation, as required.

To address publication bias, searches for grey literature also included hand-searching references of identified studies and contacting all UK MT training courses to seek any relevant unpublished MA or PhD theses.

Study Selection

Inclusion Criteria

Studies included in the review met the following criteria:

- Reporting on primary research (any study type)
- In English Language
- Published within the last 20 years (2001 – 2021)
- Reporting on *adult informal/family carers*; not including paid carers
- Reporting on carers of people with *dementia* rather than other diseases/conditions
- Studies where the family carer took part in the MT
- Reporting on *MT* as provided by qualified MTs, rather than interventions provided by other musicians

- Reporting on *wellbeing* of carers (including quality of life, depression, anxiety, mood)

Data Collection

Data collection and screening were performed by the first two authors, independently. Papers were screened initially using title and abstract, and then on full text. Any discrepancies were discussed and resolved according to the inclusion criteria above.

Data extraction forms per study design were used, based on those by The Cochrane Collaboration (2021) and NICE (2012; see supplementary material, appendix 2).

Quality Assessment

As selected studies were likely to be of varied study design, two different tools were employed. The Effective Public Health Practice Project Quality Assessment Tool for Quantitative studies (EPHPP, 2009) was chosen as it was designed specifically for quantitative studies across a variety of study designs (Thomas et al, 2004), and scores a global rating of either 'strong', 'moderate' or 'weak' which were used to frame the findings.

The Critical Appraisal Skills Programme assessment tool (CASP, 2021) for qualitative studies is suggested by the Cochrane Methods Group as an appropriate tool to assess methodological quality in qualitative studies (Noyes et al, 2018).

For studies employing mixed methods, quantitative and qualitative data were assessed separately, using the appropriate tool. Any uncertainties in rating were checked by the second author who provided an independent rating; results were discussed, and a conclusion made.

Data Synthesis

Due to the heterogeneity in study design, outcomes and methods of intervention, a meta-analysis was not possible. A narrative synthesis of qualitative and quantitative data relating to the different intervention methods employed was undertaken addressing the parallel aims of evidence of effect and change pathway.

The methods applied followed guidance from Popay et al (2006). This published guide has been previously tested and compared for reliability with traditional meta-analysis methods (Popay et al, 2006) and is recognised by the Centre for Reviews and Dissemination (2005).

Relationships across the data were explored, including issues of heterogeneity. Summaries of quantitative results and key points from qualitative data are reported separately for each study

and grouped by the type of intervention method. Themes relating to wellbeing were identified across the qualitative data.

RESULTS

Study Selection

From the 1152 papers identified, 10 went forward for inclusion in this review (see figure 1).

Where a paper reported results for both person with dementia and carer, only results relating to carers were extracted.

Of the 10 papers, there were two instances of partner papers (two papers reporting on different aspects of the same study; Clark et al 2018 / Tamplin et al 2018; Clark et al 2020 / Clark et al 2021), reports on which were amalgamated resulting in the inclusion of a final eight different research studies.

Overview of included studies

Study design varied with two using quantitative methods, four using a mixed methods approach, and four using qualitative methods.

Issues of heterogeneity were explored across the studies (see supplementary material, appendix 3) and summarised here.

87 carers were represented, with the majority being spouses (60). Other carers included adult children (16), family members (2), and siblings (2), with some studies not reporting this detail (Lee et al, 2020; Clark et al, 2018 / Tamplin et al, 2018).

The age range was wide (44 – 92 years), reflecting the inclusion of spouses and adult children as carers. More carers were female (57; male 27), with gender not reported for three carers who dropped out (Clark et al, 2018 / Tamplin et al, 2018).

Ethnicity and social-economic status were mostly not reported. Most carers lived with the person with dementia (59), except for seven where the person with dementia lived in a care home (Clark et al, 2020/2021). Living arrangements was not reported in one study (Garcia-Valverde et al, 2020).

Cause of dementia was often not reported, and severity ranged from early to late/advanced stages. Most studies reported on carers of people with dementia from early to moderate stages,

with only three carers of people with advanced dementia represented (Baker and Yeates, 2018; Clark et al, 2020/2021).

Interventions varied from songwriting (5), group singing (3) to a more general use of MT (2). All employed a group format, and most were held in a community setting, including six in day/medical/community centres, one in a care home, one in a rural residential setting, and one study not reporting this (Raglio et al, 2016).

It could therefore be argued that results from this review are more transferable to group MT in community settings for female spouses caring for people with early to moderate dementia, living together in their own homes.

For characteristics of included studies, see table 1 in supplementary material.

Quality Assessment

Quality assessment ratings were used in the synthesis to help determine the strength of evidence of reported results. Ratings are noted in table 1 and reported in more detail in appendix 4, both found in supplementary material.

Of the 8 studies, five were feasibility/pilot studies, and there were no Randomised Contolled Trials (gold standard in terms of hierarchy of evidence, Peat et al, 2002). Overall, the strength of evidence was weak, with common flaws in quantitative studies including small sample sizes, and only one study employing a control group, in which no blinding was present, and participants chose to which group they were assigned. Assessors were often the MTs providing the intervention and little attention was given across the studies to confounding factors. Three studies reporting quantitative data were rated 'weak' and three 'moderate'. Qualitative studies generally gave more information about study participants and research processes, but in all except one study, the MTs providing the intervention were also the interviewers, therefore increasing the risk of vested interest. Confounders such as participants responding more positively at post-intervention because of their existing relationship with the therapists need to be considered.

Data Synthesis

Overview

All 8 studies reported increased wellbeing following MT but only three (of the six quantitative studies) reported statistically significant results, and of those, two were rated 'weak' in terms of scientific quality, and one 'moderate'. Qualitative data were used to corroborate findings and

gave indications as to how and why MT may be a useful intervention; this includes themes around the use of the medium of music, the process of creativity, and the role of the therapist.

For themes extracted from qualitative data, see tables 2 – 7 in supplementary material.

1. Group Songwriting in MT

Four studies reported on the effects of songwriting in MT: Baker et al (2018), Baker and Yeates (2018), Clark et al 2020/2021 and García-Valverde et al (2020; papers 1 – 5 in table 1).

Of these, three referred to underlying theory, citing Baker (2015) as a model and rationale for the intervention. The fourth study was co-written by Baker herself (Baker and Yeates, 2018), so intervention methods were likely to be similar across the studies. In three studies, the carer attended alone, in Clark et al 2020/2021 study, they attended with the person with dementia.

1.Baker et al (2018)

Participants engaged in six weekly 1 hour songwriting sessions, facilitated by a MT.

Quantitative data: no significant differences were found in any measure. A small reduction in depression for participants at post-intervention was recorded, with a moderate effect size for the intervention group (d = 0.64; 95% CI = -0.40, 1.61) and small negative effect size for the control group (d = -0.33; 95% CI = -1.47, 0.81). No differences were found in scores for Quality of Caregiver-Patient Relationship or Positive Aspects of Caring, indicating that MT may not affect these dimensions. The authors reported that relationship scores were high at baseline; this could explain why there was no change at post-intervention.

This study did include a comparison group but as participants chose whether to be in the intervention or control group it did not provide a true control. The sample size (14) is small and underpowered for a quantitative study. The MTs providing the intervention also collected the data, therefore performance bias cannot be excluded. This study was therefore rated '**moderate**' in quality, limiting its strength of influence.

Qualitative Data: the authors identified six themes: sharing the whole carer journey; we're singing the same tune; gaining clarity around the carer journey; we all fit under the same umbrella but we're miles apart; we can stand up for ourselves, we've got stronger, and songwriting groups fill a gap not met by other support groups. From analysis of the data relating to wellbeing, the following themes were identified for this review: Togetherness, Confidence, Awareness, Identity, Strength and Resilience, and Creativity (see supplementary table 2 for results).

2.Baker and Yeates (2018)

Participants engaged in four 1 hour songwriting sessions, facilitated by two MTs.

Qualitative data: five themes were identified, experience exceeded expectations; co-creating a song is meaningful; the song product is meaningful; learning through the songwriting process; having a voice and being heard. The following themes relating to wellbeing were identified for this review: Togetherness, Awareness, Positive Experience, Validation, Confidence, and Music and Lyric Creation (see supplementary table 3).

The MTs providing the intervention also conducted the interviews, therefore participants may have responded more positively because of their existing relationship with the therapist.

3.Clark et al (2020)

Participants engaged in six 1 hour songwriting sessions, facilitated by a MT.

Quantitative data: no statistically significant changes were found for any measure, although there was a reduction in scores with small effect size for depression (d=0.20, CI = -1.0 to 0.6) and burden (d=-0.45, CI = -1.3 to 0.4) at post-intervention. Small improvements without significant difference were also reported for: 'Independent Living' (d=-0.93, CI = -1.8 to 0), 'Physical Super-Dimension' (d=-0.48, CI = -1.3 to 0.4), 'Happiness' (d=-0.42, CI = -1.3 to 0.4) and 'Relationships' (d=-0.32, CI = -1.2 to 0.5). A small negative change was found in the 'Coping' dimension of the AQol-8D scale (d=0.24, CI = -0.6 to 1.1).

The sample size is small and underpowered for a quantitative study (14), and 4 carers dropped out. The MTs facilitating the intervention also administered the assessments and interviews, and little consideration was given to confounding factors, therefore the quality rating given was '**weak'**, making this study's influence negligible.

Qualitative Data: Five themes were identified: Positive experience, Togetherness, Challenge, Music, and the Role of the Therapist (see supplementary table 4). One participant with advanced dementia found engaging in the process challenging, suggesting that this intervention may be more suitable for people with early to moderate stages of dementia.

4.Clark et al (2021)

Qualitative data: a fuller account of the qualitative data from the Clark et al, 2020, study reported five themes: positive shared experience; engaging and valuable for stimulation; meaningful opportunities for reflection; promoted interaction and collaboration; diverse challenges which were supported. Further themes identified for this review include Togetherness, Reflection, Validation, Identity, Music, and Creativity (see supplementary table 5).

The MTs also undertook the interviews in this study; therefore, participants may have responded in a more positive manner. This is acknowledged by the authors, who include an epoché statement, describing 'bracketing off' any preconceptions from their previous clinical experience.

5.García-Valverde et al (2020)

Participants engaged in twelve 1 hour songwriting sessions, facilitated by a MT.

Quantitative data: this is the only study reporting on group songwriting to find significantly different results, with positive trends of moderate effect size for depression (p=0.01; CI=0.91-9.69; d=0.57), anxiety (p=0.04; CI= -0.71-9.38; d=.53) and self-esteem (p=0.03; CI = -4.24-0.14; d=-0.47). Improved scores with significant difference and moderate effect size were also found from the Quality-of-Life subscales, 'Mental Component Summary' (p=0.02; CI=-9.95—0.57; d=-0.57) and 'Mental Health' (p=0.004; CI=-10.51—1.89; d=-0.70).

The State-Trait Anxiety Inventory (STAI; Spielberger et al, 1983) has two subscales, one measuring anxiety levels for a person at that moment (S-STAI) and one measuring how anxious a person feels generally (T-STAI). The authors reported significant differences with a reduction in anxiety for S-STAI at post-intervention, with a moderate effect size. No significant difference was found for the T-STAI. This could suggest that MT has a positive effect on reducing anxiety in the moment, but perhaps these effects are not transferable to other aspects of life.

It is worth noting that although the intervention model may have been similar across the studies, García-Valverde et al (2020) employed double the number of MT sessions. This could suggest that a longer intervention period (12 or more sessions of MT) may be more likely to produce significant results.

Although larger than previous studies described, this study still had a relatively small sample size (21) with 3 carers dropping out. All measures were self-administered, so performance bias is less likely, but due to study design and confounding factors not really mentioned, the quality rating given was '**moderate',** limiting its strength of influence.

Summary

Due to small sample sizes and weak to moderate ratings of quality for quantitative studies, there is limited evidence to suggest that group songwriting in MT has a positive effect on wellbeing for carers of people with dementia.

Qualitative data suggests that songwriting in MT may have a positive impact for participants, with the following themes identified across the studies: Togetherness, Awareness, Validation, Positive Experience, Confidence, Strength and Resilience, and Identity.

Participants identified aspects of the process which made the intervention successful, including:

- The use of music as a mechanism for inclusion, expression, and reflection
- The creative process as a mechanism for problem solving, stimulating self-expression and motivation
- The created song itself as a source of resilience
- The role of the therapist in facilitating inclusivity

(See supplementary tables 2 – 5)

2. Group Singing in MT

Two studies reported on the effects of Group Singing in MT: Clark et al (2018)/Tamplin et al (2018), and Lee et al (2020; papers 6 – 8 in table 1). In both studies, the person with dementia and carer attended together.

8.Tamplin et al (2018)

Participants engaged in 20 2 hour group singing sessions, facilitated by two MTs. *Quantitative data:* no significant differences were found for any measure, including relationship quality (QCPR), satisfaction with life (SWLS), positive aspects of caring (PACQ), depression (PHQ-9) and flourishing (FS). The authors reported that some scores were high at baseline and were mostly maintained over the 20-week intervention period.

The sample size is small and underpowered for a quantitative study (12), and 3 carers dropped out. There is not much consideration for confounding factors, therefore the quality rating given was '**moderate'**, giving the study a limited strength of influence.

Qualitative data: this focused on feedback regarding the appropriateness of the outcome measures, which is not included in this synthesis, as it does not relate directly to wellbeing.

6.Clark et al (2018)

Qualitative data: a fuller account of the qualitative data from the Tamplin et al, 2018, study reported five themes: supportive therapeutic facilitation and design features; made group singing more accessible; fostered new empathic friendships; enhanced relationships between person with dementia and carer; and led to personal feelings of wellbeing for both person with dementia and carer. Following analysis of data for this review, these themes were identified: Happiness, Togetherness and the Role of the Therapist (see supplementary table 6). Again, the MTs facilitating the intervention undertook the interviews, so this may have affected results and performance bias cannot be excluded.

7.Lee et al (2020)

Participants engaged in six 1 hour group singing sessions facilitated by a MT.

Qualitative data: four themes were identified: social connection; happiness and rejuvenation; reconnection with the self; and supporting the carer-cared for relationship. Following analysis of data relating to wellbeing, these themes were identified: Togetherness, Happiness, Relaxation, Confidence, Identity, Music, and the Role of the Therapist (see supplementary table 7).

Only four carers took part in this study, although small sample sizes are acceptable for in-depth qualitative research (Smith et al, 2012). The researcher conducted the interviews, not the MTs, therefore performance bias is less likely to have occurred than in other qualitative data included in this review.

Summary

There was moderate evidence of no significant impact from the quantitative data relating to Group Singing in MT. Qualitative data suggests that this intervention may positively affect wellbeing, particularly in terms of increasing happiness, shared experiences, receiving peer support, increased confidence and strengthening identity. Participants identified aspects of the process which made the intervention successful, including:

- music as a mechanism for encouraging inclusion and relaxation.
- the role of the therapist in facilitating an ethos of inclusion and acceptance.

Studies were small with regards sample size and also small in number (2).

3. Group MT

Two studies reported on a more general application of Group MT: Brotons and Marti (2003) and Raglio et al (2016; papers 9 and 10). In both studies, carers attended alongside the person with dementia. Both included a follow-up period (Brotons and Marti 2003, two months, and Raglio et al, 2016, one month).

9.Brotons and Marti (2003)

Participants engaged in 11 MT sessions, facilitated by MTs.

Quantitative data: no significant difference was found in Caregiver Burden Questionnaire (X2= 9.19, p=0.01), or in the Beck Inventory for depression (X2 = 9.38, p=0.009). The authors did find a significant difference for anxiety in the STAI-S, suggesting carers were less anxious at post-intervention (X2=14.72, p=0.001).

Qualitative data: data relating to carers was minimal, with the authors commenting that the intervention helped them relax and encouraged self-expression.

Again, sample size was small (14) and the intervention took place in a residential setting where other activities and care was provided, making it difficult to attribute the results to MT alone. The quality assessment given was therefore '**weak**', making this study's influence negligible.

10.Raglio et al (2016)

Participants engaged in twelve 40 minute 'Active Music Therapy' sessions, facilitated by a MT.

Quantitative data: positive significant differences were found in results at post-intervention for anxiety and burden, with anxiety scores being maintained at one month follow-up. Only mean scores are given and there is no calculation of effect size, level of significance, or confidence intervals, making the results less reliable. One outcome measure is named as 'The Burden Interview' with no referencing, so it is unclear which tool this is and whether it is a validated measure. Sample size was very small for a quantitative study (4), and the quality assessment rating given was '**weak**', giving this study a negligible strength of influence.

Summary

Due to the poor quality of research with both studies rated as 'weak' these results cannot really contribute to the evidence of effectiveness for MT on wellbeing for carers of people with dementia.

DISCUSSION

The evidence found is not of adequate scientific strength to make any claim that MT does positively affect wellbeing for carers of people with dementia, or not. To explore this further, more research is necessary, with quantitative studies larger in sample size and more rigorous in design, ensuring validated outcome measures, independent assessors, and consideration of confounding factors. More comprehensive reporting, including key information about how studies were conducted and full results, would also improve scientific quality.

However, within this assessment of low scientific quality, there were some promising results showing a decrease in anxiety, depression, burden, and an increase in self-esteem and mental health for carers at post-intervention. Three studies reported a significant decrease in anxiety; only one study gave an effect size, which was moderate (García-Valverde et al, 2020). These aspects that were affected need to be considered within a wider understanding of how participants experience benefit, and the qualitative data offers insight here, with strong themes consistently emerging across the data: 'Togetherness', 'Validation', 'Happiness/Enjoyment', 'Awareness', 'Strength', 'Confidence' and 'Identity'. Importantly, MT provided a 'safe space' (Julia, in Clark et al, 2021) for participants to connect with their emotions and allow these to be expressed

> *It probably unloads …all the emotional feelings that you do hang on to that you don't even realise are there, sometimes it helps to get them out…it was good and it was cathartic.* (Natalie, in Baker and Yeates, 2018, p.13).

Being heard and understood with empathy was viewed as important, and this was sometimes in contrast to general experiences

> *It's pretty isolating and a lot of friends and other people don't understand… Even my siblings don't understand the way they [the group] do* (FCG2, Clark et al, 2018).

Receiving emotional support may increase resilience and wellbeing for carers, whilst also enabling them to continue caring (Balfour, 2020). MT also allowed space for carers to focus on themselves; having 'time for themselves' and 'care for themselves' are two factors identified as contributing towards increased wellbeing and health (Oliveira et al, 2018; Daley et al, 2018, respectively).

Carers appreciated meeting with others *'in the same boat'* (Lotte, in Baker et al, 2018) and developed strong, supportive peer relationships

> *I think that's gone beyond the music, which is fantastic and you go away feeling good because you've been singing but then you've also met all these people that you can just sit*

> *and talk to. That's really important because we form special bonds'* (FCG12, Clark et al, 2018).

For those attending with the person they cared for, there was an appreciation of having something positive to share together

> *It was something that we could do together that was a happy thing* (FCG2, in Clark et al, 2018).

Providing opportunities for shared experiences and connection between couples is also associated with increased wellbeing

> *…continued sense of connection between partners is linked to lower distress levels, lower burden and higher caregiver confidence* (Lewis et al, 2005, cited in Balfour, 2020, p.125).

Group Songwriting in MT

Half (five) of the included papers reported on the use of songwriting in MT. This act of creation and specific inclusion of melody and lyric composition was identified as a facilitator for expressing emotion, and the final product of a finished song was also used as a tool to help carers cope going forward. However, when attending with the person with dementia, this intervention may be more appropriate for early to moderate stages; one person with later stages of dementia was less able to engage with the process (Clark et al, 2020).

Music, Creativity and the Role of the Therapist

Interesting comments from the qualitative data provide reflections on the use of music and creativity and why MT may successfully engage. Music itself was described as a mechanism to enable self-expression, as well as a comforter "*I think this helped to settle her"* (FC4, in Lee et al, 2020). Engaging in musical activity was experienced by some as positive and all-encompassing, removing everyday concerns for a while

> *And we are having fun … You can completely switch off from everything else* (FCG12, in Clark et al, 2018).

Music is acknowledged as a better motivator than words alone, "*with the music, you have to interact… with other people. Even with each other, too"* (Mei, in Clark et al, 2020, p.9)

Music is also a described as inclusive and a leveler, "*We were all doing one thing whether we were good or bad at it"* (FC4, in Lee et al, 2020, p.7).

In some respects, this was a result of the skill of the MTs, who provided facilitation so that all could participate and engage at any level

> *…an environment of acceptance created in this group meant they could continue to access and engage in their lifelong passion for singing* (Clark et al, 2018).

This was partly achieved by choosing appropriate songs and pacing the music and sessions appropriately for group members, "*Having the slower songs made it so much easier"* (Michelle, in Clark et al, 2020, p.9).

Creativity itself was acknowledged as a therapeutic and stimulating process, with one participant directly linking creativity with improved wellbeing and problem solving, "*I've always believed that creativity helps you deal with life's problems"* (Alison, in Baker et al, 2018, p.9).

Key recommendations from these results include the use of creative music interventions, such as songwriting, with a focus on tailoring pace for individuals to ensure inclusivity. A further recommendation is for the employment of Music Therapists to facilitate the interventions, who are trained to tailor sessions to meet individual needs and manage group dynamics, providing safe, therapeutic spaces for people to freely express.

LIMITATIONS

There are several limitations to the included evidence. The papers were from Australia and Europe only, therefore not representing a worldwide perspective. Socio-economic factors, ethnicity and diversity of populations included were largely not reported on.

Most of the research had a primary focus on the person with dementia, with outcomes for carers a secondary concern. People with dementia were most often in early to moderate stages, with only three (from 87) carers looking after someone in later stages of dementia.

Most of the carers were female (54) spouses (60) and lived with the person with dementia, therefore male carers are underrepresented in this review.

With regards the review itself, extensive steps were taken to identify all relevant papers, including contacting UK MT training centres for unpublished papers, and contacting authors directly to request more information or English translations. The search, selection and quality assessment processes were supported by the second author, who provided independent assessments; however, the data synthesis was completed by the first author alone, due to time restraints.

CONCLUSION

There was no strong evidence to suggest that MT supports wellbeing for carers of people with dementia, with quantitative studies limited in strength of influence due to weak to moderate quality assessment ratings. Promising results were found in the qualitative data, suggesting that

MT may positively influence wellbeing, with the specific use of music, the creative process, and the role of the therapist facilitating a 'safe space' for carers to express, be heard, and develop strong, supportive bonds with their peers. Carers are a population group at high risk of poor mental and physical health (NHS, 2019) and providing interventions to support wellbeing may help negate this risk.

More robust research is required; specifically, quantitative studies should employ larger sample sizes with more rigorous design methods, ensuring the use of validated outcome measures, independent assessors, and consideration of confounding factors. In reporting, more comprehensive information is required, particularly regarding confounding factors and results.

Linking outcomes directly to carer physical and mental health is also recommended, to further explore the link between wellbeing and health in this context.

DECLARATION OF INTEREST

The authors report no conflict of interest.

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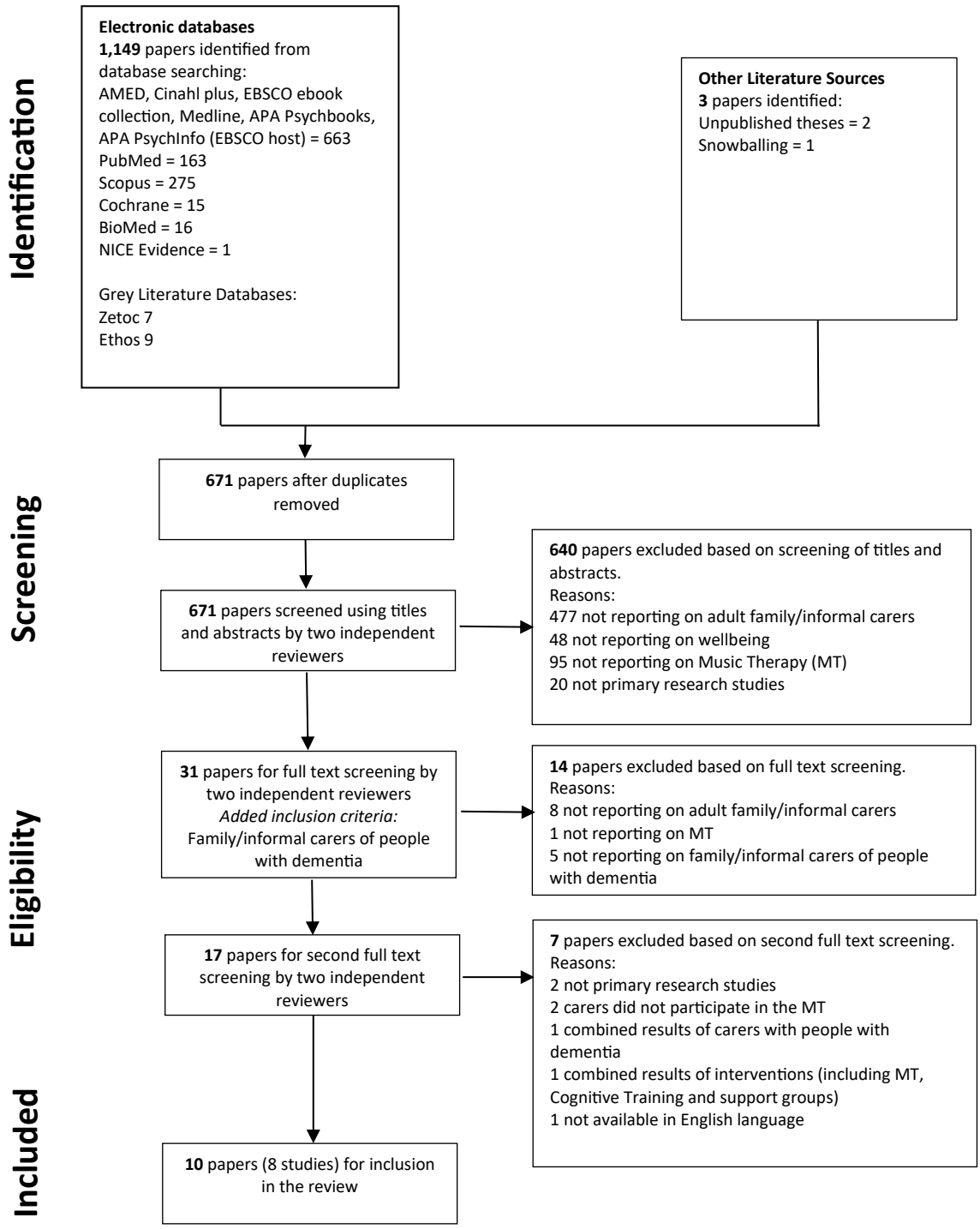


Figure 1. Flow diagram of selection process for included studies.

Appendix 3: Case Summary

Case Two

Maria, Leo, Louisa and Issac - Danny Boy

On first meeting

My first interview with this family was in September 2021, not long after the end of our second national covid lockdown. I remember being greeted at the door by Leo, and invited into the living room to sit at the table with Maria and Leo for our interview. Louisa has advanced dementia; Maria is Louisa's daughter and Leo her grandson. Louisa was asleep upstairs at the time of the interview. Issac (Maria's husband) was also present but working in the kitchen. This is a case that involves a family rather than a couple, and from first meeting I was struck by how close they seemed; very caring towards each other. Maria and Leo are very open and passionate about sharing their experiences with me throughout the three interviews.

Background

Louisa has mixed dementia (Alzheimer's and Vascular) and was referred to Mindsong by the Managing Memory Together team (Gloucestershire Health and Care NHS), to help with stimulation and relief from dementia symptoms. Until very recently Louisa lived on her own, but at the time of our first interview, Leo had just moved into the home to provide 24/7 care, and is with his grandmother most of the time. Paid carers were coming in for additional support but this recently stopped and the family are now providing for all Lousia's care needs. Louisa's dementia is advanced and she is dependent for all aspects of care, with limited conversation.

Louisa lived in [name of country] for nine years and this is where Maria was born. On her return to the UK, Louisa worked as a carer for [name of organisation]. She had an unhappy and abusive first marriage and sadly her second husband died 42 years ago. Louisa had two children, Maria, and Maria's estranged half-brother, and two grandsons, of whom Leo is the younger, aged 23. Maria works to keep both her house and her mother's house up together, as well as providing care for her mother. Maria also has significant health problems herself, including mental ill health and respiratory illness.

First Interview

This is the first of three interviews and the aim is to set the scene; to find out more about the research participants and their experiences of living with dementia, before the MT starts.

Maria sits at the table in the living room with myself, and Leo sits just behind Maria in an armchair. Isaac comes in towards the end of the interview. The camera captures Maria and Leo (and their dog, who comes in and out).

Four main themes were identified from completing IPA on the transcript and video recording of this first interview: Views of the Care System; Threats and Dangers; Identity; Experiences of Dementia - Fear and Loss.

Exploration of themes

Views of the care system

Maria and Leo are passionate in their discussions about this topic. They speak with intensity and pace, often speaking over each other and it feels as if they really do need to tell their story, to have someone listen to their experiences. They both use strong language to communicate disappointment and anger at the lack of support in the system and the way they and Louisa have been treated, including the words: 'diabolical … despicable … abandoned … terrible'. Their experiences have led them to believe that the whole care system is 'systemically broken'.

Their experience as a family, and for Louisa as a person dependent for all care needs, has been negative and they believe has at times resulted in Louisa becoming ill with UTI infections, due to lack of care. An example of this is given where professional carers failed to check Louisa's urine for possible dehydration: 'disgusted and horrified … it's abuse … how easy is it to pick up a white commode, to tip it to the side and check the colour of the pee.'

The lack of support for the family has had some serious consequences, with Leo feeling that he has 'completely lost my life' and Maria attempting suicide: 'I couldn't cope, and it just broke me'. Again, the use of strong language with the words 'completely' 'lost' and 'broke' indicate the significant effects events have had on their lives.

There is a definite feel of 'them and us', with the family believing that because they have stepped in to provide care, they are no longer a priority in the system. Maria speaks of wanting to hold someone to account for the 'huge failures' but not knowing how to do this. The family

have a set of cameras around the house so they can monitor Louisa when they are not there, and feel that this has added to the 'them and us' dynamic: 'we are the enemy because we are the only ones who care, because we have cameras.' Again, the use of the word 'enemy' indicates how strongly Maria feels about the situation.

Maria and Leo believe that being in hospital, and particularly in a care home, would be damaging and detrimental to Louisa's health: 'abandoned in a care home … they'll just dose her up'. The word 'abandoned' has emotional connotations and portrays Maria's strength of feeling against her mother moving into a care home. This view seems to have come from Louisa's own wish not to go into a care home, which 'she is vehemently against' and also views of some of the professional carers; Maria recounts them saying to her: 'the second you put her into a home ... we don't even give her 12 weeks.'

Maria is clear regarding what would help: 'proper, tailored, specialist care' and Leo reinforces this: 'educated care'. They believe that at present the care system is based on monetary gain: 'care is commercial, it's all about the money' and that this needs to change to a system based on respect and dignity: 'there's no care given to her feelings, her dignity, what she would like'.

Threats and Dangers

As well as the dangers expressed regarding the care system and being admitted to hospital or a care home, Maria speaks of threats from people in the neighbourhood, feeling the need to keep Louisa's house looking nice from the outside so that it isn't a target for burglary: 'they were eyeing Mum's house up'. Maria also spoke of her lawnmower being a target: 'they were trying to steal my lawnmower'.

Covid 19 is another threat and Maria feels that being in hospital or a care home would increase that threat for Louisa: 'shove Mum in a hospital, bed-block, covid 19, it's all on the increase again'. The words 'shove' and 'bed-block' indicate Maria's distrust and low expectations of levels of care her mother might experience if she was admitted to hospital.

Identity

Louisa came from a large family and is described by Maria as: 'very, very family orientated'. This resonates with the close-knit family feeling from Maria and Leo throughout the interview. Maria describes her mother as 'a beautiful, beautiful, wonderful lady' but that dementia changes her personality, especially around 'sundowning' times of the day (later in the afternoon or evening): 'when the devil comes in'. The word 'devil' portrays just how stark the

contrast can be from the 'beautiful' presentation Louisa gives when she is calm, earlier in the day. The use of this phrase also indicates an acknowledgement that something is coming in and affecting Louisa, that she is not herself, and that the dementia is causing these difficult experiences.

Maria describes close bonds with her mother and this seems to influence her own identity: 'Mum is my life'. She speaks of a fear of losing her mother: 'when there's nothing ... I don't know how I'm going to cope then' and indeed, when her mother was very poorly in hospital, found herself unable to cope and attempted suicide. This closeness between mother and daughter presents as almost a symbiotic relationship; the health of Louisa intimately linked with Maria's mental health and stability.

In answering a question about her life and relationships, Maria states that she has had 'an awful lot of unpleasant things' happen in her life, and in particular mentioned upsetting experiences with her brother. Maria states: 'I've been a fighter all my life' with the view 'what doesn't kill you makes you stronger'. Leo also confirms that his grandmother, Louisa, has had a hard life: 'she wouldn't get treated nicely' and I wondered if these past experiences are also linking into the present experiences the family are enduring.

Experience of Dementia – Fear and Loss

The family are having a challenging time with experiences due to dementia, and describe the overall experience as 'horrendous'. Maria comments that the changes in her mother are 'heartbreaking', and that her mother as she was, is 'rarely there'. Louisa can become aggressive and violent towards Maria and Leo, and this is hard to bear: 'When she's screaming and shouting and hitting you and you know, it's really hard … it is full on and it does break you.' Again, there is an intensity and passion in the way Maria speaks about this, and the words 'horrendous' and 'heartbreaking' express just how extremely challenging these experiences have been for the family.

Maria and Leo speak of many losses, including relationships where family members have found the dementia experiences too much: 'my uncle ... was going down the same road as my Mum and so he's really distanced himself because I don't think he can cope with going through the rawness of it.' Leo describes the loss of his brother: 'he's been my rock, he's been my best friend my whole life ... and he's just like, washed his hands of her.'

Leo moved into Louisa's home and is looking after her for much of the week, often 24/7. He describes losing his business, friends, girlfriend and opportunities: 'I can't stay, friends ... I haven't had a girlfriend in how long ... I've completely lost my life.' This has been very distressing for Leo and he expresses this with tears and his head in his hands. He expresses fear about not knowing a path for the future: 'I'm terrified.'

This huge loss has been a consequence of caring. The family also express a loss of Louisa herself, and Maria's relationship with her mother is changing, as her mother confuses her with other members of the family that she bears resemblance to. Louisa projects relationships and experiences from the past onto Maria: 'Sometimes she sees me, I'm all of her sisters, I'm her mother ... I'm Mrs Black when she's in a rage.' The name 'Mrs Black' portrays how dark and frightening these moments must feel, for both Maria and Louisa. Past conflicts interact with the present for Louisa, and Maria bears the brunt of this: 'I am the focus of all her memories, her life. Because I look like her sister.' Both Maria and Leo comment on the 'hard life' Louisa has experienced: 'she wouldn't get treated nicely' and understand that these experiences are interacting with her dementia symptoms: 'we all know that she can't help it'.

Second Interview

Watching the Sixth MT Session Together

The aim of this 'Interpersonal Process Recall Interview' (Kettley et al, 2015), is to try and discover how the research participant experiences engaging in the MT. The participant and researcher watch a recording of the sixth session of MT, and the participant comments on the video, with particular reference to how they felt or what they experienced at the time of the session. The transcript from this interview is analysed using IPA, consistent with the other two interviews.

The participant is also supported to choose one significant musical moment for analysis based on the selection criteria 'something important is happening here' (Bond, 2007, see chapter 4 for more information on selection). This selected musical moment becomes another data source for analysis.

This interview took place in Louisa's lounge, with Louisa, Maria and Leo all present. The video was played on the TV, and Louisa was very engaged, watching, sometimes smiling and singing along.

Three themes were identified from IPA on the transcript and video of this interview: Identity; Power of Music; Language and Pace of the interview.

Exploration of Themes

Identity

Maria speaks of a shared identity, using 'we' in reference to herself and her mother's enjoyment of the music: 'we love it, don't we'. As described in the first interview, her mother's state of wellbeing is deeply linked to her own: 'It makes me happy because it makes Mum happy'.

The music seems to reinforce a sense of identity for Louisa; when she is engaged in the music, Maria can see her mother as she used to be, and there is a sense that this upholds their past relationship: 'It brings her back to me ... Mummy again.' Maria describes these moments as 'a gift ... I see all of my Mum again and it's precious.'

The music also appears to uphold Maria's biographical identity, reminding her of memories from childhood, including her father's favourite music: 'my Dad loved Rod Stewart' and of close times with her mother: 'she sang it to me when I was a little girl'. Music has had an important role in Maria's life story; she named her first child 'Danny' because her Mum used to sing 'Danny Boy' to her: 'That's why I named Danny Danny, Mum used to sing it to me every morning.'

Power of Music

Enabling and Empowering

Maria identifies music as providing stimulation for Louisa: 'direct impact on the brain ... stimulus ... reaching so many aspects of her brain'. During the MT sessions, Maria sees Louisa engaging in multiple cognitive processes that doesn't happen at any other time:

> ...this is a real breakthrough. Because there is a complete ability to understand and put different processes together, singing the words, playing in tune, and obviously, being with [therapist's name] as well ... to see Mum use all those different skills, I haven't seen that for a long time.

Musical processing continues beyond session times; on one occasion, Louisa seems to have processed song memory during her sleep, being able to remember and sing a song through in the morning after thinking about it the night before: 'she had the song in her head and literally

she went to bed thinking about the song and starting the thought process and overnight she remembered the whole song.'

Leo comments that Louisa's ability during MT seems to go against the trend of decline due to dementia: 'Nanna's singing and her ability to remember those things are trending in the opposite direction'.

Louisa engages in the present moment through music, and in MT, she is the focus and the centre of interactions. Maria reinforces this during our interview, commenting on the music and saying to her mother: 'You're the star there, love, you're the star'. Music is a positive experience that Louisa can still participate in: 'she can still keep up'.

Relationships

The MT sessions reinforce a sense of identity for Louisa, which is precious to Maria. In turn, this strengthens their relationship, enabling Maria to connect with her mother again as she was: 'I love doing it with Mum, because ... it brings her back to me.' It reminds Maria of times from childhood that are precious: 'she sang it to me when I was a little girl, it's one of our favourite songs'. In the light of the challenges in their relationship when there are times of violence as Louisa confuses Maria for one of her sisters, this is a positive reinforcement of the real and present relationship between Louisa and Maria.

New Learning

Maria speaks of wishing to help Louisa to learn new skills; in the context of music and the capacity that it appears to bring back, she feels this might be possible: 'It's just you need to learn, we need to put the notes on the keys for you so that you can learn'.

Music as a Tool

The MT also provides learning opportunities for the family: 'we've learnt so much through the Music Therapy'. From working with the therapist, the family have learnt how to use music as a distraction tool to lighten Louisa's mood: 'this is the tool that Mindsong has given us ... so that we now have the music to be able to use as a positive tool, to um, deflect situations if we can see a trigger.' This has made a significant difference: 'It's given us the tools to be able to cope as a family'.

Memories and Emotions

Maria states a belief that musical memories are 'imprinted' in the brain, and through these imprints we can access 'all sorts of happy thoughts and memories'. The word 'imprinted' expresses Maria's belief that music can be deeply embedded in the brain, and still accessible despite dementia.

The music accesses many memories for Maria, of happy times in her childhood. She expresses happiness and 'joy' at seeing her mother interact: 'Now this bit fills me with pride [wipes away a tear], it's overwhelmingly beautiful'. The strength of emotion Maria feels about this is expressed not only in her tears but also in her words: 'overwhelmingly beautiful'; a joyful, positive emotion, in stark contrast to the emotions expressed relating to Louisa's care in the previous interview, and to the negative dementia symptoms Louisa and her family endure.

Maria comments that for everyone, singing 'releases endorphins or whatever and everybody else feels happy and you know, singing does make you happy'. And that happiness is the most important thing: 'It's not about what you sound like really, is it, ... It's about ... it makes you happy to sing, doesn't it darling' *[looks at her mother]*.

Recommendations

Maria and Leo suggest developing community singing groups to bring people together and provide support and connection in the local area. They believe music could alleviate loneliness for people:

> Loneliness is a big, big key to depression and of course, state of mind, and with singing therapy if there were a couple of people in the area that could all come and meet …. a group of people could form a friendship so they don't feel so lonely.

The importance of community and support for and from other people is a key part of their thinking:

> It would bring families like us, who feel very isolated, um in with other people locally, and maybe that could be a local support structure for a group, if say I'm stuck in [name of location], and can't get here for some reason, you know, I've made friends with somebody in the same situation they could maybe do me a favour. You know, and the favour could be returned because, you know, it's bringing back that community spirit. And helping to share the load.

Leo suggests an interesting concept: ’70-year-old memory of community;’ alluding to how important community and communal memory is for older people. This seems especially pertinent as these interviews took place during the Covid 19 pandemic, where meeting together as a community was not possible.

Language and pace of the interview

It was interesting to note that the pace and dynamic intensity of this interview was very different to that of the first. This interview felt calmer, at a slower pace, with Maria, Leo and Louisa taking time to watch and engage with the video, listening to each other and with fewer moments of talking over each other. The language used is much more positive, with words and phrases such as ‘Overwhelmingly beautiful’; ‘pride’ ‘breakthrough’ ‘lovely’ ‘enjoying’ ‘gorgeous’ ‘vital’ ‘blew me away’ ‘amazing’ ‘remarkable’ being used to describe the music and Louisa’s engagement with it. This is in stark contrast to the use of language referring to support services and standards of care in our first interview.

Music Microanalysis

This is a summary of results from the microanalysis.
Time code from video of sixth MT session: 14:58 – 18:54
‘Danny Boy’, trad. English / Irish folk song

Maria and Leo chose this song for analysis because of the cognitive ability Louisa shows in her singing and playing, and its emotional importance for them as a family; Louisa used to sing it to Maria as a child, and Maria named her eldest son after this song.

Description of the Context

This song comes near the start of the MT session, at 15 minutes in. Louisa is sat at the table, with a glockenspiel in front of her and a beater in her hand. Maria is sitting in the chair behind her, and Sally (the Music Therapist), sits opposite Louisa with her guitar, out of the picture captured by the video camera. Louisa had just been playing the glockenspiel with Sally accompanying on guitar. When Louisa stops playing, Sally suggests they have a song, mentioning ‘Danny Boy’. Louisa begins to play it on glockenspiel, mouthing the words, and then begins to sing.

Brief Description of the Music

Louisa begins to sing ‘Oh Danny Boy’, matching the key that Sally is gently playing on guitar. She also plays the glockenspiel, picking out the rhythm of the melody. Louisa hesitates after

the first line, looking at the glockenspiel and seeming to not know what to play. Sally suggests: 'shall we start it together?' and begins to sing. Louisa looks up at Sally, then joins in, singing with her and playing the glockenspiel, again picking out the rhythm of the melody.

The music is gentle and there feels a warmth of sound throughout. The bright G major key and consistent rhythmic picking from Sally's guitar hold the song at a steady pace, but there is also flexibility in pacing, with some rallentandos (slowing up), especially when Louisa appears to need more time to take a breath. Sally's guitar playing and singing is gentle and very warm, and Louisa's singing and playing sits over the top of this, being slightly louder in dynamic. Maria occasionally joins in; her singing is also gentle. There is a thread of musical connection between Louisa, Maria and Sally which feels fragile but beautiful.

Louisa is aware of Maria's presence throughout, despite Maria sitting behind her mother, out of her sight and also mostly out of sight on the video. At two points, Louisa verbally calls to Maria, saying 'Come on [name]' to encourage Maria to join in, and then later to both Sally and Maria: 'Come on girls'. At moments, the music brings out Louisa's sense of humour. She changes the words in the last line of verse one, singing 'you can't use up!' then looks up at Sally and laughs a little, and Sally laughs too. Louisa turns to Maria as well, as if trying to bring her in on the joke. She offers the glockenspiel to Sally: 'do you want to have a go?' and Maria encourages her to continue singing. Following a clearing of her throat, Lousia says 'pardon me for being rude, it was not me, it was my food!' and then continues to join in, singing and playing.

Towards the end of the song, Louisa seems tired and says 'I can't', and this seems to reflect her physical frailty and vulnerability. Maria encourages her: 'Come on Mum, I don't know the words', and Louisa joins in, singing again with Sally to the end of the song.

Therapist Techniques

The choice of this song is significant, as it holds many family memories for both Louisa and Maria. Maria remembers her mother singing it to her as a child, and has even named her eldest son after the song. Suggesting a familiar song that holds emotional significance increases the chance of connection for Louisa. It also strengthens and upholds the relationship between Louisa and Maria, acknowledging shared past experiences but also providing a shared experience in the present moment.

Sally plays in G major, the key they had been playing in previously, and the key in which Louisa starts singing the song. Sally plays at a gentle pace, giving Louisa time to remember the song and join in with the singing. Louisa is physically quite frail, and Sally's pacing also allows for moments where she needs more time, sometimes for breathing, and at other times where Louisa just seems to need a moment.

Sally sings with a warm, present tone, loud enough to encourage Louisa to sing, but still allowing Louisa's voice to be louder and more present in the texture. At times when Louisa stops singing (for example at the beginning of the second verse), Sally continues, and Louisa looks up at her and then joins in again. By continuing, Sally is inviting Louisa to join her, and Louisa does so.

Discussion

These four minutes of music reflect many of the themes found in the IPA. The song is part of the family's shared identity and history, and hence, engaging in the moment together provides opportunities to uphold and strengthen the relationship between mother and daughter, especially as Louisa is very aware of Maria's presence, and calls her by name to join in with her. This resonates with Maria's belief that the music brings Louisa back to her: 'It brings her back to me ... Mummy again'.

The music brings out aspects of Louisa's identity; there is a warmth to the whole experience, a willingness to engage with others and encourage them, a sense of humour, and an expressive musicality. This echoes Maria's comment in the interview: 'I see all of my Mum again and it's precious.' The music also reflects how physically frail and vulnerable Louisa is at present (and this is true for Maria too).

Cognitively, Louisa is very much engaging in the present moment, and uses many different skills at once to interact, including singing, playing, interacting with Sally and Maria, initiating the song and moments of humour and joint interaction. Louisa recognises Maria as her daughter and responds to her in a loving and inclusive way. As Maria says in our interview, there aren't many times when her mother can engage in so many different cognitive processes at the same time:

> ...this is a real breakthrough. Because there is a complete ability to understand and put different processes together, singing the words, playing in tune, and obviously, being with Sally as well... to see Mum use all those different skills, I haven't seen that for a long time.

Sally's singing and playing is beautiful, warm and inviting, sitting underneath Louisa's music in a holding and supporting manner, with pacing focussed on enabling Louisa to interact. This person-centredness is reflective of how the family are focussed on providing the best care they can for Louisa, which is often at great personal cost.

The MT addresses all of Kitwood's flower petals:

Attachment: Louisa recognises Maria as her daughter and is aware she is with her throughout, despite Maria sitting behind her. Louisa has a trusting relationship with the therapist, engaging with her and allowing her support.

Comfort: There is a warmth in the music, in the therapist's singing and guitar playing, but in Louisa's too. The therapist plays at Louisa's pace, pausing for her at times, facilitating her interaction.

Identity: This is a family song; Louisa sang it to Maria when she was young and Maria named her first son 'Danny' after this song. Louisa's sense of humour comes out in the song.

Occupation: This is a meaningful moment of connection; Louisa is singing and playing, using more cognitive skills than Maria sees at any other time.

Inclusion: The therapist uses techniques to best engage and include Louisa, most significantly in her pacing.

Love: There is love expressed as Louisa calls for Maria to join in. The fragile thread of musical connection between Louisa, Maria and Sally seems to express a feeling of warmth and love between the trio.

Third Interview

Reflecting on the whole MT experience

The purpose of this interview is to ask the participants to reflect on the experience of MT as a whole, having completed 12 weekly sessions. The interview took place in Louisa's living room, with Maria and Leo both present. Louisa was asleep upstairs.

This is a shorter interview than the other two, and most of the questions are focussed on trying to discover how Maria and Leo found the experience of engaging in the MT with Louisa.

Three themes were identified from IPA on the transcript and video of this interview: Impact of Physical Health, Covid 19 Impact and Benefits of MT.

Exploration of themes

Impact of Physical Health

Whilst Maria provides much of the care for her mother, she is not well herself and at the point of this third interview was recovering from a bout of physical illness, which she didn't describe but seemed to be linked to ongoing chest and blood pressure issues. When she is not well it makes the caring role much harder: 'Since Christmas... I haven't been very well, and that's put an awful lot of extra strain on.' She has engaged extra paid help to assist with the physical side of caring.

Covid Impact

Because of the present threat of covid, the therapist delivers MT in a mask (at the family's request) and this impacts on Louisa's ability to engage; Leo suggests that Louisa is unable to see the therapist's mouth when she sings and is sometimes unaware that it's her that's singing. However, when prompted Louisa still joins in.

Benefits of MT

In this interview, both Leo and Maria suggest that their happiness is deeply linked to Louisa's:

Leo: more than anything it's good to see her smile

Maria: When she's happy we're happy

The act of caring is easier for the family when Louisa is happy, therefore directly impacting on their own wellbeing:

> You know, it makes life so much easier you know, just, cause somebody that's happy is easy, and when somebody's upset and angry then life is very fractious and it makes life so much harder.

Engaging in the MT sessions with his grandmother has encouraged Leo to get back into music-making, which he is doing much more of now. This seems to be engaging him cognitively 'just remembering the chords' as well as bringing benefits to his mental and physical health:

> Maria: Well, that's positive for your mental health, isn't it, because you're getting back into music again yourself,
>
> Leo: it's also been helping my arthritis in my hand as well.

But the music-making can also highlight difficulties,

> One negative, which I don't suppose is negative, but, because of my arthritis in this finger, doing a bar chord and then going to type, [laughs] means I've been ghosting my keyboard effectively, so I've got [stutters] in my typing, none of it makes any sense!

The family have learnt much from the MT sessions and use music at other times of the day to engage, distract, calm or enliven. Maria comments that music is 'the only real connection that she's had'. The family use music in aiding and promoting mobility and stability:

> We sing little songs all the time to motivate her to move around … because it's the basic rhythm for her to want to patter, and you know when she, when she comes and gets up from the chair, you know you can have a little dance with her and have a little singsong with her and, which also makes her feel more stable.

With the use of the word 'patter' you can almost feel the movement Louisa, Maria and Leo make as they gently dance together. Maria acknowledges that more movement is good for Louisa's overall physical health: 'any movement is better than no movement, especially at the point which she is with her arthritis.'

Maria and Leo both express that the MT sessions have encouraged them to 'think outside the box' when it comes to caring for Louisa, not only using music as a tool but also thinking more broadly about Louisa's wellbeing, the triggers that upset her, and how she is physically: 'It's given us ideas, and it's shown us where her triggers truly are.'

Knowing the things that trigger upsetting times for Louisa has helped the family to avoid them. There is also a sense that through the experience of MT, the family have come to know Louisa more deeply as she is at present, and have heightened recognition of when things might not be right physically:

> … and it also means that we're far more aware when there is something medically wrong as opposed to just mood, or you know, overheating, dehydration, we can really tell so much easier, what it is going on.

The family spend much time and energy focused on Louisa's happiness, and Leo comments that it's as if his grandmother is 'in a Disney movie basically', controlling the environment to remove as many triggers as possible and using music and songs to motivate and help Louisa to move: 'whistle while you work'. This exemplifies the great lengths the family go to, to try to ensure Louisa's wellbeing and happiness.

I noticed that when Maria and Leo talk about the music and its effect on Louisa, their language is very positive, in stark contrast to interview one, where they express disappointment and anger regarding their experiences of the care system. Leo describes his interactions with his grandmother during the sessions as 'absolutely lovely' and 'great fun'. Maria describes the effects for her son as an 'extra positive ... ripple effect'.

In other descriptions about the sessions or the music the words used are often gentle, and sometimes evoke a child-like feel, for example: 'cuddle', 'singsong', 'dance' 'ding-dong'. This resonates with Maria's comments that she sees 'Mummy again', reinforcing the mother-daughter relationship, but almost in a child-like way.

Both describe very positive effects of the MT, summing up the experience as 'fantastic' and 'incredible'.

Conclusion

This family has experienced extremely challenging times, both in navigating the care system and in responding to the complex dementia symptoms Louisa experiences. The impact has had a significant effect on Maria's mental and physical health, and Leo has put his life on hold while he cares for his grandmother.

MT, in contrast, has been a very positive experience, reinforcing identity for Louisa, strengthening her relationships with her family, providing shared experiences in the present moment during which Louisa is able to engage and interact at a higher level of cognitive ability than at any other time. The family have learnt to use music as a tool to help them identify and pre-empt difficult situations, as well as manage Louisa's dementia symptoms.

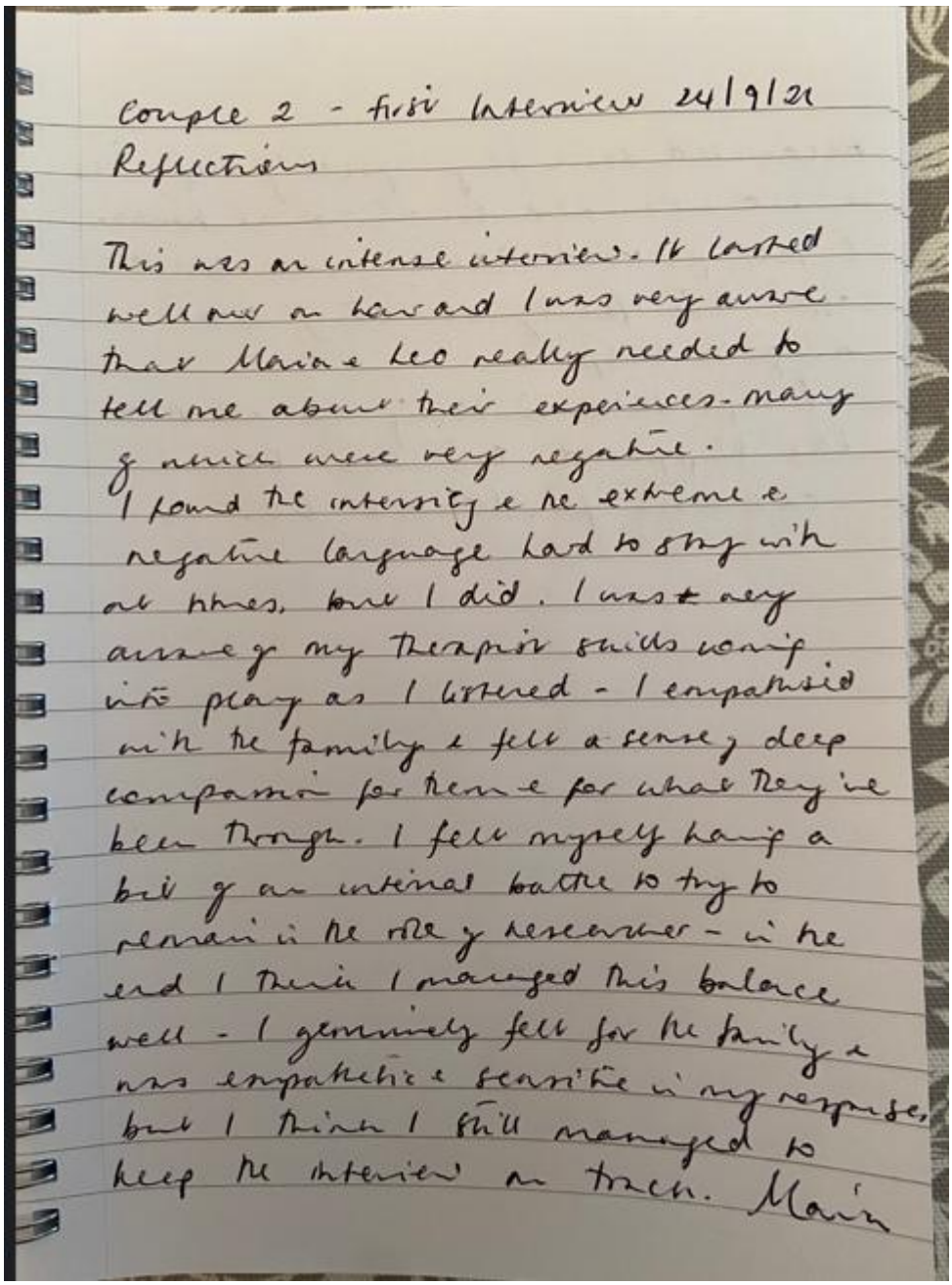
The MT clip reflects some of the main themes identified in the IPA, including identity, relationships, and improved cognitive processing. In our final interview, Maria recommends MT as a service for all who live with dementia and have a connection with music:

> It really is fantastic, everything about this particular, about music, and its influence on Mum, is amazing. And I think it should be, it should be available to everybody with dementia and Alzheimer's who have got that inclination.

Postlude

Sadly, Louisa died not long after her course of MT. She was at home and the family gave palliative care. I've spoken to Maria since, and she said in the last days together, they would lie beside Louisa and sing to her, and this would give Louisa moments of clarity, within which she was able to say goodbye. The music seems to have been a precious gift for this family, and Maria said in a phone call to me 'You [Mindsong] were the brightness in a very dark time'.

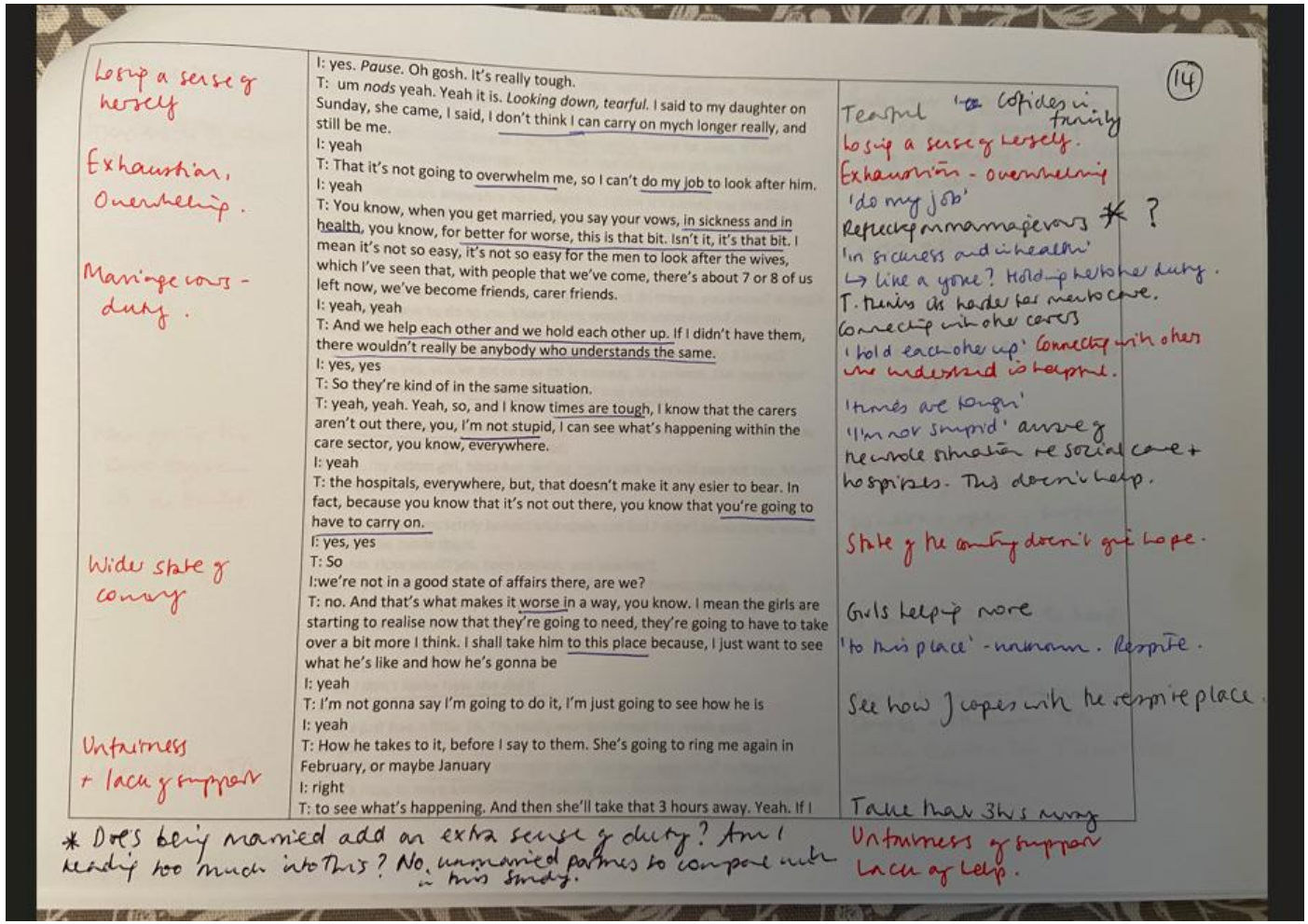
Appendix 4: Example from Reflective Journal



Couple 2 - first interview 24/9/21
Reflections

This was an intense interview. It lasted well over an hour and I was very aware that Maria & Leo really needed to tell me about their experiences. Many of which were very negative.
I found the intensity & the extreme & negative language hard to stay with at times, but I did. I was very aware of my therapist skills coming into play as I listened - I empathised with the family & felt a sense of deep compassion for them & for what they've been through. I felt myself having a bit of an internal battle to try to remain in the role of researcher - in the end I think I managed this balance well - I genuinely felt for the family & was empathetic & sensitive in my response, but I think I still managed to keep the interview on track. Maria

Appendix 5: Example from Transcript Questioning Thoughts



losing a sense of herself

Exhaustion, Overwhelm.

Marriage vows - duty.

Wider state of country

Untruness + lack of support

I: yes. *Pause.* Oh gosh. It's really tough.
T: um *nods* yeah. Yeah it is. *Looking down, tearful.* I said to my daughter on Sunday, she came, I said, I don't think I can carry on mych longer really, and still be me.
I: yeah
T: That it's not going to overwhelm me, so I can't do my job to look after him.
I: yeah
T: You know, when you get married, you say your vows, in sickness and in health, you know, for better for worse, this is that bit. Isn't it, it's that bit. I mean it's not so easy, it's not so easy for the men to look after the wives, which I've seen that, with people that we've come, there's about 7 or 8 of us left now, we've become friends, carer friends.
I: yeah, yeah
T: And we help each other and we hold each other up. If I didn't have them, there wouldn't really be anybody who understands the same.
I: yes, yes
T: So they're kind of in the same situation.
T: yeah, yeah. Yeah, so, and I know times are tough, I know that the carers aren't out there, you, I'm not stupid, I can see what's happening within the care sector, you know, everywhere.
I: yeah
T: the hospitals, everywhere, but, that doesn't make it any esier to bear. In fact, because you know that it's not out there, you know that you're going to have to carry on.
I: yes, yes
T: So
I:we're not in a good state of affairs there, are we?
T: no. And that's what makes it worse in a way, you know. I mean the girls are starting to realise now that they're going to need, they're going to have to take over a bit more I think. I shall take him to this place because, I just want to see what he's like and how he's gonna be
I: yeah
T: I'm not gonna say I'm going to do it, I'm just going to see how he is
I: yeah
T: How he takes to it, before I say to them. She's going to ring me again in February, or maybe January
I: right
T: to see what's happening. And then she'll take that 3 hours away. Yeah. If I

(14)

Tearful ← copes in family
losing a sense of herself.
Exhaustion - overwhelming
'do my job'
Reflecting on marriage vows * ?
'in sickness and in health'
↳ like a yoke? Hold up her/his/her duty.
T. thinks it's harder for men to care.
Connecting with other carers
'I hold each other up' Connecting with others who understand is helpful.
'times are tough'
'I'm not stupid' aware of current situation re social care + hospitals. This doesn't help.
State of the country doesn't give hope.
Girls helping more
'to this place' - unknown. Respite.
See how J copes with the respite place.
Take that 3hrs away
Untruness of support
Lack of help.

* Does being married add an extra sense of duty? Am I reading too much into this? No, unmarried partners to compare with in this study.

Appendix 6: Ethical Approval Letters

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

Ariennir gan Lywodraeth Cymru
Funded by Welsh Government

Wales Research Ethics Committee 1
Cardiff

Mailing address:
[redacted]
email: [redacted]
website: ww.hra.nhs.uk

Please note:

This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites until you receive HRA/HCRW Approval

10 May 2021

Mrs Margaret L Grady
Post Graduate Research Student
[redacted]

Dear Mrs Grady

Study title:	**How do family carers of people with late-stage / complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?**
REC reference:	**21/WA/0109**
IRAS project ID:	**286118**

Thank you for your letter of 06 May 2021, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005 (England and Wales)

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005 (England and Wales). The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: https://www.hra.nhs.uk/planning-and-improving- research/research-planning/research-registration-research-project-identifiers/

If you have not already included registration details in your IRAS application form, you should notify the REC of the registration details as soon as possible.

Further guidance on registration is available at: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Covering letter on headed paper [8. Covering Letter for Potential Participants]	-	16 March 2021
Covering letter on headed paper [6. Covering Letter]	-	17 March 2021
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [25. Evidence of insurance 1]	-	17 March 2021
GP/consultant information sheets or letters [16. GP referrer information letter]	V1	17 March 2021
Interview schedules or topic guides for participants [17. Interview Schedule V2]	V2	05 May 2021

Letter from sponsor [24. Letter from Sponsor]		17 March 2021
Letters of invitation to participant [4. Letter of Invitation to Participants]	V1	17 March 2021
Non-NHS/HSC Site Assessment Form [19. UWE Risk Assessment Form]	V1	17 March 2021
Other [2. Study Protocol B]	V1	16 March 2021
Other [4. CV Gary Christopher]	V1	16 March 2021
Other [10. Covering Letter for Potential Music Therapists]	V1	16 March 2021
Other [11. Participant Privacy Notice]	V1	16 March 2021
Other [24. Research Data Management Plan]	V1	16 March 2021
Other [25. Data Protection Impact Assessment]	V1	16 March 2021
Other [26. Mindsong Safeguarding Policy]	V1	24 June 2020
Other [27. Contract agreement of collaboration with Mindsong]	V1	29 September 2020
Other [30. Mindsong Information Document]	V1	16 March 2021
Other [31. References List for IRAS]	V1	16 March 2021
Other [29. Evidence of Sponsor insurance or indemnity 2]	V1	16 March 2021
Other [29. Evidence of Sponsor insurance or indemnity 3]	V1	01 August 2020
Other [23. UWE Risk Assessment Form]	V1	
Other [confirmation of no NHS involvement]		17 March 2021
Other [3. CV Gary Christopher]	V1	17 March 2021
Other [5. Mindsong Consent to share details]	V1	17 March 2021
Other [10. Covering letter potential music therapists]	V1	17 March 2021
Other [11. Participant Privacy Notice]	V1	17 March 2021
Other [20. Research Data Management Plan]	V1	17 March 2021
Other [21. Data Impact Assessment Form]	V1	17 March 2021
Other [22. Mindsong Safeguarding Policy]	V1	17 March 2021
Other [23. Contract of collaboration with Mindsong]	V1	17 March 2021
Other [25. Evidence of Insurance 2]	V1	17 March 2021
Other [25. Evidence of Insurance 3]	V1	17 March 2021
Other [26. Mindsong Information Document]	V1	17 March 2021
Other [27. Reference List for IRAS]	V1	17 March 2021
Other [28. Data sharing agreement]	V1	17 March 2021
Other [IRAS Responses]	V1	05 May 2021
Participant consent form [6. Mindsong consent to share]	V1	16 March 2021
Participant consent form [14. Consultee information sheet and declaration form]	V1	16 March 2021
Participant consent form [16. Participant Consent Form - Family Carers]	V1	16 March 2021
Participant consent form [17. Participant Consent Form - Music Therapists]	V1	16 March 2021
Participant consent form [18. Protocol B Consent Form - Family Carers]	V1	16 March 2021
Participant consent form [19. Protocol B Consent Form - Music Therapists]	V1	16 March 2021
Participant consent form [13. Consent Form A - Family Carers]	V2	05 May 2021
Participant consent form [14. Consent Form B - Person with dementia]	V1	05 May 2021
Participant consent form [15. Consent Form C - Music Therapists]	V2	05 May 2021
Participant information sheet (PIS) [7. Participation Information Sheet]	V1	16 March 2021
Participant information sheet (PIS) [9. Music Therapists Participation Information Sheet]	V1	16 March 2021

Participant information sheet (PIS) [12. Protocol B Participation Information Sheet]	V1	16 March 2021
Participant information sheet (PIS) [13. Music Therapists Protocol B Participation Information Sheet]	V1	16 March 2021
Participant information sheet (PIS) [7. PIS A Family Carers]	V2	05 May 2021
Participant information sheet (PIS) [8. PIS B Person with dementia]	V1	05 May 2021
Participant information sheet (PIS) [9. PIS C Music Therapists]	V2	05 May 2021
Participant information sheet (PIS) [12. Consultee Information and Declaration Sheets]	V2	05 May 2021
REC Application Form [REC_Form_17032021]	-	17 March 2021
Referee's report or other scientific critique report [22. UWE Endorsement Report]	-	03 November 2020
Referee's report or other scientific critique report [18. UWE endorsement report]	-	17 March 2021
Research protocol or project proposal [1. Study Protocol A]	V1	16 March 2021
Research protocol or project proposal [1. Study Protocol]	V2	05 May 2021
Response to Request for Further Information	-	06 May 2021
Summary CV for Chief Investigator (CI) [3. CV Maggie Grady]	-	17 March 2021
Summary CV for supervisor (student research) [3. CV Warner]	-	17 March 2021
Summary, synopsis or diagram (flowchart) of protocol in non technical language [2. Flowchart]	V1	17 March 2021

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality- assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 286118 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project. Yours

sincerely,

[redacted]

Dr Catherine J Craig Nurse
Chair, Wales REC 1 e-mail: [redacted]

Faculty of Health & Applied Sciences Glenside Campus Blackberry Hill Stapleton

Bristol BS16 1DD Tel: [redacted]

Our ref: JW/lt 3rd June 2021

Maggie Grady

Dear Maggie

Application Number: HAS.21.05.150

Application title: How do family carers of people with late-stage / complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?

REC reference: 21/WA/0109 IRAS project ID: 286118

Your NHS Ethics application and approval conditions have been considered by the Faculty Research Ethics Committee on behalf of the University. It has been given ethical approval to proceed with the following conditions:

- You comply with the conditions of the NHS Ethics approval.
- You notify the Faculty Research Ethics Committee of any further correspondence with the NHS Ethics Committee.
- You must notify the Faculty Research Ethics Committee in advance if you wish to make any significant amendments to the original application.
- If you have to terminate your research before completion, please inform the Faculty Research Ethics Committee within 14 days, indicating the reasons.
- Please notify the Faculty Research Ethics Committee if there are any serious events or developments in the research that have an ethical dimension.
- Any changes to the study protocol, which have an ethical dimension, will need to be approved by the Faculty Research Ethics Committee. You should send details of any such amendments to the committee with an explanation of the reason for the proposed changes. Any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee.
- Please note that the Research Ethics Sub-Committee (RESC) is required to monitor and audit the ethical conduct of research involving human participants, data and tissueconducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the RESC and its committees.

Please note that your study should not commence at any NHS site until you have obtained final management approval from the R&D department for the relevant NHS care organisation. A copy of the approval letter(s) must be forwarded to Leigh Taylor in line with Research Governance requirements.

Please note: In light of the current situation regarding COVID-19, we can only authorise an immediate start for activities that do not breach either national laws or University policies (for further information please click on the following link https://intranet.uwe.ac.uk/tasks- guides/Guide/research-and-enterprise-covid-19-

information#part1). In these uncertain times, law and policy may change swiftly and frequently. We are, however, continuing to scrutinise and grant ethical approval for activities that cannot take place at present, to ensure that once the situation changes and activities can go ahead, the research is not unnecessarily delayed.

What this means for your application:

1. If your application DOES NOT involve activities affected by the current crisis (e.g. online surveys or telephone interviews etc.) then you may start your research as soon as you receive this formal notification of your ethical approval;
2. If your application DOES involve activities affected by the current crisis then you must not start your research until you are lawfully and safely able to do so, and when it does not breach the University's policies. This will affect the dates you have supplied on your application form in relation to start and finish. When you have new dates, please can you write to us in order that we can add this information to your file?

If you are a doctoral student and this will affect your research timetable, please speak to your Director of Studies and the Graduate School for advice on how time delays will be supported by the University.

The Faculty and Research Ethics Sub-Committees (FRECs and RESC) are here to advise researchers on the ethical conduct of research projects and to approve projects that meet UWE's ethical standards. Please note that we are unable to give advice in relation to legal issues, including health and safety, privacy or data protection (including GDPR) compliance Whilst we will use our best endeavours to identify and notify you of any obvious legal issues that arise in an application, the lead researcher remains responsible for ensuring that the project complies with UWE's policies, and with relevant legislation https://intranet.uwe.ac.uk/whats- happening/sites/gdpr/updates/pages/research-and-gdpr-compliance-update-08-may- 2019.aspx. If you need help with legal issues please contact safety@uwe.ac.uk (for Health and Safety advice), data.protection@uwe.ac.uk (for data protection, GDPR and privacy advice).

Please remember to populate the HAS Research Governance Record with your ethics outcome via the following link: https://teams.uwe.ac.uk/sites/HASgovernance.

We wish you well with your research. Yours sincerely

Dr [redacted]
Faculty Research Ethics Committee
[redacted]

c.c. Cathy Warner

Appendix 7: Study Protocol

(including changes in green in case research takes place within a covid lockdown)

1. Study Protocol

This protocol has regard for the HRA guidance and order of content

Text in green indicates changes that would be followed if Covid 19 restrictions are in place at time of data collection.

FULL/LONG TITLE OF THE STUDY

How do family carers of people with advanced / complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?

SHORT STUDY TITLE / ACRONYM

Experiences of family carers of people with dementia and Music Therapy

PROTOCOL VERSION NUMBER AND DATE

- Version 0.2 May 2021

RESEARCH REFERENCE NUMBERS

IRAS Number: 286118

SPONSORS Number:

FUNDERS Number:

SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor

I also confirm that I will make the findings of the study publicly available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

For and on behalf of the Study Sponsor:

Signature:	Date:
Name (please print): Professor Olena Doran	Position: Associate Dean (Research), Faculty of Health and Applied Sciences, University of the West of England, Bristol
Chief Investigator: Signature:	Date:
Name (please print): Margaret Grady	

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KEY STUDY CONTACTS

Chief Investigator	Margaret Grady Tel: Email:
Study Co-ordinator	Dr Catherine Warner Tel: Email:
Sponsor	Professor Olena Doran, Associate Dean (Research), Faculty of Health and Applied Sciences, University of the West of England Bristol BS16 1QY. Tel: e-mail:
Joint-sponsor(s)/co-sponsor(s)	N/A
Funder(s)	Self funded by student (Chief Investigator)
Key Protocol Contributors	Margaret Grady (Student and Chief Investigator) Dr Catherine Warner (Director of Studies, PhD Supervision Team) Dr Gary Christopher (Supervisor, PhD Supervision Team)
Committees	Graduate School, UWE Bristol graduateschool@uwe.ac.uk

STUDY SUMMARY

Study Title	How do family carers of people with late-stage / complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?
Internal ref. no. (or short title)	Experiences of family carers of people with dementia and Music Therapy
Study Design	Qualitative: Interpretative Phenomenological Analysis (IPA) and musical Microanalysis
Study Participants	Family carers of people with late-stage or complex dementia where the person with dementia is still being cared for at home.
Planned Size of Sample (if applicable)	5 - 6 couples (5 or 6 people with late-stage or complex dementia and their primary family carer)
Follow up duration (if applicable)	N/A
Planned Study Period	1/4/2020 – 31/7/2025
Research Question/Aim(s)	How do family carers of people with late-stage / complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?

FUNDING AND SUPPORT IN KIND

FUNDER(S) (Names and contact details of ALL organisations providing funding and/or support in kind for this study)	**FINANCIAL AND NON FINANCIALSUPPORT GIVEN**
UWE, Bristol Professor Olena Doran, Associate Dean (Research), Faculty of Health and Applied Sciences, University of the West of England Bristol BS16 1QY. Tel:	Sponsor for the research. This is a PhD study being undertaken at UWE Bristol, Faculty of Health and Applied Sciences (HAS) (Non-financial support)
PhD Supervision Team Dr Catherine Warner Dr Gary Christopher	Overseeing research and providing guidance and support. (Non-financial support)
Mindsong, Music for Dementia Karen Lawton, CEO	Collaborating organisation. Sourcing participants for the research and providing the Music Therapy intervention. (Non-financial support)

ROLE OF STUDY SPONSOR AND FUNDER

UWE, Bristol, Faculty of Health and Applied Sciences (HAS) is the sponsor of this research. This is a PhD study being undertaken at UWE Bristol (HAS) and the student's Supervision Team will have oversight of the research at every stage. The study will also be subject to UWE's PhD assessment procedures to ensure quality and integrity of the research.

Mindsong is a Gloucestershire-based charity that specialises in supporting people with dementia and their carers through music and Music Therapy www.mindsong.org.uk. Mindsong is the collaborating organisation for this research and will be sourcing participants and providing the intervention (Music Therapy), which is a pre-existing service. Mindsong is not funding any part of the research and will not hold any influence over the study design, conduct, analysis and interpretation, writing, or dissemination of results. Mindsong will not influence or control any of the final decisions regarding any aspects of this study. A letter of agreement between UWE Bristol and Mindsong is attached with this document. A more detailed contract between UWE Bristol and Mindsong will follow once Ethics Approval has been granted.

ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITEES/GROUPS & INDIVIDUALS

The study sponsor (UWE Bristol, HAS) is responsible for overseeing the quality and integrity of the research via the research Supervision Team and UWE's Graduate School's ongoing assessment procedures for PhDs.

The researcher's Supervision Team will supervise, guide and oversee the research project at every stage.

Public involvement has included asking family carers of people with dementia for feedback on Participant Information Sheet, Consultee Information Sheet and Interview Schedules ahead of commencing the study. Feedback has been sought on the following areas:

- Whether the explanation of the study is clear
- Whether the research participants' involvement is clearly explained
- Whether the interview questions are suitable and appropriate

Feedback shaped the final versions of these documents. Family carers involved in this aspect of the research were existing users of Mindsong's 'Music Therapy at Home' service and will therefore not be potential research participants.

KEY WORDS:

Dementia, Alzheimers, Family Carers, Music Therapy,
Carers, Home-based,

STUDY FLOW CHART

Please see document attached.

STUDY PROTOCOL

How do family carers of people with late-stage / complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?

1. BACKGROUND

There is a growing body of research suggesting that Music Therapy is an effective intervention for people with later stages of dementia, supporting wellbeing and quality of life (Hsu et al. 2015, McDermott et al., 2012; Ridder et al., 2013). This is reflected in recently updated NICE Guidelines which suggest Music Therapy as an intervention to support people with dementia (NICE 2019, Dementia QS184). However, there is a paucity of research regarding the effects of Music Therapy for family carers participating alongside the person with dementia they are caring for. Earlier research suggests positive outcomes for family carers engaging in this way; Clair and Ebberts (1997) report that Music Therapy enhanced 'purposeful joint participation' between couples, and Brotons and Marti (2003) found that Music Therapy helped family carers to relax and express their feelings more openly. More recently, Hsu et al. (2015) and Melhuish et al. (2017) report benefits for staff in care homes when engaging in Music Therapy alongside their clients. Baker and Yeates (2018) explore family carers' experiences of group songwriting, and Allan (2018) reports improvements in relationships for people with dementia and their family carers following group music therapy. However, there seems to be no recent literature focussing on the experiences of family carers and how this is affected by engaging in Music Therapy alongside the people they are caring for.

A Systematic Review of literature relating to Family Carers of People with Dementia and Music Therapy is planned as a preparatory stage to this research. This will be carried out between November 2020 – July 2021.

- A brief description of the proposed study

The aim of this research is to highlight the experiences of family carers of people with later stages or complex dementia, and in particular to explore how they experience Music Therapy when participating alongside the person they care for.

Interpretative Phenomenological Analysis (IPA) and Microanalysis of music from Music Therapy sessions will provide a means for deep exploration, allowing emerging themes and concepts to be identified (Smith et al., 2012; Wosch and Wigram, 2007)

- A description of the population to be studied

Family carers of people with late-stage or complex dementia; unpaid, primary carers of people with dementia where both are still living at home.

Research participants will be identified from Mindsong's 'Music Therapy at Home' service; a pre-existing, bespoke service that supports this particular client group. Mindsong is the collaborating organisation for this research. www.mindsong.org.uk

People who have been referred to Mindsong's 'Music Therapy at Home' service will be eligible to participate in the research study. These participants will be:

A couple: a family carer and person with late-stage dementia or dementia with complex symptoms, where the person with dementia is being cared for in their own home.

Family carer is the main carer: this could be a spouse, partner, daughter, son, friend, etc. The family carer is living with the person with dementia and is the primary carer.

The person with dementia will also be involved in the research; music from the Music Therapy sessions, which involves both person with dementia and family carer, will be video recorded and analysed using musical Microanalysis.

Covid 19

The client group this research focuses on is likely to include older people, who are more at risk of Covid 19. It is hoped that by the time of data collection (September 2021) the virus will be more under control and restrictions will have been relaxed further. However, if this is not the case and the country experiences ongoing or further restrictions, the research will be adjusted to interview and deliver therapy in online formats only, via Zoom.

Careful consideration will be given to safeguarding during the online Music Therapy sessions and interviews. Before sessions and interviews begin, the researcher will talk to all participants (including the Music Therapists) about the importance of finding a 'safe space'; a room or space that is private and as free from interruptions as is possible.

All safety features will be enabled to ensure secure meeting space (such as waiting room, password encrypted, personalised meeting invites). Recordings of the interviews and 6th Music Therapy session would be made on Zoom and stored on secure UWE OneDrive, once on UWE OneDrive, the recordings would be deleted from the encrypted devices on which they were made. For more details regarding processes of sharing and storing data, please see section 8.6.

The wellbeing and safety of participants will remain paramount throughout the research study.

2. RATIONALE

The primary aim of this research is to investigate how family carers of people with late-stage or complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they are caring for. This will include any impact the therapy may have on their experience of their caring role.

There are an estimated 670,000 unpaid carers in the UK looking after someone with dementia, saving the economy around £11 billion a year (Alzheimer's Society, 2014; Carer's Trust 2018). The challenges of this complex role can create stress in every area of life, including social, financial, emotional, physical and psychological strain (Alzheimer's Society, 2016; Etters et al., 2008; Newbronner et al., 2013). This affects carers' health and ability to care, which may lead to an earlier admission to care home or hospital for the person with dementia (Etters et al., 2008). Family carers are recognised as a population group at risk, being 'twice as likely' to suffer from poor health to their contemporaries (NHS Long Term Plan 2019 p 42). There is often little attention or support for this particular client group, with carers sometimes feeling that "As a carer you become invisible as a person" (quoted in Oliveira et al., 2018). Attending to their own needs is often difficult, yet if they are not supported, their mental and physical health and that of the person they are caring for are both at risk.

This research intends to focus on carers supporting people with later stages of dementia, or those with complex symptoms. From the researcher's clinical experience, challenges faced by carers in

these particular situations are often compounded by difficulties in leaving the house, due to mobility problems or the amount of confusion that a different environment presents for the person with dementia. This results in community-based services and support groups being inaccessible, and there are very few home-based services to support. The accumulative losses the progression of dementia creates is ongoing, and many carers report caring whilst coping with a living bereavement, or 'dementia grief' (Blandin and Peppin, 2015).

Complex symptoms experienced with diagnosis of Frontotemporal Dementia, Dementia of Lewy Bodies, or causes of Young Onset Dementia can include hallucinations, changes in personality, the loss of inhibitions and empathy, and these symptoms bring further specific challenges for family carers. The incidence of co-morbidities for a person living with dementia is also high, with an estimated figure of 30% of people living with Vascular Dementia or Alzheimer's Disease also experiencing depression, and this figure rising to 40% for those living with dementia as a result of Parkinson's or Huntingdon's diseases (Kitching, 2015). Again, this compounds the challenges of the caring role for family carers.

'Mindsong, Music for Dementia' is a Gloucestershire based charity that delivers home-based Music Therapy for people with late-stage or complex dementia and their family carers and includes developing personalised musical strategies to support day to day care. Results show increases in wellbeing for both person with dementia and family carer, and a decrease in carer stress following the intervention (Melhuish et al., 2019). Examining how and why this intervention supports by looking closely at the experiences of family carers before, during and after the intervention will give greater understanding of the needs of this client group and how these might be supported.

Mindsong works closely with local organisations, including the Gloucestershire Alzheimer's Society branch and Gloucestershire NHS. Receiving NHS funding for the service and attending NHS Dementia Strategy meetings gives the potential for any findings to influence policy and practice at a local level. In publishing the outcomes of the research, the scope of influence may extend further, with potential interest from other music therapists, anyone working in dementia care, and national organisations supporting people with dementia and their carers.

3. THEORETICAL FRAMEWORK

Key words: Qualitative, Relativist, Constructivist, Phenomenology, Idiographic, Interpretivist, Inductive

As a researcher, I feel comfortable working with subjectivity. Resonating with a relativist position, my belief is that reality is constructed from within, where the 'truth' is subjective and all truths or realities are of equal value (Frisby, 2021). One person's truth or reality may be very different from another's. Indeed, the same person may even experience different realities at different times, depending on external influences and experiences at certain points in time. This reflects a constructivist ontology, where a person's reality is built through their experiences and interactions in the world and is constantly changing as they relate to new experiences (Leavy, 2014).

My research question sits firmly within the qualitative paradigm, as I am aiming to look at the lived experiences of family carers of people with dementia as they engage in Music Therapy. I am interested in discovering personal, individual experiences and, again, am dealing with the

subjective; the truth constructed by each individual, which will be affected by their own, unique, individual experiences.

As such, the phenomenon in question is highly complex, influenced by many different factors and deeply personal in nature. Using an inductive approach, starting with the exploration of individual experiences on a micro level and then gradually broadening the lens to look at these experiences in relation to each other, will give a rich and detailed insight into this phenomenon.

I plan to use 'Interpretative Phenomenological Analysis' (IPA) as my methodology, which places the researcher very much in the research alongside the research participants, engaging with them through the interview process. Although I will have an interview schedule, in IPA the aim is to discover rich, personal accounts, and to that end, the interviewer may wander from the schedule depending on the answers given by the research participant. If a different question could uncover a deeper truth, then the researcher will stray from the schedule and ask it, directly influencing the course of the data uncovered (Smith et al., 2009). In interpreting the data, it is also consistent with IPA for the researcher to aim to have an 'insider's perspective' (Conrad, 1987) to interpret from the participant's point of view, but also to stand back and review the data from a more objective perspective (Smith et al., 2009).

In addition, the inclusion of 'microanalysis' of music created within the Music Therapy sessions has the potential to uncover deeper revelations of participants' experiences than verbal interviews alone (Wosch and Wigram, 2007). Musical Microanalysis also allows for a study of interactions between the family carer, person with dementia and therapist within sessions, and ensures the inclusion of the person with dementia in the research. Although, in this case, people with dementia are not the primary focus of the research, they are of course key to the whole context, and improving their quality of care is one of the motivators for this research.

Reflexive Statement

I have worked as a Music Therapist in dementia care for over twelve years and therefore have a lot of clinical experience in this field. My theoretical approach as a therapist in this context is underpinned by the work of Tom Kitwood, particularly his theory of personhood, which suggests that the focus should always be on the person as a holistic being, rather than the dementia diagnosis itself (Kitwood 1997). As expressed in his formula below, Kitwood suggested that a person's experience of dementia (D) is a complex interplay of a number of factors, including personality (P), biography (B), health (H), neurological impairment (NI) and social psychology (SP):

D = P + B + H + NI + SP

(Kitwood, 1993)

This clearly resonates with the constructivist ontology described above.

Whilst this underpinning and clinical experience could be a useful lens during analysis stage, I also need to be very aware of assumptions or pre-conceived ideas I may bring because of this. I need to be able to 'bracket' these away, remaining sufficiently reflexive throughout in order to remain true to the participants' original meaning within the data (Smith et al, 2009).

Potential Conflict of Interest: I (the researcher) am employed by the collaborating organisation, 'Mindsong', on a part time basis and am Director of Music Therapy for Mindsong. Any research conducted would take place outside these employed hours. Both Mindsong and I are aware of the

need to remain impartial and independent throughout the different stages of research. I would not conduct any of the Music Therapy included in this research. An initial letter of agreement between UWE and Mindsong is attached with this protocol, and a contract will follow in time, after Ethics Approval has been granted.

4. RESEARCH QUESTION/AIM(S)

How do family carers of people with late-stage / complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?

The primary aim of this research is to discover personal, lived experiences of family carers of people with late-stage / complex dementia, and how these are affected by engaging in Music Therapy alongside the person they care for.

4.1 Objectives

1. To explore lived experiences of family carers of people with dementia.
2. To explore lived experiences of family carers of people with dementia when they engage in Music Therapy with the person they care for.

4.2 Outcome

An in-depth understanding of some personal, lived experiences of family carers of people with dementia, and how their experiences of caring may be affected by engaging in Music Therapy with the person they care for. This will give an indication as to whether this application of Music Therapy is a suitable intervention to support this particular client group.

A thesis and research papers will be produced to communicate results of the study. Conference presentations will also aid dissemination of results. Results from this study have the potential to influence clinical and policy decisions relating to supporting this client group.

5. STUDY DESIGN and METHODS of DATA COLLECTION AND DATA ANALYSIS

With the aim of exploring and understanding specific experiences, a qualitative approach would best suit this study. *Interpretative Phenomenological Analysis (IPA)* would provide a means for deep exploration, allowing an illumination of relevant themes and concepts to emerge (Smith et al., 2012).

Microanalysis of selected moments of music from the Music Therapy sessions will provide another source of rich, qualitative data for analysis (Wosch and Wigram, 2007).

Data Collection:

Interpretative Phenomenological Analysis (IPA)

In-depth semi-structured interviews will be conducted with each of the family carers (research participants) at three stages:

1. Before the Music Therapy intervention

2. During the Music Therapy intervention at mid-point (after session 6) – IPR interview (see below)
3. After the Music Therapy intervention has finished

Open ended questions will focus on the experiences of the participants and allow each carer to express their thoughts and feelings.

An Interpersonal Process Recall interview (IPR, Kettley et al, 2015) will be conducted at the second stage (during the Music Therapy intervention). This will involve the participant and researcher watching a video replay together of the sixth Music Therapy session. The participant would be encouraged by the researcher to stop the video at any point, reflecting on how he/she felt at that moment in the session. The participant would also be supported to choose a moment in the music to be analysed using microanalysis (see section on microanalysis below).

If Covid 19 restrictions allow, the interviews will take place face to face in each participant's home. This is to make participation easier for the family carer (so that they don't have to find additional care for the person they are caring for in order to take part in the interviews). However, the researcher recognises that taking part in the interviews may impose a burden on family carers and so will work flexibly with each carer to find the most convenient way (for them) of conducting the interviews. This could include having some interviews online or splitting the interviews into two or three shorter sessions if necessary.

If Covid 19 restrictions are in place, interviews would take place online only, via Zoom. **The researcher will set up each Zoom link for the interviews, making sure that all safety features are enabled, including a personalised and password encrypted link, and waiting room enabled (so only the participant and researcher can access the meeting). The researcher will ask for consent to record the interview at the start of each interview (and this will also be covered in the initial consent form). The Zoom recording will then be uploaded to secure UWE OneDrive and then deleted from the encrypted laptop it was made on.**

Participants will be given one to one tech support by a member of the Mindsong team if necessary, in order for them to access this means of communication.

The researcher (Chief Investigator and PhD student) will conduct all interviews, and these will be recorded via Zoom and stored on secure OneDrive via a UWE encrypted laptop, as detailed above.

Face to face interviews would be video recorded onto a UWE encrypted device. Video recording allows body language and facial expressions to be captured as well as dialogue, therefore giving a richer data set than dialogue alone. Consent to video record the interviews will be gained from the family carers at the start of the study, and the researcher will also check again with the family carer at the start of each interview.

The interview schedule for interviews 1 and 3 was developed following guidance from Smith et al (2012). In addition, family carers of people with dementia were asked for their feedback on the interview questions, as to whether they felt they were suitable and appropriate. Their feedback helped to create the final interview schedule.

Transcripts of the interviews will be made by the researcher and member checking may be used to ensure an authentic transcription. The research Supervision Team will also be involved in giving advice and feedback at all stages.

Microanalysis

Video recordings will be made of each research participant's sixth session of Music Therapy. These recordings will be made by the relevant Music Therapists on an encrypted device and shared with the researcher via UWE OneDrive. **If the therapy sessions are online via Zoom (due to Covid 19 restrictions), the sixth session will be recorded on Zoom and shared with the researcher by the relevant Music Therapist using secure UWE OneDrive. The recording will then be stored on secure OneDrive and deleted from the device it was made on.** It is standard policy for Mindsong to record some Music Therapy sessions for purpose of clinical supervision. However, in this case, a video recording of the 6th session for each participant/couple would be used for research purposes. Consent to video record would be gained from the family carers at the start of the study and also, whenever possible, from the person with dementia involved. Although this will be covered in the initial consent form, the therapists will also check at the start of the sixth session that it is ok to record and will show the device to the person with dementia if this helps to aid understanding.

During the IPR interview where the researcher and research participant watch the sixth session of Music Therapy together, the research participant will be asked to select one significant musical moment for analysis based on the selection criteria 'something important is happening here' (Bond, 2007). This selected musical moment (which could be just a few minutes long, or part of a song, or a whole song, or an improvised piece of music), becomes another data source for analysis (see microanalysis section below). Transcripts of the music will be made by the researcher, which will include creating a graphic, notated score for each musical moment. Member checking may be used to validate the authenticity of findings.

Data Analysis:

All stages of analysis will be conducted by the researcher, Margaret Grady. The research Supervision Team will continue to have oversight of the process and give guidance and advice at each stage. The research will also be subject to UWE Bristol HAS ongoing assessment procedures for rigour and quality.

IPA

Each transcribed interview will be analysed looking at different levels of interpretation, as is consistent with IPA methods (Smith et al, 2012). This will include the following steps:

1. Immersing in the data – reading and re-reading the transcription, repeated listening to the interview, bracketing own thoughts and assumptions.
2. Initial noting – alongside the transcription, noting any initial descriptive, linguistic and conceptual comments.
3. Developing emergent themes – looking for themes that are emerging from the comments and original text. Noting these alongside the transcript at the points they occur.
4. Looking for connections across the themes and creating super-ordinate themes where appropriate. Notating evidence from the original transcript alongside.

This is an iterative rather than linear process and may require the researcher to revisit stages at different points. The researcher will be analysing the data using the hermeneutic circle, looking for meaning in its smaller parts (e.g., words, sentences, phrases) as well as the data set as a whole (the whole interview), and how these may interrelate (Smith et al, 2012). The data will also be interpreted within the knowledge of the context, whilst also remaining true to the apparent original meaning of the text.

Each 'case' (analysed interview) will be written up individually.

5. This process will be repeated for each interview.
6. The researcher proposes an extra step here - synthesising results from the second (IPR interview) and the microanalysis of music.
7. Looking for patterns across interview stages – initially, patterns will be explored across all participants' interviews at each stage, (e.g., across all the interviews undertaken at stage 1, before the Music Therapy intervention).
8. Following this stage, the researcher will look for any patterns emerging across the whole data sets.

Microanalysis

Trondalen's approach to musical microanalysis is inspired by both phenomenology and hermeneutics (Trondalen 2007), making it an ideal method to use alongside IPA. Following the selection by the research participant of a section of music, analysis follows a series of steps (some of which are iterative):

10. Acknowledging any known aspects of the case (dementia diagnosis, clinical history, for example) and bracketing these aside so that the researcher can approach the music in an open, unbiased manner.
11. Immersing in the data – repeated listening to the music so that the researcher becomes very familiar with it. This might include a time of 'body listening' (noting any movements that come from listening to the music).
12. Listen again with a focus on structural elements – using a graphic score, notate elements of sound and intensity as experienced and measured in time. This may include style, form, texture, harmony, rhythm, instruments, etc. Note musical relationships between the clients and therapist.
13. Listening again with a focus on how the elements above might relate to any comments or movements made by the participants.
14. Listening again with a focus on looking for the potential effect of the music within the Music Therapy process, e.g., what is the music doing here?
15. 'Phenomenological horizontalisation' (Trondalen 2007) – notating all the themes that have come to light with the aim being to 'dwell within the results so far' (Trondalen, 2007, p202) before bracketing them off.
16. Engage in another open listening, including a body listening. Note any repsonses.
17. 'Phenomenological Matrix' (Trondalen, 2007), summarise the data in terms of: the music, the potential meaning of the music, the potential 'effect' of the music within the therapeutic process.

18. The researcher proposes a further level of analysis here, involving the interaction of the results from the IPA analysis of the second (IPR) interview with the results from the microanalysis - this corresponds with step 6 in the IPA analysis process (as described above).
19. Each 'case' (analysed musical moment) will be written up individually and will feed into steps 7 and 8 of the IPA process.

Further Analysis: A further stage of analysis will synthesise results from the IPA and musical microanalysis. Revelations and insights from both could combine to enrich the understanding of personal experiences, perhaps deepening, corroborating, or even providing contradiction. IPA lends itself to working alongside other qualitative methods (Eatough and Smith, 2017) and combining this with musical microanalysis will create a rich data source for analysis and discussion stages.

The Clinical Intervention

Mindsong's 'Music Therapy at Home' intervention is a pre-existing service for people with late stage / complex dementia and their family carers. Although the researcher will be interviewing family carers about their experiences of participating in this intervention and analysing sections of music from sessions, it is the participants' *experiences* that the researcher is interested in, rather than the intervention itself.

Mindsong Music Therapists will deliver the Music Therapy intervention (and not the researcher). The researcher will transcribe, code and analyse the interviews and music. Again, the research supervisory team will be involved in giving advice and feedback.

6. STUDY SETTING

The researcher will mainly be working from home on a UWE Bristol encrypted laptop. Activities undertaken here will include:

- Accessing referrals from Mindsong for potential research participants – these will be shared using UWE OneDrive.
- Speaking on the phone / via online method to potential participants to explain research study and hear their thoughts about taking part.
- Liaising with the Supervision Team from UWE on aspects of the research via Microsoft Teams.
- Completing a Systematic Review of literature relevant to family carers of people with dementia and music therapy.
- Collecting and storing consent forms from research participants.
- Interviews with the research participants may be conducted online, via Zoom, with the researcher working from home. The researcher will ensure a safe and confidential space whilst conducting the interviews.
- Data collection and storing on encrypted laptop / recording device: making transcriptions of interviews and clips of music therapy sessions.

- Data analysis: analysing interview transcripts and music using IPA and Microanalysis.
- Writing up findings and putting them into context.
- Writing papers for publication and the final thesis.

The researcher will occasionally work from UWE's Glenside Campus if this provides opportunities to meet with the Supervision Team face to face.

If Covid 19 restrictions allow, interviews with the family carers will take place in the research participants' homes. This is to make participation easier for the family carer (so that they don't have to find additional care for the person they are caring for in order to take part in the interviews). If more convenient for the family carers, interviews may take place online, using Zoom. This will also happen if Covid 19 restrictions are in place at time of data collection. Participants will be given technical support to access Zoom by a member of the Mindsong team, if necessary.

The Music Therapy intervention will be delivered by Mindsong Music Therapists (and not the researcher). This will take place in the participants' homes, as is standard procedure for this pre-existing service. If Covid 19 restrictions prevent this, all therapy will take place online via Zoom. The safety and wellbeing of participants will remain paramount throughout the research study.

7. SAMPLE AND RECRUITMENT

7.1 Eligibility criteria

7.1.1 Inclusion criteria

Potential research participants will be identified from Mindsong's 'Music Therapy at Home' service; a pre-existing, bespoke service that supports this particular client group. Mindsong is the collaborating organisation for this research.

This service is well established in Gloucestershire and receives regular referrals from local GPs, Community Dementia Nurses, Mental Health Teams, and Alzheimer's Society Dementia Advisers. People who have been referred to Mindsong's 'Music Therapy at Home' service will be asked if they would like to take part in the research study. These participants will be:

- A couple: a family carer and person with late-stage dementia or dementia with complex symptoms, where the person with dementia is being cared for in their own home.
- The person with dementia would have a formal diagnosis of dementia (of any cause).
- Family carer is the main carer: this could be a spouse, partner, daughter, son, friend.
- The family carer is living with the person with dementia and is the primary carer.
- As Mindsong is a charity operating in Gloucestershire, participants will be from the Gloucestershire area.
- As interviews and therapy may be conducted online, research participants would need access to a computer or tablet and have a basic level of computer literacy. [N.B. Mindsong is able to provide some individual technical support to assist access to Zoom, the preferred method of online delivery.]

7.1.2 Exclusion criteria

- Paid / professional carers
- Those with earlier stages of dementia (i.e., not dependent for care needs)
- Family carers who also have dementia
- Family carers who do not speak English (unless a family member can translate). The researcher is not fluent in any language other than English.
- Family carers with no access to a computer or tablet, or who would find online methods difficult or stressful (even with a level of support).

7.2 Sampling

7.2.1 Size of sample

Five or six couples (five or six people with dementia and their primary family carers) from Mindsong's 'Music Therapy at Home' referrals would be recruited to take part in the research.

Since the intention is to discover detailed accounts of personal experience, a large sample size would be too unwieldy. This study aims to concentrate on producing in-depth data from personal accounts with richness and depth of understanding coming from the many levels of interpretation consistent with IPA research. Smith et al. recommend an ideal sample size of between three and six, this being small enough to manage the amount of data, and large enough for comparisons to be made across the individual accounts (Smith et al., 2012 p.51).

This research is likely to include older people and it is anticipated that there may be some attrition in data due to ill health or death of participants or the people they are caring for. It may be necessary to recruit more participants if this is the case. Incomplete data may still be used with the participant's consent, if this feels appropriate.

7.2.2 Sampling technique

Purposive sampling will provide a sample representative from this particular population. The sample will be derived from Mindsong's referrals to the pre-existing service, 'Music Therapy at Home'.

Mindsong has agreed to be the source for participants for this research study and the researcher has chosen to only recruit from referrals to this service because it is uniquely designed for family carers of people with late stage / complex dementia providing home-based care, and therefore is directly relevant to the research question.

7.3 Recruitment

People referred to Mindsong's 'Music Therapy at Home' service will be asked by Mindsong's Administrator (and not the researcher) if they would be interested in taking part in the research. If they agree, their details will be shared by Mindsong with the researcher using UWE OneDrive. The researcher is also the Director of this service and already has access to the referrals, but for the purpose of this study, potential participants' details who have given consent will be shared with the researcher using UWE OneDrive.

Referral form and initial assessments (already carried out by Mindsong as part of their existing service) will provide information for screening purposes. This will include type of dementia and how this is affecting daily life, giving an indication of challenges and what stage the dementia may be at.

Potential participants will be contacted by phone or online via Zoom to ask if they would like to take part in the research. A participant information sheet with details of the study and their involvement would be given to each potential participant. Potential participants would be encouraged to discuss their decision to take part or not with other family members or friends. A further conversation with the researcher may also be necessary, and the potential participants would be given time (a week) to consider their decision.

7.3.1 Sample identification

The researcher will identify potential participants from Mindsong's referral and initial assessment documents.

The identifiable personal information will include name, contact details, age, gender, type and stage of dementia, and any particular challenges the couple are experiencing. Data from each research participant will be given a random pseudonym by the researcher. This will happen at point of first interview and all data relating to each participant will then be coded with the relevant pseudonym, and all identifiable data removed.

7.3.2 Consent

Informed Consent from Research Participants

For the purpose of this research study there is a collaborating organisation, 'Mindsong' www.mindsong.org.uk

The researcher will be sourcing participants from Mindsong's existing 'Music Therapy at Home' service. Mindsong will be providing the Music Therapy intervention. A letter of agreement to collaborate is attached with this form and a full contract of collaboration will be created from UWE Contracts team once data management plans are in place and ethical approval has been granted (from NHS REC and FREC).

People referred to Mindsong's 'Music Therapy at Home' service will be asked at point of referral if they would be interested in taking part in the research. Mindsong's Administrator (and not the researcher) would ask this question. If yes, they would be asked for consent for the researcher to screen their details in order to identify potential participants for the research study. Details would then be shared from Mindsong to the researcher via secure UWE OneDrive. This will include personal and sensitive data, for example: names, contact details, dementia diagnosis.

Potential participants identified will then be contacted by phone or online method to ask if they would like to take part in the research.

Informed Consent from Family Carers

Informed consent will be gained from the family carers for all aspects of the research, including taking part in the interviews, having a Music Therapy session video recorded, processing data and having results written up or presented (although information at this point will be pseudonymised).

A participant information sheet with details of the study and their involvement would be given to each potential participant. Potential participants would be encouraged to discuss their decision to take part or not with other family members or friends. A further conversation with the researcher may also be necessary, with the opportunity for the potential participant to ask questions about the research and procedures involved. Consent will be recorded on the consent form (document 13).

As well as consent to participate in the research, consent for participants' data to be collected, stored, analysed and presented in the final thesis / papers will also be sought. Only the researcher will see the raw data and will store this on secure, UWE approved OneDrive. Consent will also be sought for the researcher's Supervision Team to view processed data occasionally, for the purpose of giving advice and guidance.

Informed Consent from the Person with Dementia

Wherever possible, informed consent from the person with dementia will be sought. This research focuses on family carers of people with *later stages* or *complex* dementia, however, there may be cases where the person with dementia, although with reduced capacity, may still be able to provide informed consent. In these cases, using the Participation Information Sheet (document 8), the researcher would take time to talk through the research with the person with dementia, and sensitively help them to make sense out of what is being asked. The researcher would encourage them to have conversations with their family / friends before making a decision. If they agreed to take part in the research, they would be asked to complete the consent form (document 14). A visual prompt sheet alongside the Participation Information Sheet may also be useful.

Family Carer acting as Consultee for the Person with Dementia

This is a complex area and where the researcher and family carer believe that capacity to give informed consent is fluctuating or not possible, the family carer would also be asked to consider making a 'consultee declaration' on behalf of the person with dementia. This involves the family carer thinking about participating in the study from the perspective of the person they are caring for, taking into consideration their best interests and any previous decisions the person may have made about taking part in research studies. A consultee information sheet will support the decision-making process, and the family carer would be encouraged to discuss with their wider family / friends before making the decision with the researcher (please see supporting document 12). The consultee declaration form would record the decision to go ahead with the research, should this be the case (document 12).

Seeking Ongoing Consent

In addition to consent being given at the start of the project and recorded on the consent and consultee declaration forms, the Music Therapist will be asked to check with both the family carer and person with dementia at the start of session 6 for consent for the video recording of this

session to go ahead; explanation of this may be aided by showing the recording device. If at any point either say no or show any distress to being recorded, the recording will stop.

The researcher will also check at the start of each interview that the family carer is happy to go ahead and consents to the interview being recorded. This is detailed on the Interview Schedule (document 17).

The participants will be able to withdraw from the study at any time and this will not affect their access to the Music Therapy intervention. Their data can also be withdrawn up to the point of data analysis stage (four months following their agreement to take part). At this point, their data would be anonymised and integrated into the data set and so could not at that point be removed.

Informed Consent from the Music Therapists

The research study will be explained in full to Mindsong's Music Therapy team at the start of the project, and their informed consent to take part will be sought. This will include consent for the video recording, transcribing and analysing of parts of their Music Therapy sessions with the research participants.

As the researcher is Director of Music Therapy for Mindsong, the therapists will be asked if they would like to take part by a different member of the Mindsong team. It will be made clear that there will be absolutely no obligation to take part and their decision will not affect any future employment opportunities from Mindsong. They will also be able to withdraw at any point up until data analysis, and again this will not affect their relationship with Mindsong or any future work opportunities.

8. ETHICAL AND REGULATORY CONSIDERATIONS

8.1 Assessment and management of risk

The Clinical Intervention: The Music Therapy at Home intervention has been designed to be person centred and to support the wellbeing and quality of life of both the person with dementia and family carer, therefore it is anticipated that there will be positive benefits for participants engaging with this intervention.

Mindsong's Music Therapists are specialists in working in dementia care. The researcher (who will be conducting the interviews) is also an experienced Music Therapist with 12 years' experience of working with people with dementia. All Mindsong Music Therapists are DBS checked and attend regular Safeguarding training.

A risk assessment is attached with this protocol, and Mindsong's Safeguarding and Health and Safety policies (the latter which includes a section on lone working).

Interviews with Family Carers: Because the focus of the research is on discovering family carers' experiences, some upsetting material may arise. The researcher will ask the family carers to only respond in interview as openly and honestly as they feel comfortable, stressing that they can stop at any time if they wish to. The researcher conducting the interviews is a qualified Music Therapist, with 12 years of clinical experience in this field, which includes talking to family carers about their

experiences. The interviews will be conducted in a sensitive manner and participants' wellbeing will be paramount.

The interviews provide an opportunity for family carers to tell their story, to explain their thoughts and feelings about their situation and caring role. From the researcher's clinical experience, this has been a positive experience for clients previously worked with. There is a potential for increased self-awareness for the family carer, and the researcher and Music Therapy team involved are well placed to signpost to other support services if this becomes appropriate.

The researcher recognises that taking part in the interviews may impose a burden on family carers and so will work flexibly with each carer to find the most convenient way (for them) of conducting the interviews. This could include having some interviews online or splitting the interviews into two or three shorter sessions if necessary.

Careful consideration will be given to safeguarding during any online Music Therapy sessions and interviews. Before sessions and interviews begin, the researcher will talk to all participants (including the Music Therapists) about the importance of finding a 'safe space'; a room or space that is private and as free from interruptions as is possible. Safety features will be enabled, including using a unique, password encrypted Zoom meeting invitation for each participant.

There are no anticipated disadvantages to taking part in the research. However, if any participant found the intervention or interviews upsetting in any way, they would be offered extra support, and the option of withdrawing from the study giving no reason. Extra support would mean access to a different member of the Mindsong Music Therapy team, who would be available to talk to.

Mindsong has Health & Safety and Safeguarding policies that will be followed by all Music Therapists and the researcher whilst conducting the research. If any disclosure is made during the interviews (e.g., if the carer reveals that he/she is suicidal or gives information about intent to harm others) the researcher will follow the processes highlighted in Mindsong's Safeguarding policy (attached).

8.2 Research Ethics Committee (REC) and other Regulatory review & reports

Full ethical consideration will be given to this research study and an application to NHS Research Ethics Committee (IRAS project ID: 286118) and UWE's Research Ethics Committee is being made. The researcher will ensure the following:

For NHS REC reviewed research

- Substantial amendments that require review by NHS REC will not be implemented until that review is in place and other mechanisms are in place to implement at site.
- All correspondence with the REC will be retained.
- It is the Chief Investigator's responsibility to produce the annual reports as required.
- The Chief Investigator will notify the REC of the end of the study.
- An annual progress report (APR) will be submitted to the REC within 30 days of the anniversary date on which the favourable opinion was given, and annually until the study is declared ended.

- If the study is ended prematurely, the Chief Investigator will notify the REC, including the reasons for the premature termination.
- Within one year after the end of the study, the Chief Investigator will submit a final report with the results, including any publications/abstracts, to the REC.

Regulatory Review & Compliance

HRA and NHS REC approval is being sought via IRAS. Approval from UWE's Research Ethics Committee is also being sought. Participant enrolment will not commence until these approvals are in place.

This protocol also details how the study will move forward if Covid 19 restrictions mean that face to face therapy and interviews cannot take place. If any further changes are necessary, the amendments to the research study will be submitted for approval to these committees before the research continues.

Amendments

It is unlikely that there will be any significant amendments to this study after Ethics approval has been sought. However, if unforeseen circumstances result in significant changes being required, the Chief Investigator (researcher) will make an application to the REC with the amendment. Amendment history will be tracked using the protocol version number.

8.3 Peer review

Two independent experts have reviewed and endorsed this study via UWE Bristol HAS's Research Design Registration Process (RD1). The research will continue to be assessed for quality and integrity by UWE's Graduate School assessment procedures for PhDs.

The researcher's Supervision Team comprises two experts in the field of Mental Health and Qualitative research with vulnerable populations:

Dr Catherine Warner (Director of Studies)

Senior Lecturer UWE, Programme Leader for MA in Music Therapy (Psychology)

Expertise in qualitative research in music therapy with vulnerable populations, in particular using IPA, microanalysis of music and thematic analysis, has published articles in research ethics in relation to people with dementia, is a scrutineer for the FREC, and has a track record of involving people with learning disability in participatory research, including doctoral and post-doctoral work. For the past 4 years has been a lead partner in two Erasmus+ European projects relating to reducing early school leaving through music therapy knowledge. Currently authoring two books on music therapy supervision and music therapy training respectively for Routledge.

Dr Gary Christopher (Second Supervisor)

Senior Lecturer UWE (Psychology)

Ageing Well Lead at UWE Bristol (Psychological Science Research Group) and Executive Committeee member of the British Society of Gerontology. Examples of recent research:

emotional response to diagnosis of dementia, healthy ageing, psychological effect of nostalgia, resilience in older adults, body image in older adults.

Expertise in mixed methods research, questionnaires, experimental paradigms, online testing. Interests in ageing, dementia and affective disorders.

8.4 Patient & Public Involvement

Public involvement has included the development of Participation Information Sheets, Interview Questions and schedules. Draft versions of these documents were sent to family carers of people with dementia for their feedback on the following:

- Whether the explanation of the study is clear
- Whether the research participants' involvement is clearly explained
- Whether the interview questions are suitable and appropriate

Feedback shaped the final versions of these documents (also attached). Family carers involved in this aspect of the research were existing users of Mindsong's 'Music Therapy at Home' service and therefore not potential research participants.

The researcher is hopeful that as well as publication of papers, a conference event could provide a platform to present findings of the research. Potentially, research participants could be involved in presenting the findings, if they choose to do so.

8.5 Protocol compliance

If any accidental deviations from the protocol occur, these would be documented and reported to the Supervisory team and Sponsor immediately. Documentation will be held by the Chief Investigator (researcher).

8.6 Data protection and patient confidentiality

Data Management

A Data Management Plan and Data Protection Impact Assessment have been conducted to make sure that the research is GDPR compliant (attached). Data Sharing and Processing Agreements will also be in place with the collaborating organisation, Mindsong.

Mindsong's 'Music Therapy at Home' Administrator will share referrals with the researcher for screening purposes (with potential participants' consent), to enable the researcher to identify potential participants. Sharing documents will be via secure UWE OneDrive.

All data collected will be stored on the researcher's UWE approved encrypted OneDrive account, which will only be accessed by the researcher. The researcher will transcribe and analyse data on a UWE encrypted laptop, and a backup of data will be made on a second encrypted OneDrive

account. The researcher will only share processed, pseudonymised data with the Supervision Team for guidance and feedback purposes. Any sharing would be via secure OneDrive. Any hard copies of data (for e.g., written transcriptions or graphic scores) will be kept in a locked filing cabinet which only the researcher can access.

Each research participant will be randomly given a pseudonym for the purpose of the research, and personal identifiable data will be removed and replaced by this pseudonym from point of the first interview throughout the course of the research study. Therefore, all data stored will have no identifiable features.

Interviews will be video recorded by the researcher on a UWE encrypted device (either in person or via Zoom) and stored in a locked filing cabinet which only the researcher can access. The Music Therapists will make video recordings **(or Zoom recordings)** of the sixth Music Therapy sessions for purpose of musical Microanalysis. This will be shared with the researcher only, via UWE OneDrive. These recordings will be uploaded and stored on secure OneDrive and accessed by the researcher on a UWE encrypted laptop. Once uploaded, recordings made on the original devices will be deleted.

At the end of the research period, after the thesis and related papers have been written, all collected data will be destroyed, according to UWE's secure waste disposal system; electronic data will be deleted and hard paper copies shredded.

All those involved in the research study and with access to data (the researcher and Supervisory Team) will adhere to the requirements of the Data Protection Act 1998. A Data Protection Management Plan and Data Protection Impact Assessment for this study is attached with this document. Data Sharing and Processing Agreements are also in place with the collaborating organisation, Mindsong, and are also attached. The Chief Investigator (researcher) will act as the Data Custodian for the duration of this study.

8.7 Indemnity

This is to clarify the University of the West of England, Bristol ("UWE") insurance arrangement for employees and for students working under the supervision of a UWE employee and where the project is included on an authorised UWE research register.

For research which is not deemed a clinical trial (i.e., not on UWE's clinical trials register) UWE's Professional Indemnity policy provides insurance cover for indemnity against legal liability for damages and claimant's costs and expenses arising out of any act, neglect, error or omission (i.e., wrongful advice given in good faith).

UWE's Employers Liability Insurance is in place to protect UWE's employees if they are harmed whilst engaged on UWE business, should UWE be held legally liable.

UWE's Public Liability insurance policy covers legal liability for third party personal injury, death, disease or illness to any person or loss or damage to third party property. Details of the Employers / Public and Professional Indemnity policy covers are attached.

8.8 Access to the final study dataset

Only the researcher (Chief Investigator) will have access to the final dataset.

9. DISSEMINIATION POLICY

9.1 Dissemination policy

The researcher (Chief Investigator) will own the data created from this research study.

A final study report (thesis) will be completed and submitted to UWE Bristol's Research Repository.

Papers for publication will include:

- A Systematic Review, looking at established literature documenting evidence of effectiveness of Music Therapy for improving wellbeing of carers
- A paper summarising the findings of the research for journals including British Journal of Music Therapy, Journal of Dementia Care
- An executive summary report will be produced for participants and other interested parties.

Mindsong plan to host a conference event to disseminate results to local organisations and partners. The researcher will also apply to present findings at the British Association of Music Therapy conference, the International Culture, Health and Wellbeing conference, and others that may be relevant.

Research participants will be asked if they would like copies of other papers produced from the research.

9.2 Authorship eligibility guidelines and any intended use of professional writers

The researcher (Margaret Grady) will be responsible for writing the final study report and will be the lead author.

The researcher's writing will be reviewed by the Supervision Team. The researcher will be the sole author and will not use professional writers.

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20. APPENDICIES

11.1 Appendix 1- Required documentation

1. Study Protocol
2. Flowchart of Protocol
3. CVs of the research team
4. Letters of Invitation to Participants
5. Mindsong consent to share contact details
6. Covering letter for Potential Participants
7. Participant Information Sheet A – Family Carers
8. Participant Information Sheet B – Person with Dementia
9. Participant Information Sheet C - Music Therapists
10. Covering letter for Potential Music Therapists
11. Participant Privacy Notice
12. Consultee Information Sheet and declaration form
13. Participant Consent Form A – Family Carers
14. Participant Consent Form B – Person with Dementia
15. Participant Consent Form C – Music Therapists
16. GP / referrer information letter
17. Interview Schedules
18. UWE endorsement report (RD 1 report)
19. UWE Risk Assessment Form
20. Research Data Management Plan
21. Data Protection Impact Assessment
22. Mindsong Safeguarding Policy
23. Contract agreement of collaboration with Mindsong
24. Letter from Sponsor
25. Evidence of Sponsor insurance or indemnity
26. Mindsong Information Document
27. Reference List for IRAS
28. Data Sharing Agreement UWE Bristol and Mindsong

Appendix 8: Participant Information Sheets
8a – for the Family Caregiver

Any changes due to COVID-19 restrictions are indicated in green text.

Participant Information Sheet A

Research study: 'How do family carers of people with advanced / complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?' V2 May 2021 IRAS: 286118

Invitation

You are invited to take part in research taking place at the University of the West of England, Bristol. It is funded by the researcher, Maggie Grady. Before you decide whether to take part, it is important for you to understand why the study is being done and what it will involve. Please read the following information carefully and if you have any queries or would like more information please contact Maggie Grady, Faculty of Health and Applied Sciences (HAS), University of the West of England, Bristol: Margaret.grady@live.uwe.ac.uk or Tel: *********

Who is organising the research?

The project lead and researcher is Maggie Grady. Maggie is a PhD student at UWE Bristol (HAS). Dr Catherine Warner is Director of Studies for this study, and Dr Gary Christopher is a Supervisor.

What is the aim of the research?

This research is looking at the experiences of family carers of people with late-stage or complex dementia who are still being cared for at home. Music Therapy can be a beneficial intervention for the person with dementia but this research study seeks to find out the experiences of *family carers* who engage in the Music Therapy alongside the person they care for. Music Therapy might support their own wellbeing and mental health and results from the study have the potential to influence policy and services at a local and national level.

The research question is: **'How do family carers of people with advanced / complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?'**

To help answer this question I (the researcher, Maggie Grady) will be conducting three interviews and video recording some music from a Music Therapy session. The music from this session may include your music and the music of the person you are caring for. The

aim of the interviews and music recording is to collect information to analyse. All information collected will be pseudonymised; which means it will be given an alternative, random name and therefore no identifiable data will be used during the analysis or writing up of the study.

The results of this study will be analysed and used in a report made available on the University of the West of England's open-access repository. The pseudonymised results may also be used in conference papers and peer-reviewed academic papers.

Why have I been invited to take part?

You have been invited to take part because you have been referred to Mindsong's 'Music Therapy at Home' service and indicated at referral that you would be willing to talk about your experiences as a family carer. We're interested in gaining your views about your experiences of engaging in the Music Therapy, and also in the care you give to your family member.

Do I have to take part?

You do not have to take part in this research. It is up to you to decide whether or not you want to be involved. If you do decide to take part, you will be given a copy of this information sheet to keep and will be asked to sign a consent form.

As well as interviews with you, this study also involves video recording music from one of the Music Therapy sessions and therefore includes the person with dementia you are caring for. If that person can no longer give informed consent for this to happen, I would ask that you consider making a 'consultee declaration' and decision on behalf of the person you are caring for (please see attached consultee sheet). This is in addition to providing your own consent. Please consider the decision to take part carefully from both perspectives. Your wellbeing and the wellbeing of the person you care for will remain paramount throughout the study.

If you do decide to take part, you are able to withdraw from the research at any stage without giving a reason, and this will not affect your access to the Music Therapy intervention. You are also able to withdraw your data up until the point of data analysis, where all information will be pseudonymised and hold no identifiable features. This point will take place 4 months from the date you signed your consent form. At this point, all data will be anonymised and integrated into the data set and so it will not be possible for it to be removed.

If you want to withdraw from the study within this period, please write to Maggie Grady: Margaret.grady@live.uwe.ac.uk or telephone *********.

Deciding not to take part or to withdrawal from the study does not have any penalty and you are still entitled to the Music Therapy intervention.

What will happen to me if I take part and what do I have to do?

If you agree to take part in this study we would ask you to:

- Participate in the 12 Music Therapy sessions alongside the person you care for. How you do this is up to you, you can play, sing, or just listen if you prefer. There is no right or wrong way to play and the decision not to play will also be respected.
- If Covid 19 restrictions are in place, all therapy sessions and interviews would take place online, via Zoom. A member of the Mindsong team will provide technical support to help you access this if that would help.
- Participate in three interviews, answering as openly and honestly as you feel comfortable, about your thoughts, experiences and feelings as a family carer and your experiences of engaging in the Music Therapy intervention.
- The first interview would be before the Music Therapy intervention starts, the second interview will be after session 6 of the Music Therapy and the third interview would be after the 12th session of Music Therapy.
- The interviews will be conducted by Maggie Grady (researcher) and would take place in your home (if you are happy with this). They would last about an hour each in length.
- If more convenient, the interviews could take place online, and / or could be split into two or three sessions of shorter duration.
- The interviews would be video recorded on a UWE encrypted recording device or via Zoom if online.
- The researcher (Maggie Grady) would make transcripts of the interviews and check with you on any details that might seem unclear.
- A video recording (or Zoom recording if online) of the 6th Music Therapy session would be made by your Music Therapist and shared with the researcher (Maggie Grady) via secure UWE OneDrive. This is a secure online storage and sharing facility, provided by UWE Bristol. In the second interview, we would listen to this together and you would be asked to choose a small clip of music to be looked at in more detail. Maggie would make a transcript of this music too.
- All transcripts / data will be pseudonymised, which means it will be given a different name and recorded and stored under this name, making all data from this point onwards with no identifiable features.
- Your pseudonymised data would be analysed with interview data from other pseudonymised participants.

What are the benefits of taking part?

Potentially, this gives you an opportunity to talk about how you are feeling which can be helpful for wellbeing. The Music Therapy intervention is designed to support the wellbeing and care for both you and the person you care for. Previous participants in the service have reported increased wellbeing, and decreased stress and anxiety for both the person

with dementia and family carer. It is also hoped that this research will result in a better understanding of how Music Therapy might be able to support family carers.

What are the possible risks of taking part?

We don't anticipate any disadvantages to you or the person you care for. If either of you find any of the interviews or sessions upsetting, you would be offered extra support, and the option of withdrawing from the study. Extra support would mean access to a different member of the Mindsong Music Therapy team, who would be available for you to talk to.

Our Mindsong Music Therapists are qualified therapists and highly experienced in dementia care. The researcher, Maggie Grady, is also a Music Therapist with over 12 years' experience of working in this context and so will be highly sensitive to situations. The wellbeing of you and the person you care for remain paramount throughout the research study.

What will happen to your information?

All the information we receive from you will be treated in the strictest confidence.

All the information that you give will be kept confidential and pseudonymised at point of collection. This means that a different, random name would be given for all data created from your interviews and the data coded with this pseudonym. Any identifiable features (like your name) would be removed.

The only circumstance where we may not be able to keep your information confidential is if you disclose any information where you or the person you care for are at risk of harm. In this case Mindsong's Safeguarding procedures would be followed but your consent would always be sought in sharing any details.

Mindsong will share referral forms with the researcher (Maggie Grady) via secure UWE OneDrive. This is a secure online storage and sharing facility, provided by UWE Bristol. Referral forms include your contact details, the diagnosis of dementia for the person you care for, and other relevant information to your situation, such as any other health concerns that may impact the Music Therapy.

Your Music Therapists will share the video recording of session 6 via UWE secure OneDrive. Once uploaded to secure OneDrive, the therapist's original recording of the session would be deleted.

All data will be stored securely on UWE OneDrive and any hard copies (transcripts, for example) will be kept in a locked filing cabinet. Only the researcher (Maggie Grady) would have access to the data. The researcher's Supervision Team (Dr Catherine Warner and Dr Gary Christopher) would have occasional access to processed, pseudonymised data for monitoring and support purposes, and any data sharing would be via secure UWE

OneDrive. This is accordance with the University's Data Protection Policy, the Data Protection Act 2018 and General Data Protection Regulation requirements.

Your pseudonymised data will be analysed together with other interview and file data, and we will ensure that there is no possibility of identification or re-identification from this point.

Once the final report has been written and papers for publication completed, your data will be destroyed using UWE's disposal system. Electronic copies would be deleted and hardcopies shredded.

Where will the results of the research study be published?

A report will be written containing the research findings. This report will be available on the University of the West of England's open-access Research Repository, and other papers for publication or conference presentation may be made.

A hard copy summary of the report will be made available to all research participants if you would like to see it. Key findings will also be shared both within and outside the University of the West of England. Anonymous and non-identifying direct quotes may be used for publication and presentation purposes.

Who has ethically approved this research?

The project has been reviewed and approved by NHS Research Ethics Committee (NHS REC) and UWE's Faculty for Health and Applied Science Research Ethics Committee (FREC).

Any comments, questions or complaints about the ethical conduct of this study can be addressed to the Research Ethics Committee at the University of the West of England at:

Researchethics@uwe.ac.uk

What if something goes wrong?

If you have any complaints about the research study in the first instance you can contact Maggie Grady or Dr Catherine Warner. Any complaints or queries will be discussed with Dr Catherine Warner (as Director of Studies for this research study).

What if I have more questions or do not understand something?

If you would like any further information about the research, please contact in the first instance:

Maggie Grady (PhD student researcher) Margaret.grady@live.uwe.ac.uk or tel: *******

Or

Or Dr Catherine Warner (Director of Studies) catherine.warner@uwe.ac.uk

A note regarding Covid 19 restrictions

We are hopeful that by the time this research takes place (September to December 2021) restrictions will have been lifted and face to face interviews and therapy may be possible. However, if restrictions are in place, we will use Zoom as an online method of delivery.

Thank you for considering taking part in this research.

You will be given a copy of this Participant Information Sheet and your signed Consent Form to keep.

Appendix 8: Participant Information Sheets

8b – for the Person with Dementia

Participant Information Sheet B

Research study: 'How do family carers of people with late-stage / complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?'

V1 April 2021 IRAS: 286118

Invitation

You are invited to take part in research with the University of the West of England, Bristol. This is being funded by the researcher, Maggie Grady.

Before you decide whether to take part, it is important for you to understand why the study is being done and what it will involve.

Please read the following information carefully. If you have any questions, please contact:

Maggie Grady, Faculty of Health and Applied Sciences (HAS), University of the West of England (UWE), Bristol:

Margaret.grady@live.uwe.ac.uk or Tel: **********

Who is organising the research?

The project lead and researcher is Maggie Grady. Maggie is a PhD student at UWE Bristol. Maggie's research support team at UWE is Dr Catherine Warner and Dr Gary Christopher.

What is the aim of the research?

The aim of the research is to see if Music Therapy might be helpful for family members who provide care for a person with dementia. The focus of the research is to find out about family carers' experiences of engaging in Music Therapy.

Outcomes from the research may influence policy and services at a local and national level.

The research question is: **'How do family carers of people with late-stage / complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?'**

To help answer this question I (the researcher, Maggie Grady) will conduct three interviews with [name of family carer]. These would be video recorded.

Some music from one of your Music Therapy sessions would also be video recorded. The music from this session may include your music as well as music from [name of family carer], who will be attending sessions with you.

The aim of the interviews and music recording is to collect information to analyse. All information collected will be given an alternative, random name and therefore no identifiable data will be used during the analysis or writing up of the study.

The results of this study will be analysed and used in a report made available on the University of the West of England's open-access online library resource. The results may also be used in conference papers and academic journals.

Why have I been invited to take part?

You have been invited to take part because you have been referred to Mindsong's 'Music Therapy at Home' service and we would like to include music from your Music Therapy session in the analysis.

Do I have to take part?

You do not have to take part in this research. It is up to you to decide whether or not you want to be involved.

If you do decide to take part, you will be given a copy of this information sheet to keep and will be asked to sign a consent form.

This study involves video recording music from one of the Music Therapy sessions and therefore will include your music.

Your wellbeing will remain paramount throughout the study.

If you do decide to take part, you are able to withdraw from the research at any stage without giving a reason, and this will not affect your access to the Music Therapy intervention.

You are also able to withdraw your data up until the point of data analysis, where all information will be pseudonymised and hold no identifiable features.

If you want to withdraw from the study within this period, please write to Maggie Grady: Margaret.grady@live.uwe.ac.uk or telephone *********.

What will happen to me if I take part and what do I have to do?

If you agree to take part in this study we would ask you to:

- Take part in the 12 Music Therapy sessions. You can sing, play or just listen if you'd like to. There is no right or wrong way to play. If you decide not to play, this is ok too.

- The sessions will either be in your home with the Music Therapist, or online using Zoom.

- The 6th Music Therapy session would be video recorded by your Music Therapist. They would share this with the researcher (Maggie) and then delete their copy.

- Maggie would analyse a section of the music and write this up.

- [Name of family carer] will take part in the Music Therapy sessions with you.

- [Name of family carer] would also take part in three interviews, answering as openly and honestly as they feel comfortable, about their thoughts, experiences and feelings as a family carer and their experiences of taking part in the Music Therapy intervention.

- The interviews will be conducted by Maggie Grady (researcher) and would take place in your home (if you are happy with this) or online.

- The interviews would be video recorded. The researcher (Maggie Grady) would write up the interviews and check on any details that might seem unclear.

- All data would be pseudonymised, which means it will be given a different name and stored under this name.

- The video recordings from the music and interviews would be analysed by Maggie, along with data from other participants.

- Any papers or documents written with the results would not hold any identifiable data – this means that you could not be identified from any written reports or results from the research study.

What are the benefits of taking part?

The Music Therapy may bring benefits for your wellbeing, and for [name of family carer] too.

It is also hoped that this research will result in a better understanding of how Music Therapy might be able to support family carers.

What are the possible risks of taking part?

We don't think there will be any risks for you or [name of family carer].

However, if either of you find any of the interviews or Music Therapy sessions upsetting, you would be offered extra support, and the option of withdrawing from the study.

Extra support would mean access to a different member of the Mindsong Music Therapy team, who would be available for you to talk to.

The wellbeing of you both will remain paramount throughout the research study.

What will happen to your information?

All the information we receive from you will be treated in the strictest confidence.

All the information that you give will be kept confidential and pseudonymised at point of collection. This means that a different, random name would be given for all data created from your interviews and the data coded with this name. Any identifiable features (like your name) would be removed.

The only circumstance where we may not be able to keep your information confidential is if you tell us that you or [name of family carer] are at risk of harm. In this case Mindsong's Safeguarding procedures would be followed but your consent would always be sought in sharing any details.

Any sharing of information between Mindsong and Maggie will be done securely online, using the secure system provided by the University (UWE OneDrive).

Maggie's research support team (Dr Catherine Warner and Dr Gary Christopher) may see some of the data to give advice and guidance.

Once the final report has been written and papers for publication completed, your data will be destroyed using UWE's disposal system. Electronic copies would be deleted and hardcopies shredded.

Where will the results of the research study be published?

A report will be written containing the research findings. This report will be available on the University of the West of England's open-access online library resource, and other papers for publication or conference presentation may be made.

A summary of the report will be made available to you if you would like to see it. Key findings will also be shared both within and outside the University of the West of England. Anonymous and non-identifying direct quotes may be used for publication and presentation purposes.

Who has ethically approved this research?

The project has been reviewed and approved by NHS Research Ethics Committee (NHS REC) and UWE's Faculty for Health and Applied Science Research Ethics Committee (FREC).

Any comments, questions or complaints about the ethical conduct of this study can be addressed to the Research Ethics Committee at the University of the West of England at:

Researchethics@uwe.ac.uk

What if something goes wrong?

If you have any complaints about the research study in the first instance you can contact Maggie Grady or Dr Catherine Warner. Any complaints or queries will be discussed with Dr Catherine Warner (as Director of Studies for this research study).

What if I have more questions or do not understand something?

If you would like any further information about the research please contact in the first instance:

Maggie Grady (PhD student researcher)

Margaret.grady@live.uwe.ac.uk or tel: *********

Or Dr Catherine Warner (Director of Studies)

catherine.warner@uwe.ac.uk

A note regarding Covid 19 restrictions

We are hopeful that by the time this research takes place (September to December 2021) restrictions will have been lifted and face to face interviews and therapy may be possible. However, if restrictions are in place, we will use Zoom as an online method of delivery.

Thank you for considering taking part in this research.

You will be given a copy of this Information Sheet and your signed Consent Form to keep.

Appendix 8: Participant Information Sheets

8c – for the Person with Dementia, simplified version

Participant Information Sheet C

Research study: 'How do family carers of people with late-stage / complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?' V1 May 2021 IRAS: 286118

Invitation

You are invited to take part in some research sponsored by UWE Bristol.

Maggie Grady is the researcher.

Maggie is trying to find out about people's experiences of Music Therapy.

What would I have to do?

- Take part in the Music Therapy sessions – there is no right or wrong way to play and you can just listen if you like. [Name of family carer] would join in with you.
- One session would be video recorded by your music therapist and shared with Maggie.
- [Name of family carer] would also take part in some interviews with Maggie.
- All the recordings would be kept securely and all information kept confidential.
- The research team at UWE may sometimes see the data but it would have your name removed.
- Maggie would study the information to find out about people's experiences of Music Therapy.
- Maggie would then write up the results and these would be published.
- It may include quotes from you or [name of family carer] but your name would be removed so you wouldn't be identifiable.

Do I have to take part?

You do not have to take part in this research. It is up to you to decide whether or not you want to be involved. If you do decide to take part, you are able to withdraw from the research at any stage without giving a reason. You will still be able to take part in the Music Therapy sessions.

If you have any questions please contact Maggie:

Email: Margaret.grady@live.uwe.ac.uk or Tel: *********

Thank you!

Appendix 8: Participant Information Sheets

8d – for the Music Therapists

Participant Information Sheet D – Music Therapists

Research study: 'How do family carers of people with late-stage / complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?' V2 May 2021 IRAS: 286118

Invitation

You are invited to take part in research taking place at the University of the West of England, Bristol. It is funded by the researcher, Maggie Grady. Before you decide whether to take part, it is important for you to understand why the study is being done and what it will involve. Please read the following information carefully and if you have any queries or would like more information please contact Maggie Grady, Faculty of Health and Applied Sciences (HAS), University of the West of England, Bristol: Margaret.grady@live.uwe.ac.uk or Tel: **********

Who is organising the research?

The project lead and researcher is Maggie Grady. Maggie is a PhD student at UWE Bristol (HAS). Dr Catherine Warner is Director of Studies for this study, and Dr Gary Christopher is a Supervisor.

What is the aim of the research?

This research is looking at the experiences of family carers of people with late-stage or complex dementia who are still being cared for at home. Music Therapy can be a beneficial intervention for the person with dementia but this research study seeks to find out the experiences of *family carers* who engage in the Music Therapy alongside the person they care for. Music Therapy might support their own wellbeing and mental health and results from the study have the potential to influence policy and services at a local and national level.

The research question is: **'How do family carers of people with late-stage / complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?'**

To help answer this question I (the researcher, Maggie Grady) will be conducting three interviews with family carers of people with dementia and analysing these and a video recording of some music from a Music Therapy session. All information collected will be

pseudonymised, which means it will be given an alternative, random name and therefore no identifiable data will be used during the analysis or writing up of the study.

The results of this study will be analysed and used in a report made available on the University of the West of England's open-access repository. The pseudonymised results may also be used in conference papers and peer-reviewed academic papers.

Why have I been invited to take part?

You have been invited to take part because you are one of Mindsong's freelance Music Therapists, and people being referred to Mindsong's 'Music Therapy at Home' service are being invited to take part in this research. This research will involve the video recording and analysing of music from one of the Music Therapy sessions with the research participants.

Do I have to take part?

You do not have to take part in this research. It is up to you to decide whether or not you want to be involved. If you do decide to take part, you will be given a copy of this information sheet to keep and will be asked to sign a consent form.

Informed consent will also be sought from the family carers and people with dementia participating in the research. This may include a 'consultee declaration' made by the family carer on behalf of the person with dementia.

If you do decide to take part, you are able to withdraw from the research at any stage without giving a reason. You are also able to withdraw your data up until the point of data analysis, where all information will be pseudonymised and hold no identifiable features. This point will take place 4 months from the date you signed your consent form. At this point, all data will be anonymised and integrated into the data set and so it will not be possible for it to be removed.

If you want to withdraw from the study within this period, please write to Maggie Grady: Margaret.grady@live.uwe.ac.uk or telephone **********

Deciding not to take part or to withdrawal from the study does not have any penalty and will not affect any future work opportunities with Mindsong.

What will happen to me if I take part and what do I have to do?

If you agree to take part in this study we would ask you to:

- Deliver the 12 Music Therapy sessions in accordance with Mindsong's 'Music Therapy at Home' service.
- **If Covid 19 restrictions are in place, all therapy sessions and interviews would take place online, via Zoom. Mindsong can provide technical support to help you access this if that would help.**

- Video record session 6 **(or record session 6 on Zoom if online)** and share with the researcher (Maggie Grady) via secure UWE OneDrive. This is a secure online storage and sharing facility, provided by UWE Bristol.
- Maggie and the family carer will watch this session back together and choose a musical moment for microanalysis.
- Maggie will make a transcript of the clip of music for analysis purposes.
- Maggie will also conduct 3 interviews with the family carer, asking them about their experiences as a carer and of engaging in the Music Therapy sessions alongside the person they care for.
- All data will be pseudonymised from point of collection, which means it will be given a different name and recorded and stored under this name, making all data from this point onwards with no identifiable features.
- The pseudonymised data would be analysed with interview data from other pseudonymised participants.

What are the benefits of taking part?

This research study should give insights into the thoughts of family carer's experiences of Music Therapy, which may feed directly into developing our clinical service.

What are the possible risks of taking part?

We don't anticipate any disadvantages to you. If you find any aspect of the study upsetting, you would be offered extra support, and the option of withdrawing from the study. Extra support would mean access to a different member of the Mindsong Music Therapy team, who would be available for you to talk to.

What will happen to your information?

All the information we receive from you will be treated in the strictest confidence.

All the information that you give will be kept confidential and pseudonymised at point of collection. The only circumstance where we may not be able to keep your information confidential is if you disclose any information where you or the people you're working with are at risk of harm. In this case Mindsong's Safeguarding procedures would be followed but your consent would always be sought in sharing any details.

Mindsong will share referral forms with the researcher (Maggie Grady) via secure UWE OneDrive. Video **(or Zoom)** recordings of the 6th Music Therapy session would be shared with the researcher via UWE secure OneDrive.

All data will be stored securely on UWE OneDrive and any hard copies (transcripts, for example) will be kept in a locked filing cabinet. Only the researcher (Maggie Grady) would have access to the data, and the research supervision team (Dr Catherine Warner and Dr Gary Christopher) would have occasional access to processed, pseudonymised data for supervision purposes. Any data sharing would be via secure UWE OneDrive. This is

accordance with the University's Data Protection Policy, the Data Protection Act 2018 and General Data Protection Regulation requirements.

Your pseudonymised data will be analysed together with other interview and file data, and we will ensure that there is no possibility of identification or re-identification from this point.

Once the final report has been written and papers for publication completed, your data will be destroyed using UWE's disposal system. Electronic data will be deleted and any hard copies shredded.

Where will the results of the research study be published?

A report will be written containing the research findings. This report will be available on the University of the West of England's open-access Research Repository, and other papers for publication or conference presentation may be made.

A hard copy summary of the report will be made available to all research participants if you would like to see it. Key findings will also be shared both within and outside the University of the West of England. Anonymous and non-identifying direct quotes may be used for publication and presentation purposes.

Who has ethically approved this research?

The project has been reviewed and approved by NHS Research Ethics Committee (NHS REC) and UWE's Faculty for Health and Applied Science Research Ethics Committee (FREC).

Any comments, questions or complaints about the ethical conduct of this study can be addressed to the Research Ethics Committee at the University of the West of England at:

Researchethics@uwe.ac.uk

What if something goes wrong?

If you have any complaints about the research study in the first instance you can contact Maggie Grady or the CEO at Mindsong. Complaints or queries will be discussed with the Director of Studies for this research study, Dr Catherine Warner.

What if I have more questions or do not understand something?

If you would like any further information about the research, please contact in the first instance:

Maggie Grady (PhD student researcher) Margaret.grady@live.uwe.ac.uk or Tel: *******

Or

Or Dr Catherine Warner (Director of Studies) catherine.warner@uwe.ac.uk

A note regarding Covid 19 restrictions

We are hopeful that by the time this research takes place (September to December 2021) restrictions will have been lifted and face to face interviews and therapy may be possible. However, if restrictions are in place, **we will use Zoom as an online method of delivery.**

Thank you for considering taking part in this research.
You will be given a copy of this Participant Information Sheet and your signed Consent Form to keep.

Appendix 8: Participant Information Sheets

8e – Consultee Information Sheet

Consultee Information Sheet

Research study: 'How do family carers of people with late-stage / complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?'

V2 May 2021 IRAS: 286118

Introduction

We are unsure as to whether your relative/friend is unable to decide for himself/herself whether to participate in this research.

To help decide if he/she should join the study, we'd like to ask your opinion whether or not they would want to be involved. We'd ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any advance decisions they may have made about participating in research. These should take precedence.

If you decide your relative/friend would have no objection to taking part we will ask you to read and sign the consultee declaration on the last page of this information leaflet. We'll then give you a copy to keep. We will keep you fully informed during the study so you can let us know if you have any concerns or you think your relative/friend should be withdrawn.

If you decide that your friend/relative would not wish to take part it will not affect the Music Therapy intervention they receive in any way.

If you are unsure about taking the role of consultee you may seek independent advice. We would encourage you to talk this through with friends and family if that would help you to make this decision.

We will understand if you do not want to take on this responsibility.

The following information is the same as would have been provided to your relative/friend.

Research study: 'How do family carers of people with late-stage / complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?'

Invitation

You are invited to take part in research taking place at the University of the West of England, Bristol. It is funded by the researcher, Maggie Grady. Before you decide whether to take part, it is important for you to understand why the study is being done and what it will involve. Please read the following information carefully and if you have any queries or would like more information

please contact Maggie Grady, Faculty of Health and Applied Sciences (HAS), University of the West of England, Bristol: Margaret.grady@live.uwe.ac.uk or Tel: **********

Who is organising the research?

The project lead and researcher is Maggie Grady. Maggie is a PhD student at UWE Bristol (HAS). Dr Catherine Warner is Director of Studies for this study, and Dr Gary Christopher is a Supervisor.

What is the aim of the research?

This research is looking at the experiences of family carers of people with late-stage or complex dementia who are still being cared for at home. Music Therapy can be a beneficial intervention for the person with dementia, but this research study seeks to find out the experiences of *family carers* who engage in the Music Therapy alongside the person they care for. Music Therapy might support their own wellbeing and mental health and results from the study have the potential to influence policy and services at a local and national level.

The research question is: **'How do family carers of people with late-stage / complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?'**

To help answer this question I (the researcher, Maggie Grady) will be conducting three interviews and video recording some music from a Music Therapy session. The music from this session may include your music as well as music from your family member attending sessions with you. The aim of the interviews and music recording is to collect information to analyse. All information collected will be pseudonymised; which means it will be given an alternative, random name and therefore no identifiable data will be used during the analysis or writing up of the study.

The results of this study will be analysed and used in a report made available on the University of the West of England's open-access repository. The pseudonymised results may also be used in conference papers and peer-reviewed academic papers.

Why have I been invited to take part?

You have been invited to take part because you have been referred to Mindsong's 'Music Therapy at Home' service and we would like to include music from your Music Therapy session in the analysis.

Do I have to take part?

You do not have to take part in this research. It is up to you to decide whether or not you want to be involved. If you do decide to take part, you will be given a copy of this information sheet to keep and will be asked to sign a consent form.

This study involves video recording music from one of the Music Therapy sessions and therefore will include your music. Your wellbeing will remain paramount throughout the study.

If you do decide to take part, you are able to withdraw from the research at any stage without giving a reason, and this will not affect your access to the Music Therapy intervention. You are also able to withdraw your data up until the point of data analysis, where all information will be pseudonymised and hold no identifiable features. This point will take place 4 months from the date you signed your consent form. At this point, all data will be anonymised and integrated into the data set and so it will not be possible for it to be removed.

If you want to withdraw from the study within this period, please write to Maggie Grady: Margaret.grady@live.uwe.ac.uk or telephone **********

Deciding not to take part or to withdrawal from the study does not have any penalty and you are still entitled to the Music Therapy intervention.

What will happen to me if I take part and what do I have to do?

If you agree to take part in this study we would ask you to:

- Participate in the 12 Music Therapy sessions. How you do this is up to you, you can play, sing, or just listen if you prefer. There is no right or wrong way to play and the decision not to play will also be respected.
- **If Covid 19 restrictions are in place, all therapy sessions and interviews would take place online, via Zoom.**
- **A member of the Mindsong team will provide technical support to help you access this if that would help.**
- A video recording **(or Zoom recording)** of the 6th Music Therapy session would be made by your Music Therapist and shared with the researcher (Maggie Grady) via secure UWE OneDrive. This is a secure online storage and sharing facility, provided by UWE Bristol.
- Your family carer will also participate in three interviews, answering as openly and honestly as they feel comfortable, about their thoughts, experiences and feelings as a family carer and their experiences of engaging in the Music Therapy intervention.
- The first interview would be before the Music Therapy intervention starts, the second interview will be after session 6 of the Music Therapy and the third interview would be after the 12th session of Music Therapy.
- The interviews will be conducted by Maggie Grady (researcher) and would take place in your home (if you are happy with this). They would last about an hour each in length.
- If more convenient, the interviews could take place online, and also could be split into two or three sessions of shorter duration.
- The interviews would be video recorded on a UWE encrypted recording device, or via Zoom if online. The researcher (Maggie Grady) would make transcripts of the interviews and check with your family carer on any details that might seem unclear.

- In the second interview, your family carer and the researcher (Maggie Grady) would watch the video recording of the 6th Music Therapy session and choose a small clip of music to be looked at in more detail. Maggie would make a transcript of this music too.
- All transcripts / data will be pseudonymised, which means it will be given a different name and recorded and stored under this name, making all data from this point onwards with no identifiable features.
- Your pseudonymised data would be analysed with interview data from other pseudonymised participants.

What are the benefits of taking part?

The Music Therapy intervention is designed to support the wellbeing and care for you both. Previous participants in the service have reported increased wellbeing, and decreased stress and anxiety. It is also hoped that this research will result in a better understanding of how Music Therapy might be able to support family carers.

What are the possible risks of taking part?

We don't anticipate any disadvantages to you. However, if either of you find any of the interviews or Music Therapy sessions upsetting, you would be offered extra support, and the option of withdrawing from the study. Extra support would mean access to a different member of the Mindsong Music Therapy team, who would be available for you to talk to.

Our Mindsong Music Therapists are qualified therapists and highly experienced in dementia care. The researcher, Maggie Grady, is also a Music Therapist with over 12 years' experience of working in this context and so will be highly sensitive to situations. The wellbeing of you both will remain paramount throughout the research study.

What will happen to your information?

All the information we receive from you will be treated in the strictest confidence.

All the information that you give will be kept confidential and pseudonymised at point of collection. This means that a different, random name would be given for all data created from your interviews and the data coded with this pseudonym. Any identifiable features (like your name) would be removed.

The only circumstance where we may not be able to keep your information confidential is if you disclose any information where either of you are at risk of harm. In this case Mindsong's Safeguarding procedures would be followed but your consent would always be sought in sharing any details.

Mindsong will share referral forms with the researcher (Maggie Grady) via secure UWE OneDrive. Referral forms include your contact details, the diagnosis of dementia and other relevant information to your situation, such as any other health concerns that may impact the Music Therapy.

Your Music Therapist will share the video recording of session 6 via UWE secure OneDrive. Once uploaded to secure OneDrive, the therapist's original recording of the session would be deleted.

All data will be stored securely on UWE OneDrive and any hard copies (transcripts, for example) will be kept in a locked filing cabinet. Only the researcher (Maggie Grady) would have access to the data. The researcher's Supervision Team (Dr Catherine Warner and Dr Gary Christopher) would have occasional access to processed, pseudonymised data for monitoring and support purposes, and any data sharing would be via secure UWE OneDrive. This is accordance with the University's Data Protection Policy, the Data Protection Act 2018 and General Data Protection Regulation requirements.

Your pseudonymised data will be analysed together with other interview and file data, and we will ensure that there is no possibility of identification or re-identification from this point.

Once the final report has been written and papers for publication completed, your data will be destroyed using UWE's disposal system. Electronic copies would be deleted and hardcopies shredded.

Where will the results of the research study be published?

A report will be written containing the research findings. This report will be available on the University of the West of England's open-access Research Repository, and other papers for publication or conference presentation may be made.

A hard copy summary of the report will be made available to all research participants if you would like to see it. Key findings will also be shared both within and outside the University of the West of England. Anonymous and non-identifying direct quotes may be used for publication and presentation purposes.

Who has ethically approved this research?

The project has been reviewed and approved by NHS Research Ethics Committee (NHS REC) and UWE's Faculty for Health and Applied Science Research Ethics Committee (FREC). Any comments, questions or complaints about the ethical conduct of this study can be addressed to the Research Ethics Committee at the University of the West of England at:

Researchethics@uwe.ac.uk

What if something goes wrong?

If you have any complaints about the research study in the first instance you can contact Maggie Grady or Dr Catherine Warner. Any complaints or queries will be discussed with Dr Catherine Warner (as Director of Studies for this research study).

What if I have more questions or do not understand something?

If you would like any further information about the research please contact in the first instance:

Maggie Grady (PhD student researcher) Margaret.grady@live.uwe.ac.uk or tel: **********

Or Dr Catherine Warner (Director of Studies) catherine.warner@uwe.ac.uk

A note regarding Covid 19 restrictions

We are hopeful that by the time this research takes place (September to December 2021) restrictions will have been lifted and face to face interviews and therapy may be possible. However, if restrictions are still in place, we will use Zoom as an online method of delivery.

Thank you for considering taking part in this research.

You will be given a copy of this Consultee Information Sheet and your signed Consent Form / Consultee Declaration to keep.

Appendix 9: Participant Privacy Notice

Privacy Notice for Research Participants

Research study: 'How do family carers of people with advanced / complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?' V1 March 2021 IRAS: 286118

Purpose of the Privacy Notice

This privacy notice explains how the University of the West of England, Bristol (UWE) collects, manages and uses your personal data before, during and after you participate in the research study 'How do family carers of people with late-stage / complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?' 'Personal data' means any information relating to an identified or identifiable natural person (the data subject). An 'identifiable natural person' is one who can be identified, directly or indirectly, including by reference to an identifier such as a name, an identification number, location data, an online identifier, or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person.

This privacy notice adheres to the General Data Protection Regulation (GDPR) principle of transparency. This means it gives information about:

- How and why your data will be used for the research;
- What your rights are under GDPR; and
- How to contact UWE Bristol and the project lead in relation to questions, concerns or exercising your rights regarding the use of your personal data.

This Privacy Notice should be read in conjunction with the Participant Information Sheet and Consent Form provided to you before you agree to take part in the research.

Why are we processing your personal data?

UWE Bristol undertakes research under its public function to provide research for the benefit of society. As a data controller we are committed to protecting the privacy and security of your personal data in accordance with the (EU) 2016/679 the General Data Protection Regulation (GDPR), the Data Protection Act 2018 (or any successor legislation) and any other legislation directly relating to privacy laws that apply (together "the Data Protection Legislation"). General information on Data Protection law is available from the Information Commissioner's Office (https://ico.org.uk/).

How do we use your personal data?

We use your personal data for research with appropriate safeguards in place on the lawful bases of fulfilling tasks in the public interest, and for archiving purposes in the public interest, for scientific or historical research purposes.

We will always tell you about the information we wish to collect from you and how we will use it.

We will not use your personal data for automated decision making about you or for profiling purposes.

Our research is governed by robust policies and procedures and, where human participants are involved, is subject to ethical approval from either UWE Bristol's Faculty or University Research Ethics Committees. This research has been approved by NHS Research Ethics Committee (NHS REC) and UWE's Faculty for Health and Applied Science Research Ethics Committee (FREC).

NHS REC ref no: tbc

Contact details: tbc

UWE FREC ref no: tbc

Contact details: tbc

The research team adhere to the **Ethical guidelines of the British Educational Research Association (and/or the principles of the Declaration of Helsinki, 2013) and the principles of the General Data Protection Regulation (GDPR).**

For more information about UWE Bristol's research ethics approval process please see our Research Ethics webpages at:

www1.uwe.ac.uk/research/researchethics

What data do we collect?

The data we collect will vary from project to project. Researchers will only collect data that is essential for their project. The specific categories of personal data processed are described in the Participant Information Sheet provided to you with this Privacy Notice.

Who do we share your data with?

We will only share your personal data in accordance with the attached Participant Information Sheet and your Consent.

How do we keep your data secure?

We take a robust approach to protecting your information with secure electronic and physical storage areas for research data with controlled access. If you are participating in a particularly sensitive project UWE Bristol puts into place additional layers of security. UWE Bristol has Cyber Essentials information security certification.

Alongside these technical measures there are comprehensive and effective policies and processes in place to ensure that users and administrators of information are aware of their obligations and responsibilities for the data they have access to. By default, people are only granted access to the information they require to perform their duties. Mandatory data protection and information security training is provided to staff and expert advice available if needed.

How long do we keep your data for?

Your personal data will only be retained for as long as is necessary to fulfil the cited purpose of the research. The length of time we keep your personal data will depend on several factors including the significance of the data, funder requirements, and the nature of the study. Specific details are provided in the attached Participant Information Sheet. Anonymised data that falls outside the scope of data protection legislation as it contains no identifying or identifiable information may be stored in UWE Bristol's research data archive or another carefully selected appropriate data archive.

Your Rights and how to exercise them

Under the Data Protection legislation you have the following **qualified** rights:

(1) The right to access your personal data held by or on behalf of the University;
(2) The right to rectification if the information is inaccurate or incomplete;
(3) The right to restrict processing and/or erasure of your personal data;
(4) The right to data portability;
(5) The right to object to processing;
(6) The right to object to automated decision making and profiling;
(7) The right to complain to the Information Commissioner's Office (ICO).

Please note, however, that some of these rights do not apply when the data is being used for research purposes if appropriate safeguards have been put in place.

We will always respond to concerns or queries you may have. If you wish to exercise your rights or have any other general data protection queries, please contact UWE Bristol's Data Protection Officer (dataprotection@uwe.ac.uk).

If you have any complaints or queries relating to the research in which you are taking part please contact either the research project lead, whose details are in the attached Participant Information Sheet, UWE Bristol's Research Ethics Committees (research.ethics@uwe.ac.uk) or UWE Bristol's research governance manager (Ros.Rouse@uwe.ac.uk)

v.1: This Privacy Notice was issued in April 2019 and will be subject to regular review/update.

Appendix 10: Consent Forms
10a – for the Family Caregiver

Consent Form A

Research study: 'How do family carers of people with late-stage / complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?' V2 May 2021 IRAS: 286118

This consent form will have been given to you with the Participant Information Sheet. Please ensure that you have read and understood the information contained in the Participant Information Sheet and asked any questions before you sign this form. If you have any questions please contact a member of the research team, whose details are set out on the Participant Information Sheet

If you are happy to take part in this research study, including the Music Therapy intervention and the three interviews with researcher, Maggie Grady, please sign and date the form. You will be given a copy to keep for your records.

- I have read and understood the information in the Participant Information Sheet which I have been given to read before asked to sign this form.
- I have been given the opportunity to ask questions about the study.
- I have had my questions answered satisfactorily by the research team.
- I agree to participate in the Music Therapy sessions and interviews either face to face or online via Zoom.
- I agree to the video recording / Zoom recording of interviews and the sixth Music Therapy session.
- I agree to the use of my data as described in the Participation Information Sheet.
- I agree that anonymised quotes may be used in the final Report of this study.
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason.
- I understand that I can request the removal of my data up until the point of data analysis (4 months from the date this form is signed). I understand that from this point, my data would be anonymised and integrated into the data set and so could not then be removed.
- I agree to take part in the research.

Name (Printed)…….

Signature……. Date…….

Appendix 10: Consent Forms
10b – for the Person with Dementia

Consent Form B

Research study: 'How do family carers of people with late-stage / complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?' V1 April 2021 IRAS: 286118

Please ensure that you have read and understood the information contained in the Information Sheet and asked any questions before you sign this form.

If you have any questions please contact Maggie on ********** before signing this form.

If you are happy to take part in this research study, including the Music Therapy intervention and having a session of Music Therapy recorded, please sign and date the form.

You will be given a copy to keep for your records.

- I have read and understood the information in the Participant Information Sheet which I have been given to read before asked to sign this form.
- I have been given the opportunity to ask questions about the study.
- I have had my questions answered satisfactorily by the research team.
- I agree to participate in the Music Therapy sessions and interviews either face to face or online via Zoom.
- I agree to the video recording of the sixth Music Therapy session.
- I agree to the use of my data as described in the Participation Information Sheet.
- I agree that anonymised quotes may be used in the final Report of this study.
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason.
- I understand that I can request my data is withdrawn from the study up until the point of data analysis, where all information will be pseudonymised and hold no identifiable features. This point will take place 4 months from the date of signing this form.

- I agree to take part in the research.

Name (Printed)…….

Signature……. Date…….

Appendix 10: Consent Forms

10c – for the Person with Dementia, simplified version

Research study: 'How do family carers of people with late-stage / complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?' V1 May 2021 IRAS: 286118

	Please initial below
I have read and understood the information in the Information Sheet and had an opportunity to ask questions.	
I agree to participate in the Music Therapy sessions either face to face or online via Zoom.	
I agree to the video recording / Zoom recording of the sixth Music Therapy session.	
I agree to the use of my data as described in the Information Sheet.	
I agree that my anonymised quotes may be used in the final report of this study.	
I understand that I can withdraw from the study at any time without giving a reason.	
I agree to my GP or other care professional being informed of my participation in the study.	
I agree to take part in the research.	

Name: Date:

Signature:

Appendix 10: Consent Forms
10d – for the Music Therapists

Consent Form D

For Music Therapists

Research study: 'How do family carers of people with late-stage / complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?' V2 May 2021 IRAS: 286118

This consent form will have been given to you with the Participant Information Sheet. Please ensure that you have read and understood the information contained in the Participant Information Sheet and asked any questions before you sign this form. If you have any questions please contact a member of the research team, whose details are set out on the Participant Information Sheet.

If you are happy to take part in this research study, including recording and sharing for analysis the 6th Music Therapy session with the researcher, Maggie Grady, please sign and date the form. You will be given a copy to keep for your records.

- I have read and understood the information in the Participant Information Sheet which I have been given to read before asked to sign this form.
- I have been given the opportunity to ask questions about the study.
- I have had my questions answered satisfactorily by the research team.
- I agree to video record **(or record via Zoom)** the sixth session of Music Therapy with my clients who have agreed to be research participants.
- I agree to share this recording securely via UWE OneDrive with the researcher and then to delete my copy of the recorded session.
- I agree to the use of my data as described in the Participation Information Sheet.
- I understand that my participation is voluntary and that I am free to withdraw at any time.
- I understand that I can request the removal of my data up until the point of data analysis (4 months from the date this form is signed). I understand that from this point, my data would be anonymised and integrated into the data set and so could not then be removed.
- I agree to take part in the research.

Name (Printed)…….

Signature……. Date…….

Appendix 10: Consent Forms

10e – Consultee Declaration Form

Consultee declaration form

IRAS ID: **286118**

Participant Identification Number for this study:

Title of Study: 'How do family carers of people with late-stage / complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?'

Name of Researcher: Maggie Grady

	Please initial below
I [name of consultee] have been consulted about [name of potential participant]'s participation in this research project. I have had the opportunity to ask questions about the study and understand what is involved.	
In my opinion he/she would have no objection to taking part in the above study.	
I understand that I can request he/she is withdrawn from the study at any time without giving any reason and without his/her care or legal rights being affected.	
I understand that I can request his/her data is withdrawn from the study up until the point of data analysis, where all information will be pseudonymised and hold no identifiable features. This point will take place 4 months from the date of signing this form. At that point, all data will be anonymised and integrated into the data set and so it will not be possible for it to be removed.	
I understand that the sixth Music Therapy session would be video recorded **(or recorded via Zoom)** for analysis and shared with the researcher via secure UWE OneDrive. In my opinion, he/she would have no objection to this.	
I understand that relevant sections of his/her care record and data collected during the study may be looked at by responsible individuals from Mindsong and the research team at UWE (Maggie Grady, Dr Catherine Warner and Dr Gary Christopher).	
I agree to their GP or other care professional being informed of their participation in the study.	

Name of Consultee: Date:

Signature: Relationship to participant:

Researcher: Date:

Signature:

Appendix 11: Mindsong's COVID-19 Guidance

This guidance has been produced using the Government guidelines and regulations

1. Ahead of the session

- All parties (the therapists and the clients) must be well in order for the session to take place.
- Therapist must contact the client prior to their visit to check that the client is well and not self-isolating.
- Therapists should take a lateral flow test ahead of sessions and obviously only attend sessions if this is negative.
- If positive, we ask therapists to take a PCR test and not to visit clients until they have had a negative result.
- Any therapists who have a pre-existing medical condition should let the Director of Music Therapy know, so that we can ensure we are always following the best practice guidelines.
- As a rule, therapists should not enter the premises of someone who is self-isolating.
- Therapists should also not attend any sessions if they, or any member of their household is self-isolating.
- Therapists should not swap clients unless agreed by Mindsong. This is to minimise the chance of cross-infection.
- Keep your PPE in a separate bag. Your kit should include: reusable visor, face masks, washable bag, anti-bac wipes (and a container to put used wipes in) and hand gel. The bag you use should be as open at the top as possible so you can put used kit back in easily. If you are seeing two clients in one day, have 2 separate kits ready – only the visor can be used in both homes but must be cleaned between visits.
- Therapists should take their temperature ahead of visiting and if it is raised above their normal temperature then should not attend the session.

2. When working inside the house the therapist will:

- Before entering the home, sanitise their hands and wear a mask or visor.
- Ask clients to open all internal doors so handles do not need touching and to ensure good ventilation.
- Maintain 2 metre distance whenever possible, and a minimum of 1m +.
- Wipe any shared instruments with an antibacterial wipe prior to offering to the client and again when returned to the therapist. Place all used wipes in a suitable container – ideally one that can be put through a dishwasher or hot water.
- Use hand sanitiser throughout the session if required.
- Decline any drink or food from the client.
- Ensure that the number of people in the room remains as small as possible.
- If possible, ensure that the room is well-ventilated during the session.

3. At the end of the session

- Use sanitiser to clean your hands.
- Take any used wipes with you and dispose of at home. Do not remove any of your PPE until you are outside the house.

4. After the session – when you have left the home

- Remove PPE and place mask in a washable bag. If you have a 2nd session elsewhere you can use a new mask and add it to the washable bag after use.

- Carefully wipe visor with antibacterial wipes/spray in preparation for the next session.
- Keep your hand gel and package of wipes separately as you will need to wipe them down before using again. If you are immediately going on to another session, use a 2nd set for that next session.
- If possible, drive with windows open to allow good airflow.
- You may wish to change and wash your clothes after attending a session, again this should be done at 40 degrees. Your mask, in the bag, must be washed before using again at 40 degrees.
- On arrival at home wash your hands with hot, soapy water for 20 seconds and again after handling any unwashed items i.e. after loading the machine etc.
- Make sure any reusable PPE has been thoroughly cleaned, including wiping down any hand gel or packages of wipes.
- Keep 2 separate sets ready if you are seeing different clients on the same day. We advise keeping your cleaned PPE in your car boot and taking as little into your home as possible.

If you have any queries at any time, please do not hesitate to contact Maggie Grady.

maggie.grady@mindsong.org.uk

Appendix 12: Interview Schedule

Interview Schedule

V2 April 2021 IRAS: 286118

These interviews could take place face to face or online, and in one session or split into two or three sessions if this is more convenient for the family caregiver.

Interview 1: Pre-Intervention

Thank you for agreeing to take part in this research study. Are you still happy to take part?
I'm going to start the video recording now, is that ok with you?

1. Can you tell me a little about you and [name of person with dementia they're caring for]?
2. How has the diagnosis of dementia affected things?
3. You're providing aspects of care for [name], can you tell me what that entails?
4. What is it like for you, how do you feel about it?
5. How would you describe yourself as a person?
6. Has the dementia and your caring role affected this at all? If so, how?
7. Can you tell me a little about your relationship, has the dementia affected this?
8. Can you tell me about any support you receive?
9. Have you any thoughts on what might help / support your situation?

Interview 2: After Music Therapy session 6

Interpersonal Process Recall Interview

Thank you for your part in this research study. Are you still happy to take part?
I'm going to start the video recording now, is that ok with you?

During this interview the family carer and researcher (Maggie Grady) will watch a video replay together of the sixth Music Therapy session. The family carer would be encouraged by the researcher to stop the video at any point, reflecting on how he/she felt at that moment. The family carer would also be supported to choose one significant musical moment for analysis based on the selection criteria 'something important is happening here' (Bond, 2007). This selected musical moment becomes another data source for analysis.

Interview 3: Post-Intervention

Thank you for your part in this research study. Are you still happy to take part?
I'm going to start the video recording now, is that ok with you?

10. How are things for you both at the moment?
11. What has it been like for you, engaging in the Music Therapy intervention?
12. What has it been like engaging alongside [name of person with dementia]?
13. Has the Music Therapy had any effect on how you engage with each other generally, or with the wider family?
14. Has the Music Therapy had any lasting effects?
15. Have you used music more at other times of the day / aspects of care?
16. Is there anything else you'd like to say?

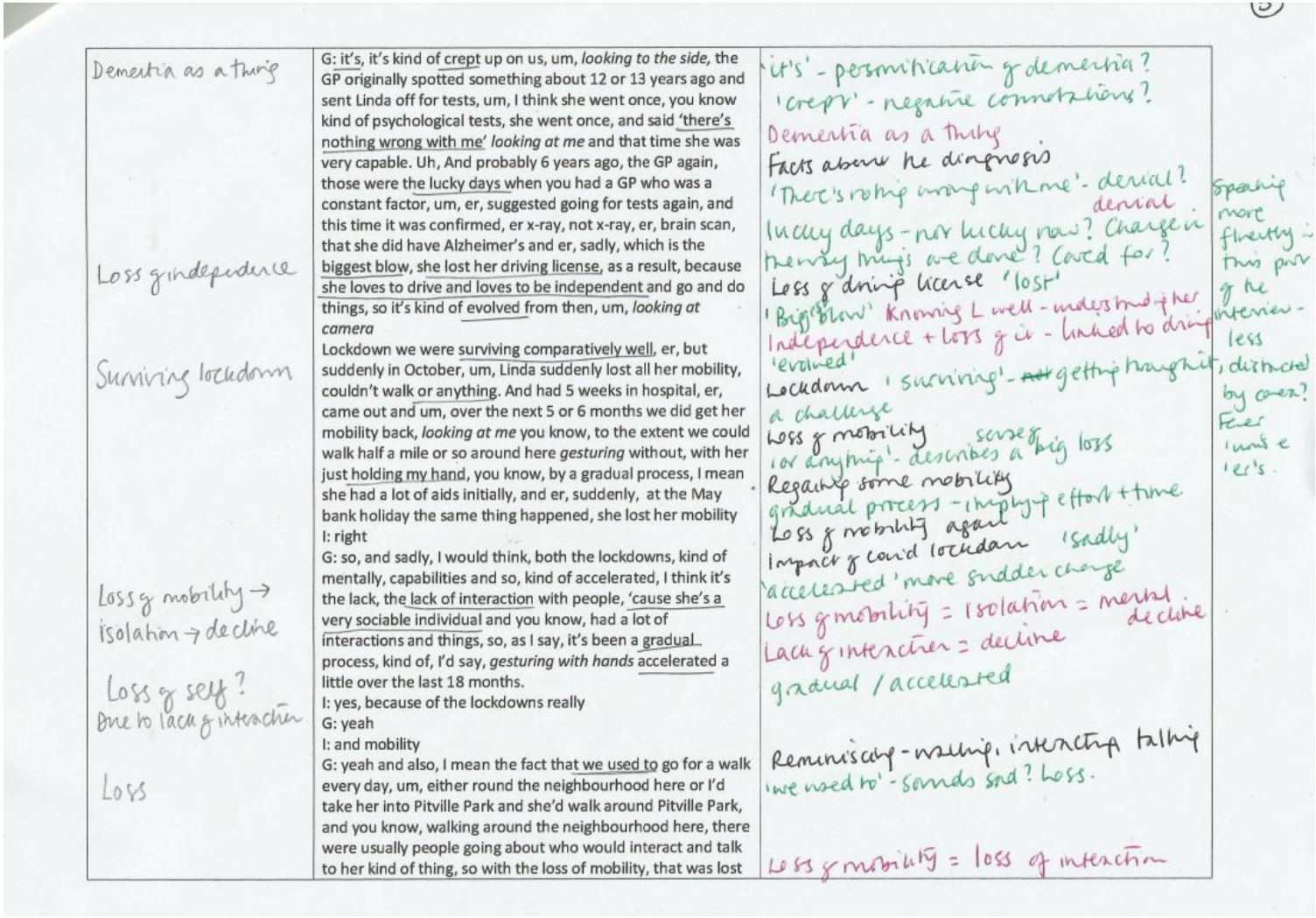
Appendix 13: Transcript Format

Video 1 Transcript – *Pseudonyms of Research Participants* (Case 1)

Initial Comments

Emergent Themes	Original Transcript	Exploratory Comments
The essence of the exploratory comments is summarised here, as 'emergent themes'.	The transcript from the video is written in this column. *Expressions such as laughter, smiles and other body language is written in italics.*	Exploratory comments are written in this column. This was done by hand and the key employed was as follows: descriptive comments in black pen, linguistic comments in green, conceptual comments in red, body language comments in pencil.

Appendix 14: Example of Transcript with comments



Dementia as a thing	G: it's, it's kind of crept up on us, um, *looking to the side,* the GP originally spotted something about 12 or 13 years ago and sent Linda off for tests, um, I think she went once, you know kind of psychological tests, she went once, and said 'there's nothing wrong with me' *looking at me* and that time she was very capable. Uh, And probably 6 years ago, the GP again, those were the lucky days when you had a GP who was a constant factor, um, er, suggested going for tests again, and this time it was confirmed, er x-ray, not x-ray, er, brain scan, that she did have Alzheimer's and er, sadly, which is the biggest blow, she lost her driving license, as a result, because she loves to drive and loves to be independent and go and do things, so it's kind of evolved from then, um, *looking at camera*
Loss of independence	
Surviving lockdown	Lockdown we were surviving comparatively well, er, but suddenly in October, um, Linda suddenly lost all her mobility, couldn't walk or anything. And had 5 weeks in hospital, er, came out and um, over the next 5 or 6 months we did get her mobility back, *looking at me* you know, to the extent we could walk half a mile or so around here *gesturing* without, with her just holding my hand, you know, by a gradual process, I mean she had a lot of aids initially, and er, suddenly, at the May bank holiday the same thing happened, she lost her mobility I: right G: so, and sadly, I would think, both the lockdowns, kind of mentally, capabilities and so, kind of accelerated, I think it's the lack, the lack of interaction with people, 'cause she's a very sociable individual and you know, had a lot of interactions and things, so, as I say, it's been a gradual process, kind of, I'd say, *gesturing with hands* accelerated a little over the last 18 months. I: yes, because of the lockdowns really G: yeah I: and mobility G: yeah and also, I mean the fact that we used to go for a walk every day, um, either round the neighbourhood here or I'd take her into Pitville Park and she'd walk around Pitville Park, and you know, walking around the neighbourhood here, there were usually people going about who would interact and talk to her kind of thing, so with the loss of mobility, that was lost
Loss of mobility → isolation → decline	
Loss of self? Due to lack of interaction	
Loss	

'it's' - permification of dementia?
'crept' - negative connotations?
Dementia as a thing
Facts about the diagnosis
'There's nothing wrong with me' - denial?
lucky days - not lucky now? Change in
denial
the way things are done? Cared for?
Loss of driving license 'lost'
'Big blow' Knowing L well - understanding her
Independence + loss of it - linked to driving
'evolved'
Lockdown 'surviving' - ~~not~~ getting through it,
a challenge
loss of mobility
sense of
'or anything' - describes a big loss
Regaining some mobility
gradual process - implying effort + time
Loss of mobility again
impact of covid lockdown 'sadly'
'accelerated' more sudden change
Loss of mobility = isolation = mental decline
Lack of interaction = decline
gradual / accelerated

Reminiscing - walking, interacting, talking
'we used to' - sounds sad? Loss.

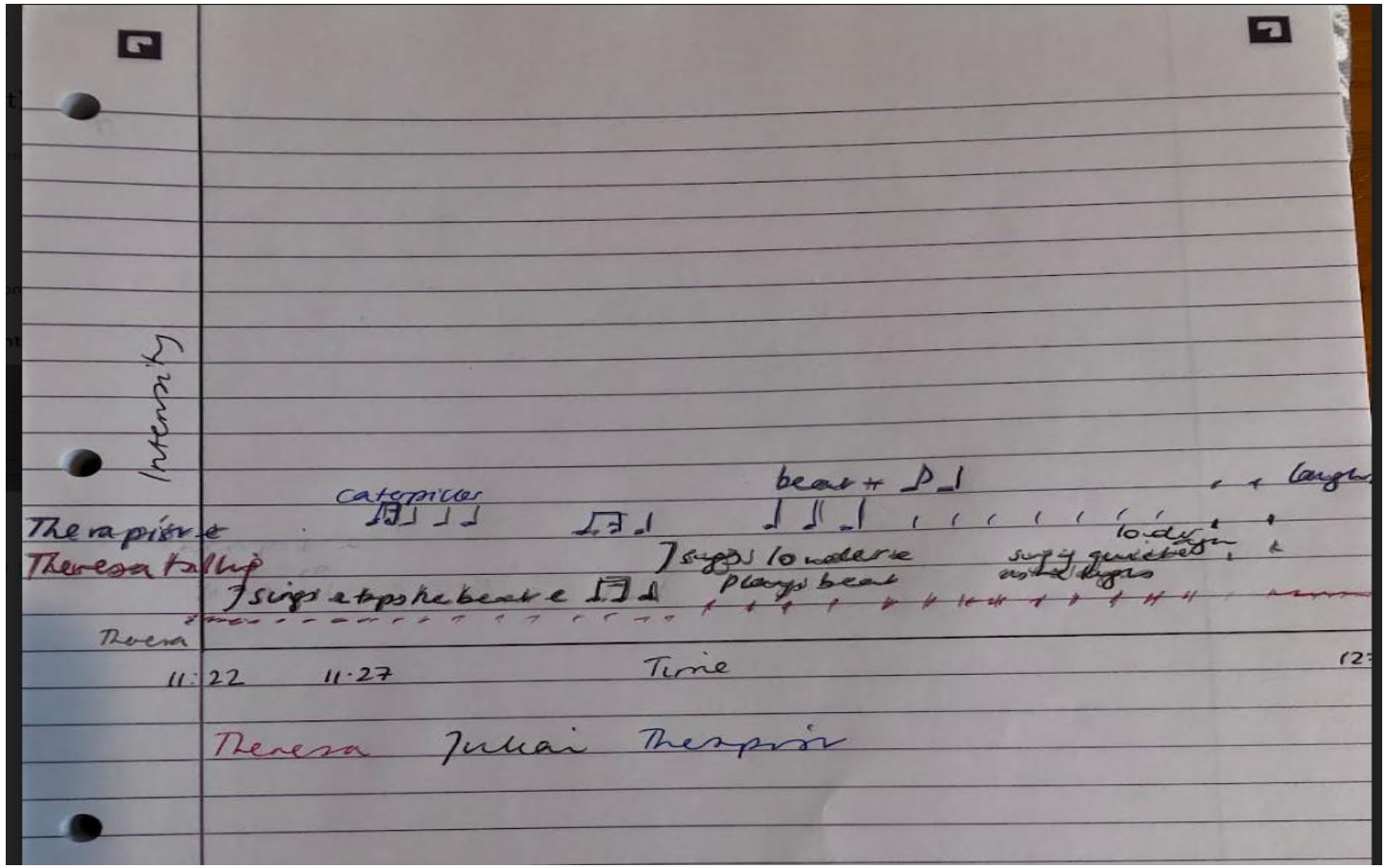
Loss of mobility = loss of interaction

Sparing more fluently - this part of the interview - less distracted by cancer? Fewer 'um's & 'er's.

Appendix 15: Table of evidence: Superordinate and subordinate themes with quotations for one case

Superordinate Theme	Subthemes	Examples from the text
1. Couplehood	Strength of, depth, love	Recounting getting married 'He just wanted to marry me'. P1 'I think that does help, if you have a loving relationship before' p6 'You know, when you've been together like us, over 60 years because, you know each other well.' P11 'You know each other's moods, instinctively know' p12 'he's the priority' p16 'He still tells me I make him feel sexy' p16 'we been good friends, as well as been in love with each other all these years.' P16
	Strength and depth of relationship makes caring easier but also harder to entrust to someone else	'I think that does help, if you have a loving relationship before' p6 'You know, when you've had such a relationship as we've had, you can't bear to, in fact you almost don't want to trust anybody else to look after him.' P16
	Marriage Vows – sense of duty	'when you get married, you say your vows, in sickness and in health, you know, for better for worse, this is that bit. Isn't it. It's that bit' p14 'do my job' p14 'be on duty' p12
	Changes in the relationship due to changes in identity, i.e. wife to carer	'I feel that I'm a carer, and not a wife' p4 Mismatch in the couplehood – 'he still thinks that I'm his wife and he doesn't realise I feel this way' p4 Changes in intimacy – 'He feels that he's perfectly, and of course he is, entitled to touch me and kiss me and hug me… But I don't want to do anything else. I couldn't… I don't know if there's something in you that just can't go back into that bit. I don't think I could cope at all really.' P11 'And you don't always feel very loved' [in return] p4

Appendix 16: Graphic Sound Intensity Profile



Appendix 17: Structural Model of Music Analysis (SMMA, Grocke, 2007)

Identifier	Components	Analysis from musical example
1.	*Style and form*	
1.1	Period of composition	1971, Country and Western
1.2	Form: sonata, ABA, verse chorus, etc	verse, chorus, chorus, bridge, chorus
1.3	Structure: predominantly simple or complex	Simple
2.	*Texture*	
2.1	(Predominantly) thick / thin texture	Predominantly medium texture
2.2	Monophonic, homophonic, polyphonic	Melody and accompaniment – guitar picking and drum
3.	*Time*	
3.1	Metre – 2/4, 5/4, 6/8 etc	4/4
3.2	Complexity and variability in metre	Same throughout
4	*Rhythmic features*	
4.1	Underlying rhythm of the work – consistent/inconsistent	Um cha – bass line bass note and chord on guitar
4.2	Important rhythmic motifs (notate)	Crotchet, crotchet, semibreve tied to a minim
4.3	Repetition in rhythmic motifs	This short short long motif is used throughout the chorus
4.4	Variability in rhythm – predictable/unpredictable	Predictable
4.5	Syncopation	Some syncopation in the verse

5	*Tempo*	
5.1	(Predominantly) fast, slow, moderate, allegro, etc	Moderate
5.2	Alterations in tempi: change of metre, use of accel and rit	Slight rit before first chorus, then back to tempo. Another slight rit into the bridge. Rit used to great extent at end of bridge going back into chorus. Lst chorus slightly slower. Rit at end of last chorus.
6	*Tonal features*	
6.1	Key structure, diatonic, modal	G major, same key throughout.
6.2	Major / minor alternations	None
6.3	Chromaticism	No
6.4	Modulation points of significance	No
7	*Melody*	
7.1	Main themes in the work	Melody in the chorus
7.2	Significant melodic fragments of each melody / theme	'take me home, country roads' bit – this is the bit that seems to spark the most interaction from Lucy.
7.3	Structure of each: propinquity, step-wise, large interval leaps	Lots of step-wise movement, some thirds and fourths
7.4	Intervals of each melody – conventional / unconventional / significant? E.g. octave	Mostly step-wise, some thirds and fourths
7.5	Shape of each melody – rounded, ascending, descending	Melody ascends, and then falls, in the verse and chorus. In the bridge it ascends and there is a pause on the highest note, before the music leads back into the chorus.

7.6	Length of phrases in each melody: symmetrical, short, long	Mostly 2 bar phrases, except in the bridge, 4 bar phrases, then 2 bar phrases, then back into the chorus.
7.7	Predominant pitch range: high/medium/low register	Medium, although it's sung in a key where The therapistand Gordon have to change octave to reach the notes.
8	*Embellishments, ornamentation, articulation*	
8.1	Trills, appogiaturas	None
8.2	Marcato, accents, detached bowing	None
8.3	Pizzicato	Picking in the guitar
8.4	Legato	Vocal line is legato
8.5	Use of mute	None
9	*Harmony*	
9.1	Predominantly consonant or dissonant	Consonant
9.2	Consonance / dissonance alternation within the work	None
9.3	Significant harmonic progressions	Bridge ends on the dominant 7^{th}, pulling the music back to the tonic.
9.4	Rich harmonies	Simple chords: I, VI, V, IV etc. Use of flattened 7^{th} (major) chord in the bridge
9.5	Predictable shift in harmonies (e.g. I, IV, V progression)	As above
9.6	Unpredictable harmonies	Not really
9.7	Cadence points – perfect, imperfect, interrupted	Plagal, imperfect and perfect cadences used.
10	*Timbre and quality of instrumentation*	

10.1	Vocal – solo/SATB or other	The therapist and Gordon's voices, sometimes Lucy can be heard
10.2	Instrumental - solo	No
10.3	Instrumental – orchestral	No
10.4	Small group, e.g. quartet, combination of instruments	Guitar and drum
10.5	Instrument groups – distinctive timbre colour	
10.6	Interplay between instruments and instrument groups	Guitar and drum continue throughout.
10.7	Layering effects (adding and reducing instrument groups)	
10.8	Resonance	Voice is the most resonant in the music.
11	*Volume*	
11.1	Predominantly loud or soft – alternations between / gradation	Predominantly mf. Some gentle crescendos, more diminuendos.
11.2	Special effects of volume: pp, ff, sfz	Softer when Lucy joins in – to bring her through the texture?
12	*Intensity*	
12.1	Tension / release	There is tension built at the end of the bridge, on the dominant 7^{th}, leading back into the familiar chorus. Also, there is anticipation of the chorus each time it comes,.
12.2	Cresc, building to peak, and resolution	In the bridge towards the end. Otherwise, natural flow of the song.
12.3	Tension in harmony, texture etc, and resolution	In the bridge, as above.
12.4	Delayed resolution or absent resolution	Pause on the end of the bridge.
12.5	Ambiguity in whether resolved or unresolved	None

13	*Mood*	
13.1	Predominant mood, as depicted by melody, harmony, insts.	Gentle mood, happy, swaying.
13.2	Feelings and emotions represented	Happy, calm.
14	*Symbolic / associational*	
14.1	Culturally specific associations, e.g. English idioms RVW	American country and western song. Connotations with 'home' – 'take me home'.
14.2	Metaphoric associations, e.g. horn call	
14.3	Symbolism in motifs (leitmotivs) imagery potential – visual, auditory or kinaesthetic	Lyrics – evoke West Virginia. Symbolism of 'home'.
15	*Performance*	
15.1	The integrity / authenticity of the performers	
15.2	Excellence of the performance (is this relevant?)	
15.3	Stylistic interpretation – artistic merit	
15.4	Articulation of feeling and emotion	
15.5	Authenticity with composer's intent	
16	*Therapeutic techniques*	
16.1	Holding	Guitar – constant rhythm. Drum pitter patter. Presence of the warm, full vocal tone of therapist.

16.2	Matching	Matching apparent mood – gentle, calm. Matching Lucy's finger movements at the end with gentle picking on the guitar.
16.2	Pacing	Slowing down and quietening when Lucy sings but keeping the momentum. Slowing down at the end.
16.3	Inviting	Slowing down at end of verse, bridge, making a bit more of 'coun-try' and then back to tempo. Allowing Lucy's sounds to come to the fore.

Appendix 18: Table of evidence: Superordinate and subordinate themes with quotations for all cases

These tables detail the sources for verbatim quotations used in the Findings chapter. The quotations are taken from transcripts of the interviews.

Superordinate Theme 1: Relationships

Superordinate Theme 1: Relationships		
Subordinate theme	**Source: case and interview number**	**Evidence**
1. Different familial relationships between the person living with dementia and family carer	Case 1, 4, 5 and 6	The four spousal relationships are very close
	Case 1 – interview 1	Gordon: 'we've been married, what, 56 years next week' *says with eye contact and a smile*
	Case 4 – interview 1	Theresa: 'we been good friends, as well as been in love with each other all these years.'
	Case 5 – interview 1	Kelly: 'it's true, there was no beginning and we both feel there'll be no end. Yeah.'
	Case 6 – interview 2	*Daniel sings 'Make you feel my love', Hazel joins in, words not really discernible. I join in too. Daniel has his arm around Hazel and keeps looking down at her.*
	Case 2 – interview 1	Maria: 'I'd been with my Mum all through my life, every single day' 'Mum is my life, she's my world'. '[Mum was always] very, very family orientated'
		Leo: 'It's very *[pause]* but you've got to get through, you've got to be there for Nan'
		Leo: 'completely lost my life'
	Case 2 – interview 2	Maria to her Mum: 'You're the star there, love, you're the star'
	Case 3 – interview 3	Leo: 'it's absolutely lovely to be able to join in, to see her smile'

	Case 3 – interview 1	Nia: ‘so I am the only girl, so I have inevitably, but with absolute willingness, been the person that [oversees the care]’. Nia: ‘we have a relationship we would never have had if it wasn’t for Alzheimer’s, and I’m much, much, much closer to him now’ Nia: ‘when I was growing up and going to Arts School, and he just couldn’t bear the mess and you know the sort of um... that sort of, he just didn’t understand it.’ ‘he’s not an easy man’.
	Case 3 – interview 2	Nia ‘it was like they were in their own … thing going on.’ Nia: ‘I was probably annoying him because I’m not doing it very well’
	Case 3 – interview 3	Nia: ‘I want to give him the gift of playing it’ Nia: ‘because I’m not very good’
2.Couplehood in spousal relationships	Case 1 – interview 1	Gordon: ‘we’ve been married, what, 56 years next week’ Use of ‘we’ throughout the text. Gordon: ‘a kind of adventure’ Gordon: ‘I always tried to get something most days, er, activity to help us’ Gordon: ‘we have our own personal battle of the roses’ Gordon: ‘we haven’t decided yet which, there’s the house of Lancaster and the house of York that’s won yet’ (‘we’ = solidarity despite individual identities) Gordon: ‘um, we’ve had a, kind of adventure, over the 50 odd years we’ve been married … so, er, just got to, as I say, take the rough with the smooth.’ ‘she’s always been the social one, I’ve been the quiet, reserved one’. ‘We used to’
	Case 1 - interview 2	Interviewer: And what's that like for you? What was that like for you, that interaction there? Gordon: Um, it's good, it's good to see Lucy, you know when she does sing, participating. Er, but I mean, the other thing is it's good to see her happy, er which, you know, you've seen today she's happy, most of the time, and she's happy when she's interacting

	Case 1 – interview 3	Lucy: (referring to dancing) 'it might be but you weren't here, I was referring to Gordon ... if we'd like to do that' Gordon: 'We've always done things together a lot' Gordon: 'We've always tended to have music' Gordon: 'Well, I mean, we've always, we've done things together a lot, so it was good ... to be able to encourage Lucy to participate.'
	Case 4 – interview 1	Theresa: 'He just wanted to marry me'. 'We're in our diamond year this year' 'I think that does help, if you have a loving relationship before' 'You know, when you've been together like us, over 60 years because, you know each other well.' 'You know each other's moods, instinctively know' You know, when you've had such a relationship as we've had, you can't bear to, in fact you almost don't want to trust anybody else to look after him.' 'He still tells me I make him feel sexy' 'we been good friends, as well as been in love with each other all these years.' when you get married, you say your vows, in sickness and in health, you know, for better for worse, this is that bit. Isn't it. It's that bit' 'do my job' 'be on duty'
	Case 4 – interview 2	*Theresa initiating engagement and physical contact from Julian e.g., pg1* *Eye contact, smiling, laughter and singing together in reaction to the music on the video, e.g., pg3* *Physical closeness, e.g., rubbing J's hand, pg9 Smiling, eye contact, communication and laughter between the two* Theresa: 'I kiss him in the morning…and then he says 'that's lovely, made my day'

	Case 5 – interview 1	Ray: ‘we’ve adjusted to each other quite well’ Kelly: ‘we have literally been together more or less, 24/7’ Kelly: ‘we’ve had our ups and downs everybody does’ Kelly: ‘He gets frustrated and I get frustrated and we shout at each other’ ‘I think that’s quite healthy, shouting’ ‘ … you have to fall out to make up, don’t you!’ Ray: ‘Randy!’ Interviewer: ‘It’s amazing that you’re so open with each other, that you can have these conversations’ Kelly: ‘yeah, oh no, we always have been, that has been a big help, I think’. Kelly: ‘he’s, as we joking call it, losing his marbles’ Ray: ‘demented!’ Kelly: ‘… so we are jokey, and because the alternative is sit and cry and be miserable’ Kelly: ‘it’s worse than having a child actually, because it’s more responsibility’ Ray: ‘this little child argues!’
	Case 5 – interview 2 From the MT video	Kelly: ‘that’s mine and R’s song’ ‘It’s true, there was no beginning and we both feel there’ll be no end. Yeah.’ ‘it’s actually, the first time we went to bed together, that was announced number one.’ Kelly: ‘That’s mine and Ray’s song’. Ray: That’s a nice song. Kelly: Yeah, that’s our song. Ray: That’s Wet, Wet, Wet that sang that. Kelly: Yep, that’s our song Ray: That’s lovely.

	Case 6 – interview 1	Daniel: 'we get on with it' D: 'we both' Hazel: 'I'm not like that' Daniel: 'yes you are' Hazel: 'no I'm not' Daniel: 'yes you are' Hazel: 'you're annoying as well.' Daniel: 'I'm annoying as well?' Daniel: 'she's going to go off [to sleep]' Hazel: 'I'm not' Daniel: You're not! *D and I laugh* Hazel: 'you're not old' '… you're not grizzly'
3.Symbiosis in the relationship between person with dementia and family carer	Case 1 – interview 1 Case 1 – interview 2 Case 2 - interview 1 Case 2 - interview 2 Case 4 – interview 1	Gordon: 'We used to...' Gordon: 'she's happy when she's interacting, er with people... I mean she's always been like that, I've been the quiet reserved one... She's been the outgoing one'. Gordon: 'she's always been the social one, I've been the quiet, reserved one' Interviewer: And what's that like for you? What was that like for you, that interaction there? Gordon: Um, it's good, it's good to see Lucy, you know when she does sing, participating. Er, but I mean, the other thing is it's good to see her happy, er which, you know, you've seen today she's happy, most of the time, and she's happy when she's interacting. Maria: 'Mum is my life; she is my world … when there's nothing... I don't know how I'm going to cope then' Maria: 'We love it, don't we! It makes me happy because it makes Mum happy' Theresa: 'I don't think I can carry on much longer really, and still be me'.
4.Relationships reconfigured by Dementia	Case 2 – interview 1	Leo: 'I can't stay friends... I haven't had a girlfriend in how long' Leo: 'he's been my rock, he's been my best friend my whole life.... and he's just like, washed his hands of her.'

	Case 3 – interview 1	Maria: 'my uncle... was going down the same road as my Mum and so he's really distanced himself because I don't think he can cope with going through the rawness of it' Maria: 'Sometimes she sees me, I'm all of her sisters, I'm her mother...I'm Mrs Black when she's in a rage' Maria: 'I am the focus of all her memories, her life. Because I look like her sister...' 'When she's screaming and shouting and hitting you and you know, it's really hard … it is full on and it does break you' 'it's heartbreaking' Leo: 'there's so many things, due to Nan's age and the life she's lived...' 'she wouldn't get treated nicely' Nia: 'we have a relationship we would never have had if it wasn't for Alzheimer's, and I'm much, much, much closer to him now' Nia: 'I'm quite angry with my brothers, because, especially one of them, has um, the one who lives really nearby, they've just chosen to totally withdraw from him, for their own reasons, but um they're, they're, it's so unacceptable, so I've spent quite a lot of time being quite angry about that, and now I just don't bother … so I don't understand that, that's what I found difficult' '[support] in terms of my family, little bit up from zero' Nia: 'we don't talk to each other anymore' p6 'I've been slapped on the wrist for being mean and nasty' 'not an easy man' Nia: 'he's very lonely ... lots of his friends have dropped away.' 'He gets very few visitors which is really sad'. Nia: 'He's completely in love with my dog ... I'm not allowed to visit him without [name of the dog] the dog, and [name of the dog] gets on his bed, and Dad talks to him all the time. Dad was never a dog person before.'
	Case 4 – interview 1	Theresa: 'I feel that I'm a carer, and not a wife' Theresa: 'He still thinks that I'm his wife and he doesn't realise I feel this way' 'He feels that he's perfectly, and of course he is, entitled to touch me and kiss me and hug me… But I don't want to do anything else. I

		couldn't… I don't know if there's something in you that just can't go back into that bit. I don't think I could cope at all really.' 'And you don't always feel very loved' [in return] 'I try not to show that side, because it's negative and I don't want to be negative if I can help.'
	Case 4 – interview 2 Case 4 – interview 3	Theresa: 'I try to keep him cheery … and keep him as happy as I can', 'I'll have a cry with them, not very often, because … at the end of the day, I also realise that he's their Dad and they love him to bits'. Theresa: 'they didn't connect with him like they normally have in the past… I think they think they're deaf and blind and dumb, just because they're quiet.'
	Case 5 – interview 1	Kelly: I think the only, I'm sure Ray won't mind me saying, the only, for me it's affected, is the sexual side, because it's, it's Ray is, becoming quite *laughs and looks at Ray* Ray: randy! Kelly: *laughs* I was gonna say [pause] where I'm not that bothered, I can like it or leave it if you like. But again, I know they have said, Mr A [consultant], he has said if it does become a problem, we can put him on some medication Interviewer: ok Kelly: but it, it was a problem, but it's, well, I think mainly because we have been sleeping in separate bedrooms when we had covid Interviewer: yeah of course Kelly: I say, we can, I mean it's not so much a problem that it, but I think Ray had great trouble, he thought I'd gone off him and all sorts of things, *looking at Ray* Interviewer: oh Kelly: I think that's probably affected him more that it has me, but I'm sure we'll come through it, most things we sort out! Ray: *mumbles something inaudibly* sorry, it's your story.

Superordinate Theme 2: Experiences of Dementia

Superordinate Theme 2: Experiences of Dementia		
Subordinate theme	**Source: case and interview number**	**Evidence**
1.The Caring Role: All-consuming and Relentless Emotional Toll Challenging dementia symptoms	Case 1 – interview 1	Gordon: 'Take the rough with the smooth' 'it's, it's kind of crept up on us, um …' Gordon: 'it doesn't leave a lot of time to do anything.' Gordon: 'disheartening' 'disappointing', '[going] through the troughs and get back on the crest of the wave again.' Gordon: 'trying to claw back', 'fight the decline' and 'combat'. Gordon: 'a big blow' Gordon: 'And sadly, I would think, both the lockdowns, kind of mentally, [decline of] capabilities and so, kind of accelerated, I think it's the lack, the lack of interaction with people, cos she's a very sociable individual and you know, had a lot of interactions and things.' Gordon: 'tied' Gordon: 'very active person'. 'I think at the moment what would help is getting Lucy to be able to go outside again'. Gordon: 'jungle', 'which I enjoy'. Gordon: '[they] kind of knocked out all the activities that [Lucy] was taking part in, er, so there wasn't that ability to go out, and do things and interact with people'. Gordon: 'at least it's not been a very sudden impact' Gordon: 'there's no kind of constant thing'

		Gordon: ‘rollercoaster’ ‘plunge’
	Case 1 – interview 2	Gordon: ‘a lot of other interactions here *[gesturing towards the video]* are kind of in a way, obviously not relevant, but not er, directly, kind of related to what's going on’.
		Lucy: ‘And I was a bit worried then, because, because when I realised that um, I didn't think about the time. It was just a thing at the time, that we were going down’.
		Lucy: ‘What time is it? Gordon: 10 past 12. Lucy: What time do you think we'll get home? Gordon: We are at home.’
		Lucy: ‘And then the other thing we had yesterday night, was it yesterday, or was it, I don’t know when it was yesterday, where were we yesterday?’
	Case 2 – interview 1	Leo: ‘I’ve completely lost my life’
		Leo: ‘I have no life; my whole life has gone … I’ve had to, I’ve gone from starting a new business this year, completely retraining everything to having this and having to drop it … and, leave, leave everything, um, leave business partners, and just have everything go’
		Leo: ‘I can’t stay, friends ... I haven’t had a girlfriend in how long ... I’ve completely lost my life.’ ‘I’m terrified.’
		Maria: ‘a beautiful, beautiful, wonderful lady’ ‘when the devil comes in’
		‘horrendous’ ‘heartbreaking’ ‘rarely there’
		Maria: ‘When she’s screaming and shouting and hitting you and you know, it’s really hard … it is full on and it does break you.’ ‘she wouldn’t get treated nicely’
		Maria: ‘but come 7 o clock, and it’s, you know, it’s time to start thinking about going upstairs *gesturing with hands* having a lovely shower, time to clean, um, if she’s not in the right space she will get angry, violent, um, she’ll beat me with her granddad stick, she’ll pinch me, she’ll punch me *M starts crying a little* She’ll kick me in the head, um, if I’m on the floor helping, taking her pants off, her incontinence pants, and

	Case 3 – interview 1	she's maybe had an accident and she feels shamed, she'll then get angry with me because *gesturing with hands* you know, she deflects her shame Maria: 'and so then she'll throw, excuse me, shit covered pants, push them in my hair, hit me with shitty towels that she's trying to bung up and clean herself with *does this action* because she doesn't want to accept help because she's embarrassed, now that's terrible. You know, and I really feel awful because she'll just **scream** at the top of her voice and 'Fuck off, get out of my house, this isn't your house, I don't want your help' and in the meantime she's like beating *breath in* It's mainly me she hits because I'm the easiest I suppose, um' Maria: 'And sometimes she sees me as, I'm, I'm all of her sisters, I'm all of her sisters, I'm her mother, and sometimes I'm her daughter, but I'm, I'm girly, I'm Rose, I'm Iris, I'm Mrs Black when she's in a rage. I'll say, I'll sit down and I'll hold her face *Puts her hands to her face* and I'll gently stroke her *strokes her face* and I'll say 'look at me love, come back, come back, look at me' and I'll say 'who am I?' *leans towards me* 'You're Mrs Black' *(in an angry voice, leaning forwards to me)* Maria: 'She's a beautiful, beautiful, wonderful lady. And she can't help it, we all know that she can't help it.' Maria: '[we're] dual caring, because we, the strain is too much, one person cannot deal with it all.' Maria: 'we're all walking on a razor's edge'. Nia: 'I don't' feel overwhelmed by it.' Nia: 'So support wise, in that way, amazing. But, I mean, you know, he's a well-off man, so, there isn't a problem with money and finances.' Nia: 'they're amazing, and so the team around him are fantastic, and I love them, and we get on really well' Nia: 'We have a relationship we would never have had if it wasn't for Alzheimer's, and I'm much, much, much closer to him now.' Nia: 'in every way it could do'

	Case 4 – interview 1	Nia: 'a very clever man, and sadly, you know, a long way, a further way to fall.' Nia: 'He's lonely, he doesn't know where he is, all the time he's confused about where he is ... sometimes he's ok about that but mostly he's upset.' Nia: 'he's very shuffly and immobile, so um, spends a lot of time in bed, which is sad, for me.' Nia: 'with absolute willingness': 'I'm in it for the long haul'. Nia: 'he fought it for quite a long time ... he's fought it really hard' Nia: 'he stopped driving which he really fought against too' Nia: I had a great big plan to get him to Westonbirt, I'd hired a wheelchair, hadn't told him about that, but anyway, you know … I couldn't even get him out of bed, I had to cancel it. Nia: But he's really lonely. *[Nodding]* And his carers are lovely but they don't really do, they don't, they can't take him out and do things, you know. He could really do with that, but it's difficult, he's not an easy man, so trying to get him to, I seem to be the only person who can get him out to do anything *[laughs]* Theresa: 'It's completely taken over … I haven't got my own life anymore, not at all, not in any way.' Theresa: 'very, very broken hearted' and seeing her friends: 'it would have been lovely to have stayed with them and chatted a bit'. Theresa: 'it's just heartbreaking. Heart-wrenching.' 'I'm finding it very difficult to always be cheery … I'm crumping a bit now. And um, finding it emotionally harder as well … I just burst into tears.' Theresa: 'It's non-stop, it's incessant … you're like a Mum with a new baby'. 'You need endless patience and of course lots of love … Got to be a strong person to do it.' Theresa: 'I get this awful anxiety ache, deep in my tummy' '[it was] the only way I could switch my head off'. 'just tried my very best to keep everything going along as much as I can.

	Case 5 – interview 1	Theresa: 'He started to get very, um aggressive, almost as if he wanted to argue … one little word that you say, that he will take it the wrong way, um, he'll be angry and throws things down, and he stamps off like a naughty boy.' Theresa: 'It's gone down and down, less and less is now being able to be done … There's still the sympathy, it's still there, although of course, two moments later it's gone.' Theresa: 'No memory. Not of anything, anybody, anywhere, there's nothing.' Ray: 'I'm still in early stages.' Kelly: 'I used to go out … I can't do that anymore because he can't be left on his own' 'I'm constantly keeping an ear out' Kelly: 'When [name of doctor] came this last, he scored 10 out of 30, in a year, which is a big …'. Kelly: 'I do everything else' and that Ray 'can't be left on his own.' Ray 'I don't feel that I am different in any way', Kelly: 'it has affected things, obviously, because like, I used to go out … I can't do that anymore because he can't be left on his own.' 'cos that was my love.'
	Case 5 - Interview 2	Kelly: 'It affects me *[crying and gesturing downwards movement with hand]* because I don't want to think about it because I know what the future's gonna be and obviously it's going to be hard, but I know I will cope.' Kelly: 'they're not such fun, as you can imagine', 'He gets frustrated and I get frustrated and we shout at each other … you have to fall out to make up, don't you!' The diagnosis was 'quite a shock'
	Case 5 – interview 3	Kelly: 'A few weeks ago, he was talking about going into the woods and not bothering to come back, but I think it was because, I mean, we're still waiting for a full assessment for his care plan, and there was just so much going on, different assessments, and I think it was just all too much.'

	Case 6 – interview 1 Case 6 – interview 2	Kelly: 'I was really down … I hadn't slept for the past two nights and I really was down in the dump and I just wanted to go to sleep and not wake up.' In this instance, it was the music therapy that 'lifted my spirits'. Daniel: 'full time carer' Hazel: 'anxiety' 'funny turn', Daniel: 'a meltdown', 'she goes off on one', 'got one on her' 'anxiety meltdown'. Daniel: 'Hazel, at times, is perfectly happy and lucid and so on, and then, I don't know what you call it, whether it's a meltdown, or she goes off on one … Parkinsons is strange because it varies from Hazel being able to walk around perfectly ok, to not being able to walk at all. … She is so variable.' 'bashed' 'damaged' 'her balance is so poor.' Daniel: 'I can cope with the physical Parkinsons side, but the mental side, is very tricky.' 'Sometimes, I'm extremely stressed out … um, so I drink red wine, probably too much … you know like, just, I can't get anywhere.' Daniel: 'a trial' 'battle on'; 'a continuing nightmare', 'I get annoyed and upset sometimes, but I think it's better to be annoyed and upset than to bottle it up'. Hazel: 'It was when I was little … I was much bigger than I am now, but was little … and I saw these people … in my dreams. And they made me scared.' Hazel: 'I might be a little bit funny, because I do have a problem … and if it gets out of control, I may have to go to my bed.' Hazel: 'lots of wobbly' Hazel: 'it's much nicer than going anywhere else, to go to bed' Hazel: 'just a little bit of an issue' Hazel: 'I was this person,' and 'before I went …'.

		Hazel: 'yes, I'm sorry … I can't help it'. Hazel: 'silly person' Hazel: 'Oh I sound awful! Listen to me!' 'I'm no good … at singing.' 'What are we going to sing?' Daniel: 'we can sing him away.' Daniel: 'I need all the help I can get' '
2. Fear Surrounding diagnosis Of the future, what might come Of losing oneself and not coping Of another covid strain and lockdown	Case 1 - interview 3 Case 2 - interview 1 Case 4 – interview 1 Case 4 – interview 3	Gordon: 'a little fearsome of, a fear of what the new coronavirus might bring up'. Gordon: '[they] kind of knocked out all the activities that [Lucy] was taking part in, er, so there wasn't that ability to go out, and do things and interact with people' Maria: 'the second you put her into a home ... we don't even give her 12 weeks.' Maria: 'they were eyeing Mum's house up'. Maria also spoke of her lawnmower being a target: Maria: 'they were trying to steal my lawnmower'. Maria: 'shove Mum in a hospital, bed-block, covid 19, it's all on the increase again' Theresa: 'it was a bit scary' 'whether we'll be spared' Theresa: 'Shock – we were just stunned. We knew that life was never going to be the same again … It was very scary.' 'that's the last thing in the world you would want to have'. 'there's no end to it really, and I know the worst is to come, I know the worst is to come, which is frightening' 'And I keep it up together because if I let go, I'll never catch up, you know? ... that it's not going to overwhelm me, so I can't do my job to look after him.' : 'I don't think I can carry on much longer really, and still be me'. Theresa: 'He sometimes forgets who I am, which is a bit scary. It's gonna happen, I know it's gonna happen, yeah.'

	Case 5 – interview 1	Kelly: 'It's the knowing in what's going to come in the future, I think he doesn't want to think about that, do you?' Ray: 'I suppose not.' Kelly: 'It affects me [*crying and indicates downwards movement with hand]* because I don't want to think about it because I know what the future's gonna be and obviously it's going to be hard, but I know I will cope.
Traumatic experiences	Case 4 – interview 3	Theresa: 'And so, I had two days in hospital with him, and he stayed in, I didn't leave until 12, … he'd just fallen asleep on a trolley. No beds. … I was absolutely done up, and I came home, I went to bed, I didn't really sleep, I cried a lot.' Theresa: 'dreadful experience' Theresa: 'I was feeling really ill myself … and I had a bit of a breakdown at the end of the next week, 'cos I'd looked after him night and day. I didn't have any rest, snatching a, half hour here or there, frightened he was gonna fall out of bed. I wasn't fine of course. And I'd had a physical and mental breakdown. I had like a *[circles on top of her head with her hand]* the top of my head was like a cloud, I couldn't think straight, I couldn't make decisions. I've never been like it in my whole life, I completely lost the plot. So stress, I suppose, and lack of sleep, anyway, the combination put me down, for the first time.' Theresa: 'because very often, as the carer, you're left to your own devices' Theresa: 'Nobody … if we hadn't been with him … nobody offered him, or indeed us, a glass of water or a drink. Nobody came to us and told us why we were sitting there and what we were waiting for.' Theresa: 'I could see him sat, outside this little room where they put us, which was off the main ward, in a chair, in his underpants and his shirt that he was wearing the day before, and he was wet, he hadn't been washed or shaved, nothing, nothing at all. He looked absolutely lost.' Theresa: 'I didn't know what to do because, what do you do, when nobody tells you what's happening?' Theresa: 'It's taken, it's 8 weeks ago now, um, and I've adjusted again.'

	Case 5 – interview 1	Kelly: 'nasty' 'somersault' 'black Ray: 'I had this phone call from the hospital … she was isolated, she was, she'd been attacking people' Kelly: 'like something out of a horror movie … this little old lady in this bed that had been pulled away from the wall surrounded by blood on the floor.' Kelly: 'if it had been anyone else, there's no doubt, he'd have gone to hospital.' Ray: 'Fortunately, I said "no, I 'm not going to hospital!"' Ray: 'I didn't enjoy my hospitalisation, I really didn't.' Kelly: 'Towards the end, she started speaking Welsh … well, just recently, [Ray] has developed a love for Welsh music … which I think is quite interesting.'
	Case 6 – interview 3	Daniel: 'Hazel was in hospital, because she was very poorly, and just lying there, not moving, unfortunately no stimulus, and very often you [*addressing Hazel and hand lightly on her arm]* were sleepy, weren't you … physically going downhill quite badly.' Daniel: 'I mean they're working on the medical front, but it's not quite the same as the emotional front … in hospital, there was no stimulation … Literally just be laying there 24 hours a day, awful … so hospital's not a good environment. … There was no other stimulus. You can understand providing that sort of close care and attention would be impossible for the NHS, because they basically have to have someone like me sitting next to the bed all day … they can't afford that. So, I understand that, but I'm glad to get her out.' Interviewer: 'Is that what happened in hospital?' Daniel: 'Absolutely, the nurses were absolutely amazed, would come and look, or tell their friends "come and have a look at this", because they'd see Hazel laying there going 'ahh, ahh', and then I'd come along and play a Spotify, Elvis Presley, or something, and 'ahh ahh' would turn into *[sings a tune to ah],* in time with the music … well then, she would sing the words. And they were all amazed. And in fact, I know that one, two of the nurses went and sang to her, cos they picked up on it.'

		Interviewer: 'That's lovely, that's really lovely. And nothing else would bring that kind of response?' Daniel: 'No, no, talking, shaking her, nothing you know' Interviewer: 'Gosh' Daniel: 'Mm, it's the only thing that got through.'
4. Views of the Care System	Case 1 – interview 1 Case 2 – interview 1 Case 4 – interview 1 Case 6 – interview 1	Gordon: I mean there's a team, a unit, call it what you will, locally in the NHS called the complex care at home, I don't know if you're aware of them? Interviewer: yes Gordon: And they've been very good, very helpful, um, setting things up, you know they've done this chair and other things, and again, talking about ways of getting access for Linda to go outside, so it's kind of still in the development stage, I mean they only got involved about a month or so ago, but um, you know so far they've been very supportive, so yeah. 'diabolical … despicable … abandoned … terrible'. Their experiences have led them to believe that the whole care system is 'systemically broken' 'disgusted and horrified … it's abuse … how easy is it to pick up a white commode, to tip it to the side and check the colour of the pee.' 'completely lost my life' and Maria attempting suicide: 'I couldn't cope, and it just broke me'. 'huge failures' 'we are the enemy because we are the only ones who care, because we have cameras.' 'I was shocked, honestly, I was shocked.' 'I know times are tough … I can see what's happening with the care sector … the hospitals, everywhere. But it doesn't make it any easier to bear …. you're going to have to carry on.' Daniel: 'They're very good, we get excellent support from everybody'.

	Case 6 – interview 3	Interviewer: 'oh that's good.' Daniel: 'and the doctor, I know a lot of people complain about their GPs, we think the [name of surgery] where we go is fantastic. You know, very, very responsive, and they have a frailty team' Interviewer: 'brilliant' Daniel: 'who come round and check up on us, and you can phone anytime, you know, so all good.' Daniel: 'Hazel was in hospital, because she was very poorly, and just lying there, not moving, unfortunately no stimulus, and very often you [*addressing H and hand lightly on her arm]* were sleepy, weren't you … physically going downhill quite badly.' 'I mean they're working on the medical front, but it's not quite the same as the emotional front … in hospital, there was no stimulation … Literally just be laying there 24 hours a day, awful … so hospital's not a good environment. … There was no other stimulus.' 'You can understand providing that sort of close care and attention would be impossible for the NHS, because they basically have to have someone like me sitting next to the bed all day … they can't afford that. So, I understand that, but I'm glad to get her out.'
5. What helps?	Case 1 – interview 1 Case 2 – interview 1 Case 3 – interview 1	Gordon: 'I think, I think the Alzheimer's Society, the activities there, what has helped is that, Lucy's a sociable person, and until the lockdown, um, I always tried to get something most days, er, activity to help us, so we went to 3 separate singing for the brain sessions for example.' Gordon: I think at the moment what would help, is getting Linda to be able to go outside again Maria: 'proper, tailored, specialist care' Leo: 'educated care'. They believe that at present the care system is based on monetary gain: Maria: 'care is commercial, it's all about the money … there's no care given to her feelings, her dignity, what she would like'. Nia: 'my kids are supportive and everybody knows, everyone I know always says how's your Dad, so people know how involved I am'

	Case 4 – interview 1	Theresa: 'My girls are wonderfully supportive, especially emotionally 'we help each other and we hold each other up' 'We did a 6-week course with about 12 or 14 people in the same boat … it was very helpful, very, very helpful. We had 2 ladies who knew about these things who were able to answer questions and gave us lots of information.' 'I would like to think that he would be happy if he would be away from me for a while.'
	Case 4 – interview 3	Theresa: 'I do tend to share; I think it's a way forward … I know quite a few people who don't share ... they struggle. And very often a breakdown happens.' Theresa: 'People that have already done it and been through it, they're the ones that give you all your guidelines if you like, because they've done it, and they know, they know exactly how you're feeling, they know exactly what to say and how to say it.'
	Case 5 – interview 1	Kelly: 'for me, it would be for him, either somebody to come and look after him, well basically I suppose so I could have a couple of days off a week' Interviewer: 'yeah' Kelly: 'I, and maybe, a Saturday night, so I can just go and know that I don't have to worry about him, so I know he's looked after, yeah. But that's my, cause that was my love'
	Case 6 – interview 1	Daniel: someone to be here Interviewer: yeah Daniel: Because Hazel is different with other people. Daniel: 'Just having someone else here, for some reason … improves the behaviour. Or I could go and do things when I wanted to do things.'

Superordinate Theme 3: Experiences of Music Therapy

Superordinate Theme 3: Experiences of Music Therapy		
Subordinate theme	**Source: case and interview number**	**Evidence**
1.Impact of Music Therapy: Wellbeing Nostalgia Identity Relationships Cognitive ability Music as a tool	Case 1 – interview 2	Interviewer: 'And what's that like for you? What was that like for you, that interaction there?' Gordon: 'Um, it's good, it's good to see Lucy, you know when she does sing, participating. Er, but I mean, the other thing is it's good to see her happy, er which, you know, you've seen today she's happy, most of the time, and she's happy when she's interacting.' Interviewer: 'Can I ask what's it like to reminisce like that?' Gordon: 'Er, yeah, it is kind of sad in a way, in that Lucy doesn't remember any of these things, very few, I mean, you get the impression that a lot of people remember, not the near past, but the distant past, and um, sadly with Lucy, she doesn't remember much of that at all.' Interviewer: 'How does it feel for you to, um, share the music with Lucy …' Gordon: 'Um, well it's nice cos it brings back, it brings back memories, er, in that particular instance, um, again, it's always good to see Lucy actually singing the words or mouthing the words, you know, because it kind of shows that there's something there, kind of thing.'
	Case 1 – interview 3	Gordon: 'I joined in and enjoyed it.' Interviewer: 'Have you enjoyed the music?' Lucy: 'I've enjoyed the music and things, yes ... It's been fantastic, it's really good … And I did enjoy it with people around who were actually singing with me.' Gordon: 'It was good because it engaged Lucy and it was interactive and kind of stimulated her, so you know, it's very beneficial in that respect … Lucy loves to communicate ... I'm not the most communicative of people so you know, communicating with other people is a beneficial, beneficial thing.'

	Case 2 – interview 2	Gordon: 'It got her more mobile and more kind of restoring a little how she was, so, it's been part of a contributory factor to an overall process.' Maria: 'We love it, don't we'. 'It makes me happy because it makes Mum happy'. Maria: 'It brings her back to me ... Mummy again.' 'a gift ... I see all of my Mum again and it's precious.' Maria: 'my Dad loved Rod Stewart' 'she sang it to me when I was a little girl'. 'That's why I named Danny Danny, Mum used to sing it to me every morning.' Maria: '...this is a real breakthrough. Because there is a complete ability to understand and put different processes together, singing the words, playing in tune, and obviously, being with [therapist's name] as well ... to see Mum use all those different skills, I haven't seen that for a long time.' Maria: 'She had the song in her head and literally she went to bed thinking about the song and starting the thought process and overnight she remembered the whole song.' Leo 'Nanna's singing and her ability to remember those things are trending in the opposite direction'. Maria: 'You're the star there, love, you're the star'. Leo: 'She can still keep up'. Maria: 'I love doing it with Mum, because ... it brings her back to me.' Maria: 'She sang it to me when I was a little girl, it's one of our favourite songs'. Maria: 'We've learnt so much through the music therapy'. Maria: 'This is the tool that Mindsong has given us ... so that we now have the music to be able to use as a positive tool, to um, deflect situations if we can see a trigger.' Maria: 'It's given us the tools to be able to cope as a family'. Maria: 'imprinted' 'all sorts of happy thoughts and memories'. Maria: 'Joy' 'Now this bit fills me with pride [wipes away a tear], it's overwhelmingly beautiful' Maria: 'Overwhelmingly beautiful'; 'pride' 'breakthrough' 'lovely' 'enjoying' 'gorgeous' 'vital' 'blew me away' 'amazing' 'remarkable'

		Leo: 'more than anything it's good to see her smile' Maria: 'When she's happy we're happy' Maria: 'You know, it makes life so much easier you know, just, cause somebody that's happy is easy, and when somebody's upset and angry then life is very fractious and it makes life so much harder.' Maria: Well, that's positive for your mental health, isn't it, because you're getting back into music again yourself, Leo: it's also been helping my arthritis in my hand as well. Maria: 'the only real connection that she's had'. Maria: 'We sing little songs all the time to motivate her to move around … because it's the basic rhythm for her to want to patter, and you know when she, when she comes and gets up from the chair, you know you can have a little dance with her and have a little singsong with her and, which also makes her feel more stable.' Maria: 'any movement is better than no movement, especially at the point which she is with her arthritis.' Maria: 'think outside the box' 'It's given us ideas, and it's shown us where her triggers truly are.' Interviewer: 'And you're using more music at different times in the week with Nan?' Leo: 'Yeah … she needs it. She likes it, she enjoys it. Sometimes she falls asleep if I just play guitar and she goes slightly quieter and quieter and quieter,' *[Maria laughs]* Leo: 'Yeah generally using it more, finding out what Nanna does and doesn't like and working around other activities to bring music in to motivate her I think has been the biggest thing that I've done, for instance, er when it comes to getting Nanna to stand up to come to the table, if she is sat down, she can be often, dozed, waking up and jaded Maria: 'Well, tired and mumbly, not jaded.
	Case 2 – interview 3	Leo: 'Well, yeah, but um, that is the wrong word, but then pop some music on and she can stand up and she goes 'ooo, ooo…' *[singing]* … and starts and comes a bit.'

	Case 3 – interview 2	Maria: ‘and that also is good for her own arthritis and her own mobility.’ Leo: ‘the right, appropriate music. And when Nan’s in the headspace and she’s in a happy, controlled environment, which is very important, she’s happy as larry.’ Maria: ‘And it’s that ability that Mindsong has given us, that ability to think outside the box, head on triggers and deal with them quickly, and it also means that we’re far more aware when there is something medically wrong as opposed to just mood, or you know, overheating, dehydration, we can really tell so much easier, what it is going on.’ Nia: ‘amazing’ ‘extraordinary’ ‘lovely’ ‘sweet Nia: ‘they were having a laugh and um, the fact that, he’s still got his sense of humour and I really hold onto that, it’s really precious.’ Nia: ‘It’s the thing that makes his life good really, music, the piano … it takes him away from all that other stuff.’ Nia: ‘He loves this … and it fills me with pleasure, pleasure for him’. Nia: ‘Straight after she [the therapist] left I played it to him and he loved it.’ Nia: ‘It’s really nice to have that time, you know, to be able to do that with him … It would be really nice to see if we could play it a bit more together.’ Nia: ‘he’s still taking out of himself or realise he’s done something or just do something funny like that and I love that, I think it’s really precious.’ Nia: ‘gave him great pleasure’ ‘he loved it’. ‘distressed and angry’.
	Case 3 – interview 3	Nia: ‘He was a man who was really troubled by his illness, I mean, he didn’t go lightly … he was fighting a lot’ ‘lifted out’ Nia: ‘So the times when he was playing music, um, were, times when he wasn’t fighting his Alzheimer’s, and so, it was lovely.’ Nia: ‘It was watching something extraordinary … unbelievably special. I think it just gave him something really special, and that gave me relief.’

	Case 4 – interview 2	Nia: 'being able to do something that he could actually do … he could keep playing even though he could barely write.' Nia: 'I just feel like it was, you know, it was music. It was not about his illness, and um, it was, it was, for me it was (indicates down with her hand) seeing him access something from before that he could do.' Nia: 'Piano was his thing' 'it was the two or three pieces that he played … it was sort of like they were just in there. And yeah, that was something really strong.' Nia: 'the lovely bit of Dad'. Theresa: 'a very big part of, um, my life' Theresa: 'he was quite grumpy, but the minute we started, it just lifts, you know it just lifts the mood and we enjoy it, we just enjoy it … it's been an uplifting experience.' Theresa: 'I really feel it's the one thing, for anyone suffering with any kind of mental suffering, I think music has got to be one of the best things to uplift you, definitely, definitely.' Theresa: 'It's been lovely to see how it's affected Julian … how it makes him feel happy and for me to watch that of course, is specially, um, nice.' Theresa: 'It's something nice to do together.' Theresa: 'Dad would sing all the way home'. Memories of camping as a family together and dancing as a couple also emerge: 'we used to do lots of jiving, didn't we!' Julian: 'tickle Mary' Theresa: 'you're doing 'Tickle Mary' again … He gets quite wicked as well. He makes jokes but he does it to everybody now.' Theresa: 'I didn't know what kind of a voice he had! I'd never heard him sing.' Theresa: 'we just enjoy it', 'I love music, I'm a great lover.' Theresa: 'you could do a quick step maybe… or a slow jive'. Theresa: 'You were making [the therapist's name] laugh'

	Case 4 – interview 3	Julian: 'Was I? How's that? Better than making you cry, innit!' Theresa: 'I was surprised um, how much of those words he remembers, it's from, it's from … a movie, way, way back film from years ago.' Theresa: 'I'd forgotten how it went until we started, and as soon as we started, it came back, and I thought that is, that is, typical, even for me.' Theresa: 'Music seems, I think it stays in the brain the longest, music.' Theresa: 'When [name of the therapist] plays he remembers them [songs], and he gets a bit, um, emotional, seems to. … It was quite upsetting for me, to see him getting emotional.' Theresa: 'But now … 6 weeks in, he's enjoying it more. The actual process of doing it has definitely helped. Helped [Julian] to control the emotions a bit more, yeah.' Theresa: 'it's quite nice to see the emotions playing on his face too, you know, not just always emotionally upset, but also emotionally enjoying it.' Theresa: 'his little ditty'. Theresa: 'Because I think that's showing his confidence. To others, I mean, he's sharing with others, he remembers, and I think it's very special.' Theresa: 'music's always been a big thing in my life' Theresa: 'next to music, it's absolutely the next thing.' Theresa: 'it's the music, it's the one thing that they seem to remember.' Theresa: 'He is a different person. The minute I put the Alexa on, if he's in a bit of a grumpy, you know, not quite his little self, within a minute or two he's singing, and that's what it's like when Mindsong comes in.' Theresa: 'You feel immediate, that he's there, he's in it, you know, and he loved it.'

	Case 5 – interview 2	Theresa: 'He was quite emotional, the first couple or three, four sessions, it would stir a memory, I presume, and that would make him upset you know.' Theresa: 'beneficial … it's brought it [music] more to the forefront.' Theresa: We loved it, absolutely loved it! … it was nice for me too. It's just the most brilliant, I thoroughly enjoyed it, I'd quite like to do it again. I just think it's the best thing … it was a pleasure to do, a pleasure to have [the therapist] in our home, and share in lovely music. Kelly: 'He's still tapping the drum … he loves it … he's really into it. You can see it in his face, can't you.' Kelly: 'Ray's got more joy out of it' 'it's like he was the star.' Kelly: 'I just wanted to go to sleep and not wake up and, then he [the therapist] came and … by half way through, I was back to being me again, it really lifted my spirits.' Kelly: 'Oh I really do enjoy it, yeah.' 'lovely, really, really, yeah.' Kelly: 'I didn't think I done it for that long actually … it does show, doesn't it'. Kelly: 'Oh God! Cut that bit out!' 'I was just thinking, we're all singing off key! … Oh God, that just sounds awful hearing that back!' Kelly: 'used to really look forward to it'.
	Case 5 – interview 3	Kelly: 'the music and the singing, it just lifted us … I mean, when [name of therapist] got here, he [indicating Ray] was really [*pulls a grumpy face]* moans, but by the time he left, he was more and more happy, and a few weeks after, I can't remember why I was down in the dumps but I was, and the same thing happened, by the time he left I was … It wasn't until that that I realized how much it was helping me as well.' Interviewer: yeah, so really lifted your mood. Kelly: oh yeah, yeah, definitely. Ray: Definitely. It was amazing therapy.

	Case 6 – interview 2	Kelly: yeah, it was, definitely. Ray: 'it's just lightened our life really'. Ray: 'refreshed' 'reborn'. 'I apparently had a voice!' Ray: 'we did engage pretty much together … it played a major part of engaging with Kelly … well it's brought us together.' Ray: '[name of therapist] left behind that book with all the songs in it' Kelly: 'all our favourite ones … he's diligent in the way he's selected them. It was very nice.' Kelly: 'make sure Ray brings his bag [of instruments] tomorrow.' Kelly: 'you put music on, it just lifts your spirits and makes you feel happy again.' Ray: 'We've been through some pretty rough patches, haven't we' Kelly: 'yeah, we have' Ray: 'But there's it's helped [the music therapy] …we, we, well, I can't help, I've got a smile on my face when I talk about it.' Ray: 'some of the assembled mob, and it's lovely, we have a singing session, and a big screen, so we got all the words, and we can join in the singing and we sing all the stuff' During this pause, Daniel attends to Hazel constantly, with a gentle manner, helping her to lie down on the sofa with a blanket, and putting music on Spotify. This has become a coping tool; when Hazel becomes anxious, Daniel finds that putting music on Spotify and singing along helps to calm her. Daniel does this now, and we gently sing songs together. Hazel gets up and moves back to the other sofa, with Daniel's support. Daniel sits next to her, his arm around her and holding her hand. He sings along to Adele's 'Make you feel my love'; Hazel and I join in. Daniel puts Hazel's glasses on and she reads the words from the screen and sings along. This feels a very warm, intimate moment, and the lines in the song: 'Go to the ends of the earth for you, to make you feel my love', seem to reflect the loving way in which Daniel cares for Hazel. Hazel appears calmer, and after the song, Daniel exhales a big sigh and

		asks ‘do you feel better now?’ to which Hazel replies: ‘yes’. Hazel looks calmer and more present with us. After checking with Daniel, I restart the recording of the interview and hence the transcript analysis from this point until the end of the interview, as Hazel had verbally agreed she felt better, and also seems calmer and more relaxed. Daniel: but we can sing him away Hazel: yes, we can sing him away. Daniel: ‘If Hazel’s being a bit agitated, we can sit her down and I can put on some music and then I can go and be doing things … music is good, it calms you down.’ Daniel: ‘it has a great calming effect’
	Case 6 – interview 3	Daniel: ‘and it gives me something I can do, whereas before, I couldn’t think of anything to do, when H’s having a bit of an anxiety attack or something’ Interviewer: ‘so music’s been a bit of a tool’ Daniel: ‘it’s a tool, absolutely’ Interviewer: ‘is that what happened in hospital? Daniel: ‘absolutely, the nurses were absolutely amazed, would come and look, or tell their friends ‘come and have a look at this’, because they’d see Hazel laying there going ‘ahh, ahh’, and then I’d come along and play a Spotify, Elvis Presley, or something, and ‘ahh ahh’ would turn into ‘*sings a tune to ah’,* in time with the music … well then, she would sing the words. And they were all amazed. And in fact, I know that one, two of the nurses went and sang to her, cos they picked up on it.’ Interviewer: ‘that’s lovely, that’s really lovely. And nothing else would bring that kind of response?’ Daniel: ‘no, no, talking, shaking her, nothing you know’ Interviewer: ‘gosh’ Daniel: ‘mm, it’s the only thing that got through.’

		Daniel: 'I think it's fantastic that Hazel has been introduced to live music like that, um, she obviously loves it' Interviewer: 'Hazel, have you enjoyed the music?' Hazel: 'Yes' Daniel: **'**When it first started, I didn't think it would make any difference, and then as it's gone along, I've realized how it does make a big difference. And, um, it's the one real thing that we've got now that works.' Daniel: 'Hazel's making a, sort of a groaning noise a lot of the time … and that shifts to being in tune with whatever song, and then possibly the words too. Well that, that's you know, she's tuning in' Interviewer: 'she's tuning into the music' Daniel: 'she's tuning in.' Daniel: 'we do, we have that every day now', Daniel: 'so we've got a small repertoire.'
2.Creativity: Creativity and health Creative flow – playfulness Magical world	Case 3 – interview 2	Nia: 'It was like they were in their own, thing going on … I'm lucky enough to be part of it.' 'it takes him away from all that other stuff… he was just absorbed in what she was doing.' Nia: 'He doesn't always respond really well to people' 'it really felt, that particular time then, that um, something was happening. And we all felt it.' Nia: 'Something was happening'. 'magic' 'a miracle', 'he sort of went off into his sort of own little trips' Nia: 'extraordinary' 'he really, really loves it, I mean he honestly thinks it's magic. We both think she's a magician!' * Nia: 'Just getting him to play, you know, play around play … being able to mess around, which is what they call it when they do that.' Nia: 'he sort of went off into his sort of own little trips.' Nia: 'it's just about going with the flow… [the therapist] helps him to sort of broaden what he's playing.'

	Case 3 – interview 3	Nia: 'when [the therapist] introduced a piece of music … I just loved the fact he didn't get fazed by that, and just sort of 'Oh, ok, so we're going into that.''
		Nia: 'magical' 'could be quite resistant',
		Nia: 'seeing Dad brought out of his illness'.
		Nia: 'take him into something different … it made me feel like there was something really magical about it, it was a bit like magic'
3.The Therapist	Case 3 – interview 2	Nia: 'she's made me play it and now I'm obsessed!' 'I want to give him the gift of playing it'.
Skills		Nia: 'he doesn't always respond really well to people'.
Role – therapist or friend?		Nia: I mean, I was amazed by that because he was not that sort of man, you know, he wasn't a sort of improvising creator, although in business I guess he was, he was creative in different ways, yeah, I don't' think it would have been something he'd have been able to even imagine him doing.
Boundaries - working in someone's home	Case 3 – interview 3	Nia: 'You know he felt a connection with Philly that he didn't necessarily even understand himself' Nia: 'Philly was sort of like a therapist, a counsellor, which I think she was to him… he would sort of talk to her and tell her things, and she would just stop and listen'.
		Nia: 'she just knows how to get him to do that. She's made me play too'.
		Nia: 'Going with the flow, … it was a time of allowing, of being able to mess around … she's introducing other … in a way that it didn't matter if it was the wrong key … it allowed [the music] to develop.'
		Nia: 'He was telling her his life story and she let him, I think he just had to say it and she let him and it was just part of the session.'
		Nia: 'There's one point where he puts his hand on her knee, and she doesn't, she doesn't make that awkward at all, and just makes gestures hand on hand that into a game too, I mean it's not weird but it could be weird, um you know, and he's quite an irascible old chap sometimes.'
		Nia: 'She could find a way to get him accessing something … she just knew how to, she just kind of got how to deal with him'
		Nia: 'Philly was sort of like a therapist, a counsellor, which I think she was to him'.

	Case 4 – interview 3	Nia: 'watching Philly getting him to improvise … was extraordinary'. Nia: 'he wasn't thinking when he was playing, he was just playing'. Nia: 'she wasn't trying to teach him anything, she just played with him, and you know, he played and she played … and in fact they coined a phrase, they called it 'messing around' Theresa: 'it's got lots of dimensions within it that are enjoyable, it's not just the singing, it's not just the playing Theresa: 'It's also nice to have somebody in your home doing something … because you spend so much time, you know, on your own … well, not literally on your own, of course not, but to have a conversation.' Theresa: 'She sat with me, she was a little bit shy for a minute, and then she started singing, woah! What an experience that was! And she wasn't singing quietly and nervously, she's singing *gesture with elbow* and she was singing all the old ones, you know, that I didn't even know she knew! It was amazing, it was amazing! … It was really, really good. And one day [name of daughter] came, she came and sat with us, and so that was a bit more of a family thing. Theresa: We loved it, absolutely loved it! … it was nice for me too. It's just the most brilliant, I thoroughly enjoyed it, I'd quite like to do it again. I just think it's the best thing … it was a pleasure to do, a pleasure to have [the therapist] in our home, and share in lovely music.
	Case 5 – interview 3	Kelly: 'a friend', Kelly: 'I think it was sad cos it felt like we were losing a friend.' Ray: When [therapist's name] left, we were both a bit, down-crest, down-fallen, and somebody [*looking at Kelly and pointing to her]* was shedding a few tears. Ray: 'we delved into him a bit' Interviewer: 'Do you think that's the music itself, or the fact that you were doing it together, or the fact that [name of therapist] was kind of facilitating it, or is it …'

		Ray: 'It was kind of group thing almost' Kelly: 'I think that the fact that Nick was, *coming in.'* Ray: 'Nick wasn't just about music, he involved himself with what was going on.' Kelly: 'He's just got that something, hasn't he, that draws you out' Ray: 'I think that we both attended, there was no differentiation at all.' Ray: 'Those things were reborn … and that's all down to Nick. Well, your …' Kelly: 'Music Therapy, innit.'
4.Music Therapy at End of Life	Case 2 – phone call after end of process Case 3 – interview 3	Maria: 'You [Mindsong] were the brightness in a very dark time'. Nia: 'possibly the most positive thing in his life towards the end.' Nia: 'When he was really dying, on the last day, I played music to him on my phone on the bed …. I felt like that was, something calming, I suppose and take him into something different.' Nia: 'the organist had a keyboard and he played the fugue that Dad played', Nia: 'rousing hymns' 'everyone had a good sing … that felt great'. Nia: 'I love that I can just sit down at the piano … start playing that one piece that I play that reminds me of Dad, it takes me back to Dad I guess, and the lovely bit of Dad.'

Appendix 19: Data Management Plan

UWE Project manager name:	Dr Catherine Warner
Student name, where applicable:	Margaret Grady
Faculty:	Health & Applied Sciences
Project Title:	How do family carers of people with late-stage / complex dementia make sense of their experiences of engaging in Music Therapy alongside the person they care for?

Research Data Management Plan version number:	**V1 March 2021 IRAS: 286118**
Date:	10/02/2021

If you have the following reference numbers, please enter them below.	
PASS code:	Click or tap here to enter text.
UREC / FREC / AWEC application numbers:	Click or tap here to enter text.
HTSC registration number:	Click or tap here to enter text.
GM registration number:	Click or tap here to enter text.

What data will you collect, create or use? Give a brief description. See Note 1
For the purpose of this research study there is a collaborating organisation, 'Mindsong' www.mindsong.org .uk Mindsong will be sourcing participants for the research from their existing 'Music Therapy at Home' service and will also provide the Music Therapy intervention. A

letter of agreement to collaborate is attached with this form and a full contract of collaboration will be created from UWE Contracts team once data management plans are in place and ethical approval has been granted (from NHS REC and FREC).

Identifying Potential Participants: People referred to Mindsong's 'Music Therapy at Home' service will be asked at point of referral (by Mindsong's Administrator) for consent to share their details with the researcher (Margaret Grady) in order to identify potential participants for the research study.

If they consent, details will be shared from Mindsong to the researcher via secure UWE OneDrive. This will include personal and sensitive data, for example: names, contact details, dementia diagnosis.

Data Collection: Other data created and collected will be from primary sources: video recordings and transcripts of interviews with research participants, and video recorded music from music therapy sessions with the research participants.

There will be twelve data subjects (research participants), who are likely to be older people, as the focus of this research is on family carers of people with dementia. The people with dementia will be involved in the creation of the music to be video recorded. Both the people with dementia and family carers are likely to be classed as vulnerable.

Volume of data - data will be collected from 3 interviews each from 6 family carers (so 18 interviews in total), and recorded music from each subject from music therapy sessions (6 recorded clips in total from the music therapy sessions).

The purpose of gathering this data is to explore the experiences of family carers, particularly when engaging in music therapy alongside the person they care for, to see if Music Therapy could be an effective intervention to support their wellbeing.

There will be sensitive data collected, as this research relates to the wellbeing of the research participants.

Please classify your data here as public, restricted or confidential. See Note 2

Data collected for this research project will be classified as 'confidential'.
How will you collect, create or access the data? See Note 3
The researcher will record interviews with the research participants onto a UWE encrypted device. Music from music therapy sessions will be video recorded by the music therapist conducting the intervention on an encrypted device and shared with the researcher via UWE OneDrive. Once shared, the music therapist will delete their original copy. Any other data held by the music therapist will be kept as confidential, as per the collaborating organisation's Confidentiality Policy (Mindsong). The researcher is also Director of Mindsong's 'Music Therapy at Home' service and oversees this service. Referrals to this service will be shared by Mindsong using UWE OneDrive. Referrals will be screened by the researcher to identify potential participants for the research, and stored securely on UWE OneDrive, with added encryption. A Collaboration Contract covering data management will be created from UWE Contracts Team. A letter of agreement is already in place and a contract will follow in time when ethics approval and data management plans are in place. Consent – informed consent will be sought from all participants. This is a complex area and where there is fluctuating consent or where informed consent from the person with dementia is not possible, a consultee declaration would be made by the family carer. A consultee information sheet will be produced to support the decision-making process and the family carer would be encouraged to discuss with their wider family and friends should they wish to. As well as consent to participate in the research, consent for participants' data to be collected, stored, analysed and presented in the final thesis / papers will also be sought. This will also include consent for the researcher's Supervision Team to see pseudonymised, processed data for the purpose of giving advice and guidance. From point of data collection all data will be pseudonymised, so data from that point onwards will hold no identifiable features. The researcher will give a random name to each participant and all data relating to them from point of first data collection (receipt of referral form) will be pseudonymised and coded with this random name. No identifiable features will be included in any reporting.

Full ethical consideration will be given to this research study and an application to NHS Research Ethics Committee has been started (IRAS project ID: 286118). Application will also be made to UWE's Research Ethics Committee.
How will the data be stored and backed up at all stages during its life course? See Note 4
Data collected from interviews and music therapy sessions will be stored on UWE approved OneDrive and each document encrypted. Any hard copies of data will be stored in a locked filing cabinet which only the researcher can access. All data will be backed up on a second secure OneDrive account.
How will the data be documented, described and maintained? See Note 5
Interviews will be documented in a word document or spread sheet. Videos recordings will be in MP4 format. A graphic or musical score will be made of the music therapy clips to be analysed. Pseudonymisation will be used; each research participant will be randomly given a pseudonym at the start of the project by the researcher, and every piece of data relating to that participant will be coded with this name from that point onwards. This includes transcripts and analyses. The key to the pseudonymisation will be held separately on an encrypted file on UWE OneDrive. Version numbers will also be clearly applied where applicable. The date, name and purpose of the data will be noted, along with the researcher's name and how the data was created and analysed.
How will your data be processed? See Note 6
Any data collected or created will be pseudonymised; each research participant will be randomly given a pseudonym at the start of the project, and every piece of data relating to that participant will be coded with this name from that point onwards. Any identifiable data can then be removed. Transcripts will be made of the interviews and these will be analysed using Interpretative Phenomenological Analysis. Music video recorded from music therapy sessions will be analysed using a method of Microanalysis. All data will be studied

and synthesised, and a final paper produced with the results. The research subjects will not be identified and no identifiable data will be used in reporting. Data will be stored on UWE approved OneDrive site and encrypted. This will ensure only those with a legitimate purpose can access the data. Only the researcher will have access to the data. Occasionally, the research Supervision Team may have access to parts of the pseudonymised, processed data for supervision and guidance purposes. Any sharing of data (for example with the supervisory team) will be via UWE OneDrive with password encryption.
Does the Data Protection Act (2018) apply to your research? See Note 7
Only data needed for research will be collected. If any data not relevant to the study is inadvertently collected it will be destroyed immediately, deleted from UWE OneDrive or destroyed manually if on a hard copy (shredded). As soon as data is collected it will be pseudonymised (see above). A Data Protection Impact Assessment has been completed.
Export controls and other legislation and regulation. See Note 8
The data collected will not have a dual use.
What Intellectual Property will be created or used in this research? See Note 9
Intellectual Property created will include final papers and thesis reporting on findings. This will remain property of the researcher (PGR student) and / or the University*.
What are your plans for long-term preservation and data sharing, where appropriate, and data disposal? See Note 10
Data collected will not be kept beyond the duration of the research study. Electronic and paper documents will be destroyed using UWE's secure waste disposal system. Hard copies will be shredded and electronic data deleted.

Final thesis and papers produced from the research will be shared via UWE Bristol Research Repository, relevant journals and conferences.
Who is responsible for enacting the different elements of the research data management plan? See Note 11
The student researcher is responsible for data management for this plan, with oversight from the Project Manager (Director of Studies).
What resources are needed to deliver the plan, and are these available? See Note 12
Encrypted UWE Bristol laptop and recording device – provided by UWE Music Therapy department UWE Bristol approved OneDrive for storing and sharing information. Additional OneDrive account for backup purposes.

Appendix 20: Therapist Techniques

This document details the techniques used by therapists to engage and support clients during music therapy (MT) sessions. This information relates to the video clips of the sixth session of MT used for microanalysis, one per case.

Case 1 – Gordon and Lucy - 'Take Me Home, Country Roads' by John Denver

Gordon chose this clip for personal reasons; memories of happy, family times together. This was a song they used to sing, and reminds Gordon of travelling together through West Virginia whilst on holiday.

Therapist Techniques

This is a familiar song that the couple know well, and holds emotional significance, reminding Gordon, and perhaps Lucy too, of happy times in the past, travelling through West Virginia on family holidays. Choosing a familiar song with emotional meaning perhaps increases the likelihood of the music being able to connect for both Gordon and Lucy, as they may feel more comfortable singing something familiar, and music that evokes happy memories.

Rhian changes the usual structure of the song, missing out a verse and instead repeating the chorus, perhaps because this is the most familiar part of the song, and Lucy seems to join in more in the chorus, with the words 'Take me Home' more visible on her lips, and her voice more audible towards the end of the song.

Rhian's vocal tone is full and warm, quite strong but not loud. I wondered whether the strong intensity in Rhian's voice was used to gently stimulate Lucy, who had previously almost fallen asleep. Rhian moderates her dynamic at times, especially at the beginning of the verses, where the singing is a little softer, or where Lucy joins in, perhaps allowing Lucy's sound to become more present in the overall dynamic of the music.

Rhian's guitar playing provides pulse and momentum, under-laying her voice in terms of timbre, pitch and intensity. Rhian's guitar picking seems to mirror Gordon's pitter-patter playing on the drum, matching his sounds as well as providing a holding framework for the song.

Rhian uses variations in tempo to signpost within the music, slowing down or using a slight pause before the chorus, or before starting the bridge.

The large rallentando before the last chorus almost act as a 'hook', building anticipation and giving time and an invitation for Lucy to join in. Rhian emphasises this by saying 'and the last one', before singing the last chorus again.

Right at the end, Rhian slows up and Lucy starts moving her right hand more on her tray. Rhian reflects this with some improvised picking on the guitar, at a similar pace to Lucy's movements. Gordon continues to gently tap the drum.

Case 2 – Maria, Leo and Louisa - 'Danny Boy' trad. English / Irish folk song

Maria and Leo chose this song for analysis because of the cognitive ability Louisa shows in her singing and playing, and its emotional importance for them as a family; Louisa used to sing it to Maria as a child, and Maria named her eldest son after this song.

Therapist Techniques

The choice of this song is significant, as it holds many family memories for both Louisa and Maria. Maria remembers her mother singing it to her as a child, and has even named her eldest son after the song. Suggesting a familiar song that holds emotional significance increases the chance of connection for Louisa. It also strengthens and upholds the relationship between Louisa and Maria, acknowledging shared past experiences but also providing a shared experience in the present moment.

Sally plays in G major, the key they had been playing in previously, and the key in which Louisa starts singing the song. Sally plays at a gentle pace, giving Louisa time to remember the song and join in with the singing. Louisa is physically quite frail, and Sally's pacing also allows for moments where she needs more time, sometimes for breathing, and at other times where Louisa just seems to need a moment.

Sally sings with a warm, present tone, loud enough to encourage Louisa to sing, but still allowing Louisa's voice to be louder and more present in the texture. At times when Louisa stops singing (for example at the beginning of the second verse), Sally continues, and Louisa looks up at her and then joins in again. By continuing, Sally is inviting Louisa to join her, and Louisa does so.

Case 3 – Nia and SJ - 'Messing Around' an improvisation

Chosen by Nia because she felt that something was happening; the therapist had introduced a new idea and SJ 'wasn't fazed by it'. Nia comments that it also shows his energy levels. Interestingly, this is a clip where Nia isn't playing, but is filming. It's just the therapist and SJ playing.

Therapist Techniques

From working with SJ in previous sessions, Penny knows the pieces SJ likes to play at the piano: Bach's C major Prelude, Beethoven's 'Ode to Joy' and 'Moonlight Sonata'. Penny uses these pieces to connect with SJ, and when SJ initiates them, Penny plays in support, validating and encouraging his playing.

Penny and SJ seem very attuned to each other, very connected, and both respond to each other's playing. Penny replies to SJ's playful staccato chords by mirroring these back, lower on the keyboard. This happens twice within the video clip. Penny matches SJ's pace and intensity of sound, sometimes continuing to play, inviting him to join her for more.

There are three moments where Penny gently challenges SJ within the music: firstly, with a change in harmony to F major, then with what feels like a musical question (GAA tune over an F major chord), and towards the end, by introducing a new piece, the Brahms Lullaby. SJ is not fazed by any of these changes or challenges, and responds by joining in, or continuing to play. When Penny plays the Brahms Lullaby, SJ plays a harmony part higher on the keyboard, following the rhythmic and melodic shape of the phrase. This feels significant; SJ is responding to Penny, joining her in the music and with a cognitive ability to play in harmony with the melodic and rhythmic shape of the tune mirrored in his playing.

There are distinct changes in articulation, pace and intensity within this clip that SJ initiates, from the gentle, flowing tune of the Bach prelude, to playful, loud and staccato chords. Penny follows SJ's changes, which highlight a sense of fun and creativity.

Case 4 – Theresa and Julian - 'A little ditty' (named by Theresa)

Theresa has chosen a song that Julian often initiates during the MT sessions. When asked why, she explained: 'Because I think that's showing his confidence. To others, I mean, he's sharing with others, he remembers, and I think it's very special.'

Therapist Techniques

Both Bethan and Theresa stop talking and turn to Julian the moment he starts singing, clearly indicating to him that they are listening to him. They play strongly on the beat of the music, and Bethan also plays some short rhythmical interjections at the end of phrases, emphasising the jaunty feel and sense of fun the piece portrays. Bethan and Theresa are clearly with Julian, going along with him and joining him in his song, supporting and encouraging him by playing with him, and giving many moments of eye contact and smiles.

It feels significant that neither Bethan nor Theresa join Julian in singing. This allows his voice to be heard clearly, and he gains a little in strength of sound as he continues to sing. This is Julian's song; he is the centre of attention and Bethan and Theresa are supporting him in this.

Case 5 – Kelly and Ray - 'Love is All Around' – Wet, Wet, Wet / The Troggs

Kelly chose this piece of music because the song is special to the couple: 'that's mine and Ray's song'.

Therapist Techniques

From previous sessions, Neil knows that this song is special to the couple, and chooses to finish each session with this song, reinforcing their closeness and love for each other. It leaves both Kelly and Ray uplifted and connected at the end of the session.

Neil begins slowly; an invitation to Ray and Kelly to join him, which they do. The song then settles into a steady pace, not too fast, perhaps making it easier to follow the lyrics and keep singing and playing. The D major key also means that the pitch range is accessible, not too high or too low.

Neil's voice and ukelele playing provide a constant, holding framework for Kelly and Ray to join in with, and there is warmth and a real sense of presence in the therapist's playing and singing. This reflects the obvious warmth and love between Kelly and Ray, expressed by the many moments of eye contact, smiles, leaning in towards each other and indicating to each other at significant moments within the lyrics of the song, for example: 'by the way that I feel'.

When Ray adds a short vocal improvisation at the end of a phrase: 'oh yes it is', Neil responds with 'ah ha', singing a little louder, indicating to Ray that he has heard his expression and is responding. This validates Ray's music and offers encouragement to continue.

Case 6 – Daniel and Hazel - Improvisation

We were not able to follow the same method of choosing a music clip to analyse as Hazel was too poorly for us to continue watching the video of the sixth session of MT. Instead, I asked the music therapist to suggest two clips for Daniel and Hazel to choose from, and Daniel chose this particular clip via email correspondence. I also checked again with both Daniel and Hazel at the start of the third interview, playing the clip of music and asking if they thought this was a good clip to choose for analysis, to which they agreed.

Therapist Techniques

Positioning

During the MT session, Neil kneels on the floor, in front of and between Hazel and Daniel. Positionally, this puts him lower than the couple; he is looking up to them. This use of positioning affects any power dynamic that might occur; Neil is coming into Hazel and Daniel's home as a music therapist, but he is keen to communicate that he is not coming in as an expert; that this is their house and he is a guest, and his lower position on the floor implicitly communicates that the session is about Hazel and Daniel, not himself. This could give a feeling of empowerment to Hazel and Daniel, and perhaps encourage them to lead the music-making.

Inviting – Mirroring and Holding

Neil starts the improvisation, playing the ukelele with a strong sense of beat. Hazel joins in, following the beat, and then playing a short-long pattern, which Neil mirrors on the ukelele. By mirroring this pattern and incorporating it into his playing, he is communicating to Hazel that he has heard her and is inviting her to continue, which she does. Neil follows Hazel's changes in pace and playing throughout, and the whole piece feels held by his strong ukelele playing. Neil begins singing, just to 'ah', in a minor key, again following Hazel's changes in pace.

Hazel gives Neil eye contact and he responds with eye contact and a smile; there is an obvious musical connection and communication between them. Neil's singing may have enabled Hazel to sing, as she then sings 'go away, go away', and Neil also mirrors this. The two continue to play, with Neil holding the music with his voice and ukelele, responding to and matching Hazel's changes in volume and pace. When Hazel starts smoothing the drum, Neil changes his playing to match, with a smoother sound on the ukelele and a change in his vocal melody. Neil watches carefully and is completely with Hazel as she finishes with a loud sound on the drum and holds her hands up.