Music and autobiographical memory:

how an analysis of Desert Island Discs may help conceptualise personalised music interventions for people living with dementia

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Abstract

Dementia disrupts the autobiographical memory system, including memories of specific episodes, personal experiences, and the facts of one's life. All these elements contribute to a sense of self. Disruption of autobiographical memory can affect psychological well-being, potentially contributing to psychological and behavioural symptoms and compromised interpersonal communication. This study explores how autobiographical memory functioning in people living with dementia can be engaged through personalised music interventions, thus optimising such interventions and potentially improving dementia care.

Three main methods are used: 1) A synthesis of two systematic reviews: the first focused on how autobiographical memory is affected across the different types of dementia; the second explored the effect of personalised music on behavioural and psychological symptoms in patients with dementia. The first systematic review (28 papers) found differences among the subtypes of dementia in relation to the temporal gradient effect, the recalled details of semantic and episodic memories and the recall of self-defining memories. The second systematic review (30 studies) found a positive but not lasting effect on behavioural and psychological symptoms. The effect was greater in active personalised music interventions than in passive listening to personalised music

2) A qualitative thematic analysis of the Desert Island Discs radio broadcasts, to understand the processes of sharing personally meaningful music choices and how music supports a sense of self. The analysis identified the emotional dimensions of autobiographical music memories; of particular salience was that of nostalgia and how music enables people to share meaningful emotional autobiographical memories, including painful and difficult ones.

3) An exploratory focus group discussion with professionals who use music interventions with people living with dementia, to contribute to theoretical conceptualization for personalised

music intervention. The analysis demonstrated how music enables emotions, especially during difficult experiences; it also highlighted the importance of each person's history and the need to find complementary ways to evaluate music interventions in dementia care.

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Preface

Following my graduation from the Social Work department, I worked in a mental health centre where I organized and coordinated groups of people with a dementia diagnosis, depression and schizophrenia, using art therapy techniques. My working experience with patients with deficits in memory and perceptual functions motivated me to learn more about the mechanisms underlying these functions.

My graduate studies in the field of neuroscience reinforced my belief that cognition depends on the interaction of the brain, the body and the environment. During one of my laboratory rotations, I focused on the role of a particular form of art ("μαντινάδα"; mantinada is a musical declaration, sung in the rhythm of accompanying music) in everyday life, through a study on the agricultural elderly population of Crete. After graduating from my master programme, I aimed to further explore the phenomenon of music in dementia care and apply the results of my future research to the design of more individualized non-pharmacological rehabilitation for people with a dementia diagnosis.

The University of East Anglia offered me a studentship to research a music intervention developed in East Anglia and with my supervisory team, we developed and submitted a protocol proposal, which was approved by the Faculty of Medicine and Health Sciences Ethics Committee. In addition, with my supervisory team and two additional members of the university, we developed two protocols for systematic reviews. Reviewing this literature regarding the effects of personalised music intervention in the psychological and behavioural symptoms in people with a dementia diagnosis, revealed some limitations in the way personalised music interventions are designed and delivered, limitations that I could identify in my proposed protocol as well. This led me to take a step back – with support from my supervisory team - to explore the relationship between music and autobiographical memory

through the lens of the people who use music to talk about and share their life history, and the views of experienced clinicians who use music interventions in dementia care. I hoped that this would then help inform the conceptualisation of personalised music interventional studies in the field of dementia research.

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Abbreviations

Abbreviations	Explanation
ABS	Aggressive Behaviour Scale
AD	Alzheimer's Disease
AMs	Autobiographical Memories
AWS	Algase Wandering Scale
BEHAVE-AD	Behavioural Pathology in Alzheimer's Disease Rating Scale
BEHAVE-AD	Behavioural Pathology in Alzheimer's Disease Rating Scale
BI	Barthel Index
bv FTD	behavioural-variant Frontotemporal dementia
C-CSDD	Chinese Version of the Cornell Scale for Depression in Dementia
CBS-QoL	Cornell Brown Scale- Quality of Life
CMAI-SF	Cohen-Mansfield Agitation Inventory-Short Form
Dem-QoL-4	Dementia Quality of Life scale
Dem-QoL-proxy	Dementia Quality of Life proxy
DIDs	Desert Island Discs
DQOL	Dementia Quality of Life
FTD	Frontotemporal dementia
fv FTD	frontal-variant of Frontotemporal dementia
GDS	Geriatric Depression Scale
GDS	Global Deterioration scale
HADS	Hospital Anxiety and Depression Scale
Int	Interviewees
MOSES	Multimensional Observation Scale for Elderly Subjects
MOSES	Multimensional Observation Scale for Elderly Subjects
nfvPPA	non-fluent variant Primary Progressive Aphasia
NPCI-C	Neuropsychiatric Inventory-Clinician version
NPI	Neuropsychiatric Inventory
PFA	Progressive non-Fluent Aphasia
PHQ-9	9-item depression scale of the Patient Health Questionnaire
QoL	Quality of Life
QOL-AD	Quality of Life in Alzheimer's Disease
QOL-AD	Quality of Life in Alzheimer's Disease
RAID	Rating Anxiety in Dementia Scale
SD	Semantic dementia
svPPA	semantic variant Primary Progressive Aphasia
TIDieR	Template for Intervention Description and Replication
VAS	Agitation Visual Analog Scale

Chapter 1: Introduction to the thesis

Introduction

This chapter provides the background for the study by examining the impact of the symptoms of dementia on individuals living with the condition and linking this with the concept of autobiographical memory. I conclude the chapter by formulating the aim and research questions for the current study and presenting the methodological approach adopted in the research.

1.1 Background and Rationale for the Study

The number of people diagnosed worldwide with dementia has reached 55 million, according to the World Alzheimer Report 2016, and it is estimated that this number will increase to more than 78 million people by 2030 (Gauthier S, 2021). This epidemiological data, along with demographic data which record an increasingly ageing population worldwide, particularly in Europe (Prince *et al*., 2015), underlies the importance of developing careful treatment, planning and care for dementia which focuses on peoples' individual needs.

Dementia was first used as a diagnostic term before the 19th century to describe a series of deficits in the cognitive and psychological domain, even if they were reversible (Berrios, 1987). The term "dementia" started to be used in a more specific way in the French Encyclopaedia; (Berrios, 1987) where it was defined as a "*paralysis of the spirit resulting from abolition of the reasoning faculty*" (Berrios, 1987), and was differentiated from other diseases that could present with similar symptoms.

There is continued debate about both the diagnostic criteria and the terminology used to describe dementia, as can be seen in the recent changes in the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-V). According to the current version, the term dementia

and all its subtypes have been replaced by the terms Major Neurocognitive Disorder, Major or Mild Neurocognitive Disorder Due to Alzheimer's disease, Major or Mild Frontotemporal Neurocognitive Disorder, Major or Mild Neurocognitive Disorder with Lewy Bodies, Major or Mild Vascular Neurocognitive Disorder (American Psychiatric and Force, 2013). Growing scientific knowledge about the diseases that fall under the DSM term "Major Cognitive Disorder" has helped to develop more effective diagnostic tools where clinicians can diagnose this complex pathological condition earlier and more accurately.

Dementia, or Major Neurocognitive disorder, as has been proposed in the latest edition of Diagnostic and Statistical Manual of Mental Disorders (DSM V) (American Psychiatric and Force, 2013), is a disorder charaterised by the chronic gradual progression of impairment in cognitive domains, such as decline in memory, learning and cognition (Fong et al., 2015).

The various symptoms of dementia depend on the stage of the disease and the different sub-types, such as Alzheimer's Disease (AD), Frontotemporal Dementia (FTD), vascular dementia (VD), semantic dementia (SD) and dementia with Lewy bodies (Lane, Hardy and Schott, 2018; Olney, Spina and Miller, 2017; O'Brien and Thomas, 2015; Engstad *et al.*, 2003; Klimova, Novotny and Kuca, 2018; Gomperts, 2016).

One of the first symptoms reported in dementia is a decline in short-term memory: people living with dementia will typically have a progressive memory loss of recent events in the earlier stages of the disease, such as forgetting conversations, losing items, having difficulties finding words or forgetting names (Arvanitakis, Shah and Bennett, 2019; Ramanan *et al.*, 2016; Baudic *et al.*, 2006).

The main symptoms of dementia cause a number of difficulties in focusing on a task as well as concentrating on an activity and performing it, even if they are familiar with it (Kirova, Bays and Lagalwar, 2015). People with a dementia diagnosis due to impairment in executive

memory, have difficulties planning a goal or making a decision (El Haj, Antoine and Kapogiannis, 2015; El Haj and Antoine, 2018).

Language is also affected in people with dementia, both the expressive and receptive aspects, such as object naming and fluency (Kempler and Goral, 2008; Banovic, Zunic and Sinanovic, 2018; Laforce, 2013). In addition, people with dementia forget simple words or misuse words in a sentence, and, as the disease progresses, their language (oral and written) becomes more difficult to understand (Ousset *et al.*, 2002; Potkins *et al.*, 2003).

Memory problems are the core symptoms for people with dementia: memory decline is present across the different types of dementia, though in different severity patterns (Kirova, Bays and Lagalwar, 2015; Nestor *et al.*, 2002). Memory consolidation, free or cued recall, recognition memory, working memory, semantic and episodic autobiographical memory systems are impaired and the decline is progressive (Kirova, Bays and Lagalwar, 2015; Potkins *et al.*, 2003).

At the later stage of the disease, these symptoms become more severe: people struggle to recognise familiar faces; they get lost in familiar environments and everyday tasks become harder (Alzheimer's, 2019). Memory loss has an emotional impact on the person and their family, friends and formal carers; everyday communication and interaction between people living with dementia and their social environment becomes challenging (Hendryx-Bedalov, 1999; Saunders *et al.*, 2012; Vasse *et al.*, 2010; Wang, Hsieh and Wang, 2013). Progressive impairments of neurological impact such as proprioception, balance, sensory changes in people with dementia, and symptoms such as agitation and apathy, have an impact on relationships with the external world.

As communication becomes more difficult, people living with dementia often experience isolation and diminished social activities (Mabire *et al.*, 2016; Saunders *et al.*, 2012). Social

isolation and reduced social interaction and communication aggravate the cognitive and behavioural symptoms in dementia. Studies on social interaction and the effect on people with dementia living in care homes, have illustrated the complexities of the phenomenon, and suggested that the emotional states of people with dementia (both negative and positive) are associated with social interaction (Austin, O' Neil and Skevington, 2016; Kontos, 2012).

Dementia research covers a broad field: from the understanding of the causes of disease at a basic science level to the development of pharmaceutical therapies or non-pharmaceutical interventions; or the improvement of health care to the exploration of more effective social policies and improved attitudes to dementia; or how new technologies are implemented in diagnosis and health care (Prince *et al.*, 2015; Prince *et al.*, 2016; Patterson, 2018; International, 2019; Alzheimers, 2019; Forsyth *et al.*, 2019; Lariviere *et al.*, 2020). The multimodal direction of research in the field of dementia aims towards people's wellbeing, as well as to increase, social engagement for people with a dementia diagnosis. Person-centred therapeutic interventions aim to empower people living with dementia to express their needs and emotions and to enable them to maintain their sense of self in communication and social contexts (Lee *et al.*, 2017; Kontos *et al.*, 2010; Birt *et al.*, 2019).

1.2 Autobiographical Memory

Autobiographical Memory (AM) is the memory system of personal experience and knowledge of specific episodes and events of one's life (Conway and Pleydell-Pearce, 2000; Fivush, 2010). AM functions to provide us with the information of who we are, and how we interact with our environment across our lifetime. With this knowledge we can understand our self, place our self in our personal and social environment and set goals for our life (Guerini *et al.*, 2019; Prebble, Addis and Tippett, 2013). In addition, when we recollect and share personal events, we rehearse a coherent sense of self and identity from the past into the future (Fivush, 2010; Conway, Singer and Tagini, 2004).

As posited in Tulving's memory theory, the AM system has two components, the episodic and semantic. The episodic component includes the personal events and facts of our life, while the semantic component refers to general knowledge and facts of our life (Tulving, 1995), with semantic and episodic components being complementary to each other. Evidence from neuropsychological research and studies with people with focal brain damage (in the medial temporal lobes and hippocampal region) support the independence and the complementary function of episodic and semantic memory (Greenberg and Verfaellie, 2010; Bayley, Hopkins and Squire, 2006; Manns, Hopkins and Squire, 2003).

According to another model, the "self-memory system" (Conway and Pleydell-Pearce, 2000) "only conceptual organisation of episodic memories within the self-memory system transforms them into autobiographical memories" (Guerini *et al.*, 2019, p. 1) and enable them to be part of the self. In Conway's model, the present conceptual self chooses autobiographical memories to build a continuity of the self (Conway and Pleydell-Pearce, 2000).

AMs have some well-defined properties and can be characterised in relation to their phenomenological details. The phenomenological qualities of AM are the following: vividness; emotional intensity; coherence; time perspective; sensory detail; valence; sharing; visual perspective; accessibility and distancing (Sutin and Robins, 2007; Montebarocci, Luchetti and Sutin, 2014).

AM has phenomenological dimensions too (Sutin and Robins, 2007). Vividness of the AM applies to the visual perception of the memory and how intense is the visual representation of the recalled event; emotional intensity is about the emotional experience and the degree of intensity when recalling the memory, as well as the intensity experienced during consolidation. Coherence is related to the rational sequence of the events as people recall them, also described as specificity (Conway, Singer and Tagini, 2004).

Time perspective refers to the recalled details of the memory, associated with the questions of "when" the event occurred and "how long" it lasted. Sensory detail is about the details experienced when an AM is recalled; sensory details in this dimension include all the senses except vision, since this is evaluated through the notion of vividness. Valence describes whether the perception of emotional experience in the recalled memory was positive or negative; again, this refers to the emotion during the event and when the event was recalled, shared is if the memory is shared with other people.

Visual perspective refers to the presentation of the recalled memory and if the person recalls it in the first or third person. This is related to the reliving of the memory while accessibility is related to the retrieval of the AM and how difficult or not it is to recall. Lastly, distancing is about the way people describe their memory and how distant they are psychological from the recalled event (Sutin and Robins, 2007).

Information about the phenomenological characteristics of AM can either be used when diagnosing in clinical research or in the development of personalised interventions aimed at specific aspects of AM that are correlated with emotion and sense of self.

Research in AM has also identified the phenomenon of 'reminiscence bump': studies in healthy adults over thirty years old, have revealed the propensity to recall more autobiographical memories from adolescence and early adulthood (approximately 10 to 30 years), compared with the number of memories from early childhood and recent life (Janssen, Chessa and Murre, 2005; Munawar, Kuhn and Haque, 2018).

There are different methods to recall memories and each method can influence the time frame of the reminiscence bump. When 'word cueing' or a 'life scripts' method is used, the recalled memories can be from early years (5-30 years and 6-30 years, respectively) while with the

‘important memories’ method, the time location of the reminiscence bump is 16-30 years (Munawar, Kuhn and Haque, 2018).

Memories from this period have been charaterised as being of great importance for peoples’ life history (Williams, Conway and Cohen, 2008). Scholars using different theoretical approaches have grappled to understand the reminiscence bump. One explanation is that many new events occur during these decades, events that are novel for the individual (Munawar, Kuhn and Haque, 2018; Pillemer, 2001). In another theoretical approach (Janssen and Murre, 2008), the reminiscence bump is examined through the cognitive aspects of events during this period, that is, how people during this period process and maintain information about their life events, and the importance of those events for the later development of each individual.

This period (10-30 years) is also very important for the development of the sense of self, to forming goals and to the development of social relationships and identity. It is also during this period that people participate in groups and create their social environment (Conway and Pleydell-Pearce, 2000). Experiences from this period will be included in their life history and their narrations, and the events from these narrations will be more likely to be recalled in later life due to the repetition of their life history (Rathbone, Moulin and Conway, 2009). This is proposed to be the “self -defining period” which includes the same time frame (10-30) (Loveday, Woy and Conway, 2020).

In a study by Schrauf and Rubin (2001), participants who immigrated during their early 20s had the reminiscence bump within the range of 10-30 years, whereas participants who immigrated in their mid-30s presented a small shift in the reminiscence bump: they recalled more memories within the time-period of their immigration and relatively fewer memories from the 10-30 years standard reminiscence bump range. The same authors found similar results in a later study, where another ethnicity group who had also experienced immigration at different ages, narrated their autobiography history (Schrauf and Rubin, 1998; Schrauf and

Rubin, 2001). The data from this kind of study suggests that the reminiscence bump is correlated with unique life events, meaningful for the formation of self.

1.3 Autobiographical Memory, Sense of Self and Emotion

The AM system is a fundamental component in the construction of how individuals experience selfhood and belong in their environment (Conway and Pleydell-Pearce, 2000).

Self, as many scholars have described, is a complex phenomenon forged in and by individuals, within a social environment and by interacting with others (Vygotskii, 1978; Gergen, 2011; Vygotsky, 1978). As Martin, Sugarman and Hickinbottom (2010, p. 27) have posited, "Our conception of a person (or psychological person) is an identifiable, embodied individual human with being, self-understanding (self), and agentive capability".

The study of self in psychology goes back to William James whose concept of self was defined by the property of continuity, which provides the individual with a sense of "connectedness" (James, 1890). For one to construct and maintain a sense of self, an individual needs to be able to relate to past experiences and events, to have a memory continuity that clusters the different identities that constitute one's self (Alea and Bluck, 2003; Prebble, Addis and Tippett, 2013). Another way to perceive identification of self is through sharing autobiographical narratives (Zahavi, 2007; Bruner, 2003; Schechtman, 1996), where the narrative self is not something given but rather something that evolves over time. The process of creating a life story is a continuous one, developing gradually and drawing a line that connects the past to the present and to the future. Constructing narratives enables people to have a holistic but not static perception of their self and identity; the sharing of autobiographical narratives is also part of the process of constructing and communicating ourselves (McAdams, 2001; McLean and Fournier, 2008; McLean, Pasupathi and Pals, 2007).

From a social constructivist perspective, people identify their self through social interaction. This approach brings together different concepts of self (Caddell and Clare, 2010; Sabat *et al.*, 2011; Harré, 1998). The way that we perceive, comprehend and maintain our self and the way we position it in the world, is a lifelong process and is based equally on personal characteristics and the achievements of each individual, as well as on social communication, being part of a group and of sharing memories (Aboulafia, 2016; Alea and Bluck, 2003; Bluck and Alea, 2009).

In one such account there are three selves: Self 1 is the embodiment experience of being a person; Self 2 is constituted from the individual's beliefs, their attitudes and skills; lastly, Self 3 is the social persona and the way that people present Self 1 and 2 in the context of a social environment (Hedman *et al.*, 2013; Harré, 1998). In another perspective (Nelson, 1996) the self is formed mainly by the sharing of memories and the social interactions; according to this perspective, autobiographical memory is a sub-category of episodic memories (Guerini *et al.*, 2019).

AMs also consist of emotional memories, events and facts about one's life and selfhood. Indeed, emotion is central in constructing the nature and characteristics of memories (Berntsen and Rubin, 2002; Conway and Pleydell-Pearce, 2000). In turn, the emotions in and of AMs play a crucial role in the development and identification of one's self (Holland and Kensinger, 2010). An example of how emotions can affect both AM retrieval and the perception of self can be found in studies where individuals with depression and a negative self-image, retrieve faster negative AMs compared with positive AMs (Lloyd and Lishman, 1975). Also, people who have recovered from depression recall more vivid negative memories in a sad mood condition and less vivid positive memories, compared to a control group (Werner-Seidler and Moulds, 2012; Werner-Seidler and Moulds, 2011; Dalgleish and Werner-Seidler, 2014).

The study of emotions is a very broad area and involves different approaches; one of the main issues in the area is the definition and taxonomy of emotions. Damasio (2010) defines emotions as a collection of unconscious neural responses to stimuli which cause observable external changes in the organism (Damasio, 2010). Emotions can be categorized as either basic emotions or self-conscious emotions. The emotions which have evolved and are identifiable across several cultures, such as anger, joy, surprise, are often described as basic emotions and can be sub-categorized further into primary and secondary (Ekman, 1999; Ekman, 2016). For example, love is a primary emotion and affection, a secondary one. On the other hand, self-conscious emotions are related to our sense of ourselves and how other people interpret and interact with these and include emotions such as shame and pride (Tracy and Robins, 2004).

1.4 Autobiographical Memory and Dementia

Understanding how AM is affected in dementia and in different types of the disease, is essential for knowing how the autobiographical memory system can be supported, in turn leading to the development of more personalized dementia care that can reinforce an individual's continuity of self.

Even with no diagnosis of neurodegenerative or other pathological disorders, there are individual differences in AM in terms of the phenomenological details or in the recollection of events. But beyond these individual differences, people living with dementia present a variety of impairments compared to the so-called healthy population. In Chapter 2, through a systematic review of the relevant literature, I examine in detail how AM is affected in different types of dementia. However, at this juncture suffice it to say that the AM system in dementia is progressively impaired (Greenberg *et al.*, 2011). Dementia causes deficits in the AM system and disrupts this circle of personal knowledge, and sense of self and identity (Kirk and Berntsen, 2018; Urbanowitsch et al., 2013). People diagnosed with dementia have difficulties with recalling and reporting events across their lifespan and giving specific details, such as

spatial or temporal information of events, as well as information about other people who were present (Hou, Miller and Kramer, 2005; Addis *et al.*, 2009; Piolino, Desgranges and Eustache, 2009).

1.5 Autobiographical Memory and Music

Music has been shown to be a very effective trigger of AMs as well to sharing and communicating personal and emotional events. Music is a stimulus which enables us to both express our emotions, but which also can evoke emotions and memories (Janata, Tomic and Rakowski, 2007).

Studies in the field of dementia and the specific characteristics of music and sound in AM retrieval (see for example Foster and Valentine (2001), Sakramo *et al*. (2014) and Cuddy and Duffin (2005)) have provided a body of evidence that supports the advantages to health care of using structured auditory stimuli in clinical applications for people with dementia. This growing body of research exploring the role of music and sound in AM and in the expression of self and emotion, can contribute to dementia care, particularly in terms of person-centered care, as it can point towards additional ways to enhance communication and support a sense of self.

1.6 Affective Processes in Musical Autobiographical Memories

When trying to understand and describe the relationship between music and autobiographical memories, one cannot exclude emotions. Indeed, emotion is argued to be a central component in music-evoked memories (Basaglia-Pappas *et al.*, 2013a; El Haj, Fasotti and Allain, 2012a; El Haj, Postal and Allain, 2012; El Haj *et al.*, 2015). In this sense, music can be seen as an instrument through which emotions are expressed and evoked, whether related to our memories or not (Strollo and Romano, 2015; Janata, Tomic and Rakowski, 2007).

Studies in emotions evoked by music indicate that nostalgia is the most common emotion (Janata, Tomic and Rakowski, 2007; Barrett *et al.*, 2010; Juslin *et al.*, 2008; Zentner, Grandjean and Scherer, 2008). Nostalgia was first described as a medical condition by the Swiss physician Johannes Hofer. This view changed and during the 19th century, nostalgia came to be considered a form of depression (Wildschut *et al.*, 2006). Current research on emotions has moved forward from that view and nostalgia is now considered to be an affective process, and a complex emotion. Nostalgia as a process involves people remembering significant past experiences, reminiscing about events that have a unique meaning in their life, and bringing back AMs that have been a big part of who they were then and have led to who they are now. Nostalgia is associated with both positive and negative states and can include both elements. It connects the person with their environment, can bring a sense of belonging and contributes to the construction of the view of self (Sedikides *et al.*, 2008; Barrett *et al.*, 2010; Routledge *et al.*, 2012).

1.7 Explanatory context of the background.

This study sought to explore the mechanisms of autobiographical memory and music interventions in dementia care. The initial approach to investigate these was to develop a qualitative study to explore an intervention known as Music Mirrors (MMs). To this end, a study was designed in which a total of sixteen potential participants -eight dyads, would be invited to participate. Each dyad would consist of a trained volunteer and a person living with dementia, participating in a MMs intervention, with video recordings of this activity constituting the data for analysis.

In this section, I will first present the origin and the aim of the MMs intervention, followed by two examples, as was described in the approved Faculty of Medicine and Health Sciences ethics application. I will then describe how the original design was revised and why a more in-depth and multifaceted approach was needed.

1.7.1 Music Mirrors

Music Mirrors (MMs) is a music and sound intervention which can then be used as a stimulus to communication between a person with dementia and formal carers, at a stage when shared meaning in communication has become significantly disrupted (Edwards, 2015). MMs was developed by a musician drawing on her personal experience in caring for her parent (http://enablemagazine.co.uk/, 2019).

The MM contains music, sounds and written words, where each set of sentence and music or sound link sparks a particular memory and involves both listening and reminiscence. It is not a tool for solitary listening but a resource to connect people with dementia with those caring for them. MMs is a reminiscence and communication resource to facilitate person-centred care. It is not a Music Therapy intervention, which would be led exclusively by a professionally registered music therapist, where for example, an individual may listen to live or recorded music or make music by playing an instrument or singing (Raglio *et al*., 2015).

Making Music Mirrors

During the process of MMs, the trained volunteer and the person with dementia talk about the person's life and capture autobiographical memories and link them with a piece of music or a sound. The volunteer transcribes the conversation into short sentences, using the person's own words wherever possible and finds the chosen music or sound that the person with dementia associates with the memory. When the person is satisfied with the result. a digital version or a hard-copy paper of the MMs can be created.

The digital version of MMs can be created by registering for an account on the MMs website and following the instructions on the site to "create a new mirror" (www.musicmirrors.co.uk). The person with dementia, with the help of the trained volunteers, fills out the online form with the text of music memory and the URL link of the music piece or sound and then submits the

Music Mirror online. A hard-copy paper version can also be created with the same information.

The MM is best created when people are in the early stages of dementia when they will still have access to detailed significant memories, and they can choose for themselves which autobiographical event they want to include in the MMs. Furthermore, language and communication difficulties are not as severe in the early stages compared to later stages of the disease. Prior to making a MM, the trained volunteer talks to the person with dementia to explain what a MM is and how it can be used. In addition, a worksheet with history prompts (family, home, education and work) is provided so that the person with dementia has time to think and talk with their family and carers, in order to be ready to talk about significant memories. The history prompts can also help the participant to organise their memories in a time frame and to choose themselves or with the help of their family members/caregivers, which memories to share.

Using a Music Mirror

The MM, with the music or sound links and the text, is held by the person living with dementia and the family members. It is then available to be shared or sent whenever it is needed. For example, in a situation where memory, orientation or language have deteriorated and communication has become more challenging, family carers may talk to the person with dementia about their memories, using the relevant sounds or music to further stimulate the memory.

If the person with dementia is admitted to a clinical care setting or there is a transition in care, the MM can be used as a personalised resource for a carer and the person with dementia to connect and communicate. Staff members can play excerpts of the personally significant sounds or music and talk about the memories on the MM, in an attempt to connect meaningfully

with the person with dementia. The person with dementia may be engaged or reassured by the familiar words and sounds.

In MMs (both in the production and the implementation), the communication between the person living with dementia and the professional or non-professional carer is through both speech and music or sound. The volunteers who have been trained in the making of MM, may or may not have a professional background in dementia care. The aim is to help anyone who is involved in a person's care to bridge the communication gap and develop meaningful interaction, to facilitate person-centred care with people living with dementia. As such, a MM will always be used with the help of a second person.

There is a website to create MMs online (www.musicmirrors.co.uk), the following excerpts I am presenting as paradigms come from there. In the first example, a person living with dementia shares a memory from her childhood and specifically, her family gatherings on Sundays and the music they used to play during these gatherings. In the second example, the person shares a memory from her childhood and hobbies (https://www.musicmirrors.co.uk/example/).

Example 1:

1. "I was one of ten children – eight girls and two boys. My mother had a shop and my grandmother lived next door. My brother Jimmy used to play the piano and had a good tenor voice – I remember us singing around the piano on Sundays, mainly hymns."

You are my heart's delight (Richard Tauber)

https://www.youtube.com/watch?v=JtgmKpcgQ30.

Example 2:

2. "I had piano lessons, but I didn't like them too much and I preferred singing. We went as a choir to a picture house to sing and I still have the photograph. The choir was run by a lovely old man, and we sang things like Nymphs and Shepherds and Wheree'r you walk."

Nymphs and shepherds

https://www.youtube.com/watch?v=_Cinx9hYiMI .

Music Mirrors is a resource that can be used in the later stages of the disease by health professionals or anyone who is involved in the care of a person with dementia, to help make a connection and interact socially with them, when other avenues of communication have become difficult or even impossible.

For my PhD thesis, I initially proposed a study that aimed to understand the procedure of MMs interventions, the communication between the person living with dementia and the trained volunteer, and the mechanisms with which this communication might reflect the person's sense of self. However, examination of the literature highlighted gaps and ambiguities in the implementation of music interventions and indicated the need for further exploration regarding their design and aims.

Many interventions have been developed rooted in practice, as MM has, but to develop knowledge there is a need to go back to explore the mechanisms that underpin them and through that, to develop theoretical understanding. Another concern identified in the literature was the person-centred characteristics of the interventions and their appropriateness for the different symptoms in dementia. I started to formulate new research questions and specifically, three questions which at the beginning were pointing in slightly different directions but seemed to be essential for conceptualizing and developing more effective and person-centred care with music interventions.

These questions are (1) how are music interventions currently implemented in dementia care? (2) how do people use music to narrate through their life histories? and (3) how is autobiographical memory affected in different dementia types? With my supervisory team, we explored the right methodological approach to address these three areas and the diverse nature of the initial research questions. Through debating what would be the best way to design a study capable of answering them, I began to reconsider the study of MMs intervention and the initial design of the study. As a social worker in a mental health facility, I had implemented arts-based interventions in dementia care. This experience allowed me to understand the limits of interventions in a clinical setting and the need to further understand the theoretical framework of the interventions and their aims. This would allow me to follow a structured design, recognize when there was a need to be flexible and how to implement an intervention in dementia care.

Along with the research questions, these considerations led me to shift the research focus and to employ three complementary methodological approaches: a systematic review; a qualitative analysis of interviews with people who used music to talk about significant events of their lives (BBC 4 Desert Island Discs broadcast); and an exploratory focus group discussion with practitioners who use music activities with people living with dementia.

In the next section of this chapter. I present in detail the research aims and the development of the initial questions. I conclude by outlining the methodological approaches that eventually were selected to explore these questions.

1.8 Research aims and methodological approaches.

The overall aim of this study is to further develop an understanding of how personalised music can engage AM functioning in people living with dementia so as to optimise personalised music interventions in dementia care. In so doing, I aimed to provide a broader

conceptualisation of the mechanisms of music interventions and how they are currently implemented in dementia care.

These aims are addressed through seven main questions:

1. What are the characteristics of the autobiographical memory system in people with dementia?
2. What are the core processes in the autobiographical memory system involved in sharing personally meaningful choices of music?
3. How can music support autobiographical memory and sense of self in people living with dementia?
4. How is music used to represent and support a sense of self?
5. How do people use music as a narrative approach to their life histories?
6. What is the effect, if any, of personalised music interventions on psychological and behavioural symptoms in dementia care?
7. How are music interventions currently implemented in dementia care?

To address these questions and develop a thematic description of the research questions, I have used three different but complementary methods. The first method involved systematically reviewing the current literature to understand how AM is affected in different types of dementia and to explore the effect of personalised music interventions in dementia care; the second was to conduct qualitative research on how people use personalised music to present AMs and insights about their life; and the third was to use an exploratory focus group discussion with practitioners from different professional backgrounds, who use music in their work with people living with dementia.

Systematic reviews require developing a specific question and undertaking a sequence of steps to answer this question (Siddaway, Wood and Hedges, 2019b; Khan *et al.*, 2003; Petticrew and

Roberts, 2006; Siddaway, Wood and Hedges, 2019a). The first step of a systematic review is to define the research question. The second step is to identify the types of studies that will be included in the systematic review. During this step, researchers need to determine the exclusion and inclusion criteria. The third step is to conduct a systematic search of the literature; this process needs to be comprehensive and transparent and described in detail, in order to be replicable. The fourth step of the systematic review is for the researcher to conclude which studies are to be included in the review, according to the inclusion and exclusion criteria.

The fifth step is to conduct a quality check by critically appraising the included studies. The final step is to extract and synthesize the data (Petticrew and Roberts, 2006). For the purposes of this study, two systematic reviews were carried out, presented in Chapter 2 and Chapter 3; the first addresses the question "How is Autobiographical Memory (AM) affected in different types of dementia?" while the second aims to understand "What is the effect, if any, of personalised music interventions on the behavioural symptoms of dementia?".

To further understand how music may be used to present AMs and support a sense of self, I conducted a qualitative analysis of the interview broadcasts from the popular radio show, "Desert Island Discs", which has been aired on the UK's BBC Radio 4 for almost eight decades.

The last study, an exploratory focus group discussion, sought the views and opinions of professionals who use music interventions in dementia care. The discussion was based on their experience in relation to the outcomes from the analysis of the two systematic reviews and the themes from the analysis of DIDs broadcast.

These three methods, the systematic review of the literature, the qualitative analysis of radio broadcasts and the exploratory focus group discussion, are complementary. Taken together, they help to address the overarching aim, which was to explore how people use music to

communicate significant events of their life to conceptualise personal music interventions in dementia care. This knowledge can then be used to inform future developments of dementia oriented and person-centred music interventions.

1.9 Chapter Summary

In this chapter, I have presented a broad outline of dementia itself and provided an overview of the most recent demographic and epidemiological data, as well as outlined some of the research domains in the broad field of dementia research. I introduced the concept of Autobiographical Memory, describing the theoretical framework that underpins the concept and defining its characteristics in the general population. I then explained the connection between the Autobiographical Memory system and sense of self and how this is affected by the symptoms of dementia. I concluded the first chapter by presenting the background of the study and how research aims and research questions were revised and developed, along with a brief description of the methodological approach I adopted.

Chapter 2: Systematic Review

"How is Autobiographical Memory affected in different types of dementia?"

Introduction

In this chapter, I discuss the outcomes of the systematic review, addressing the question "How is Autobiographical Memory (AM) affected in different types of dementia?". At the beginning of the chapter, I examine the concept of autobiographical memory in dementia. I then discuss in detail the method used in this systematic review, present the formulation of the question, the search strategy and the criteria that were included and excluded, as well as how the quality check of included studies was conducted. The chapter concludes with a synthesis of the review findings.

For the systematic review, I developed and published the protocol on PROSPERO "an international database of prospectively registered systematic reviews" (https://www.crd.york.ac.uk/PROSPERO/) (Appendix 1), and designed the search, under the guidance of and in collaboration with, the review team, consisting of my two supervisors, and Guy Peryer and Toby Smith. I carried out the search and screened the titles and abstracts, and one of my supervisors, Anne Killett, reviewed the selected studies according to the inclusion criteria. I exported the data for the included studies and analysed of the findings: the narrative synthesis is included in this chapter.

2.1 Refining the Systematic Review Question

In dementia care, the application of person-centred approaches is considered best practice (Kitwood, 2019; Fazio *et al.*, 2018). To achieve person-centred care, it is not only necessary to acknowledge each person's psychological needs but to understand how specific symptoms of the different types of dementia affect these fundamental needs (Rigby *et al.*, 2021). Both

researchers and clinicians, therefore, need to support the design and implementation of the care plan by being acquainted with individuals' needs and persons' views. A central part of a person-centred care approach is to acknowledge and understand a person's history, background, likes or dislikes, and their unique experience as someone living with dementia (Nicholson, 2017). Further to this unique experience, there is the need to explore the symptoms in each type of dementia, their differences and salience within the various diagnoses and stages, as well as how these symptoms get affected by care interventions (Kim and Park, 2017).

In Chapter 1. I referred to the growing body of research in music-evoked AMs, and the need to explore the connection of music to the AM system, in order to be able to develop additional ways to enhance communication and support a sense of self. The design and implementation of such person-centred interventions can also be improved by exploring how the AM is affected in different types of dementia or if any of its elements is preserved.

The aim of this systematic review was to critically examine the current evidence base for the specific characteristics and to systematically report the outcomes of current research regarding these specific characteristics, deficits or preservers of the AM system in the different types of dementia. Identification and exploration of the AM system in different forms of the disease can help target the specific symptoms when designing therapeutic approaches and furthermore, to exploit the intact memories and patterns of AM to benefit people living with dementia. The question for this systematic review was developed using the PICO tool (Population, Intervention/ Interest, Comparison, Outcomes) as a guide. According to the aim, the population of interest is people with a dementia diagnosis such as Alzheimer's disease, frontotemporal dementia, semantic dementia, or vascular dementia, and the intervention/ phenomenon of interest is the Autobiographical Memory system.

Dementia is a term that describes a group of symptoms, including memory decline, language deficits and difficulties in reasoning and communication. Different types of dementia have

been characterised according to what caused the decline and what are the specific symptoms (American Psychiatric and Force, 2013). Therefore, the systematic review was relevant to consider how AM is affected in the different types of dementia. The comparative dimension involves the different types of dementia, and lastly, the outcomes are standardised measurements and evaluations of AM, such as the Autobiographical Memory Interview (AMI) (Kopelman, Wilson and Baddeley, 1989; Kopelman, Wilson and Baddeley, 1990) or the Galton–Crovitz task (GALTON, 1879; Crovitz and Schiffman, 1974). These outcomes measures were included in the systematic review because these are established clinical measurements, used broadly within the research and clinical community, as was identified by the screening process.

The criteria for excluding or including studies in the review are as follows: regarding the research design, the criteria was to include both qualitative and quantitative studies that investigate how AM is affected in the different types of dementia. Including both types of research approaches generated a better understanding of the question posed and provided more information regarding the effectiveness and correlation of assessment in AM investigations. Regarding the language of publication, only studies in English were included in the review because there were no resources for translation. Regarding time frame, I included studies that were published since January 2000 and up to February 2019, in order to capture all the relevant publications up to date. Regarding the population, studies were included if they involved people with a valid diagnosis of dementia and specified the type of dementia, diagnosed using recognised diagnostic manuals such as ICD-10, DSM-IV, DSM-V.

2.2 Search Strategy and Selection of Studies

A preliminary systematic search of the following electronic published literature databases was carried out in December 2015: Medline Ovid; CINAHL; PsycINFO; Cochrane Library (Cochrane Database of Systematic Reviews); Cochrane Dementia and Cognitive Improvement

Group Specialised Register; and the ALOIS (https://alois.medsci.ox.ac.uk/). Multiple databases were used in order to increase the identification of all the relevant publications. The databases used in the systematic search are the most relevant to the field of dementia and AM. Medline Ovid is the most relevant for medical sciences; PsycINFo is relevant for studies in the field of psychology; Cochrane Database of Systematic Reviews allowed me to identify relevant reviews and to conduct a further search based on their references list. Similarly, Cochrane Dementia and Cognitive Improvement Group specialised Registered, and ALOIS have a collection of reviews and studies related to dementia. An additional search included hand-searching reference lists of relevant reviews and journals and special issues. A final supplementary search of the literature was carried out in June 2021, where I repeated the previous search process in order to bring the review up to date. The search syntax was adjusted according to the electronic databases (see Appendix 2 for the search strategy used).

In the first stage, after removing duplicates, I screened 19158 titles and, at that stage, excluded 18850 titles. The abstracts for the 308 remaining studies were screened, of which 49 studies were read in full and assessed for eligibility. In the second stage of the review, my primary supervisor also reviewed the full text of the eligible studies and we applied the Critical Appraisal tool (Downes *et al.*, 2016) for eligible studies to decide which studies met the inclusion criteria. The flow diagram in Figure 1 shows the PRISMA flow chart with the search process, which led to the 28 studies included in the review (Moher *et al.*, 2009).

In Table 1. I summarise the characteristics of these 28 studies as follows: first author and publication date; the size of the sample; the numbers of participants with a diagnosis of dementia, as well the specific type of dementia diagnosis; the gender of the participants; the score of Mini Mental State Examination test (MMSE); the age of the participants; residential status and recruitment source; the main outcomes.

Figure 1:PRISMA Flow chart for Systematic Review 1

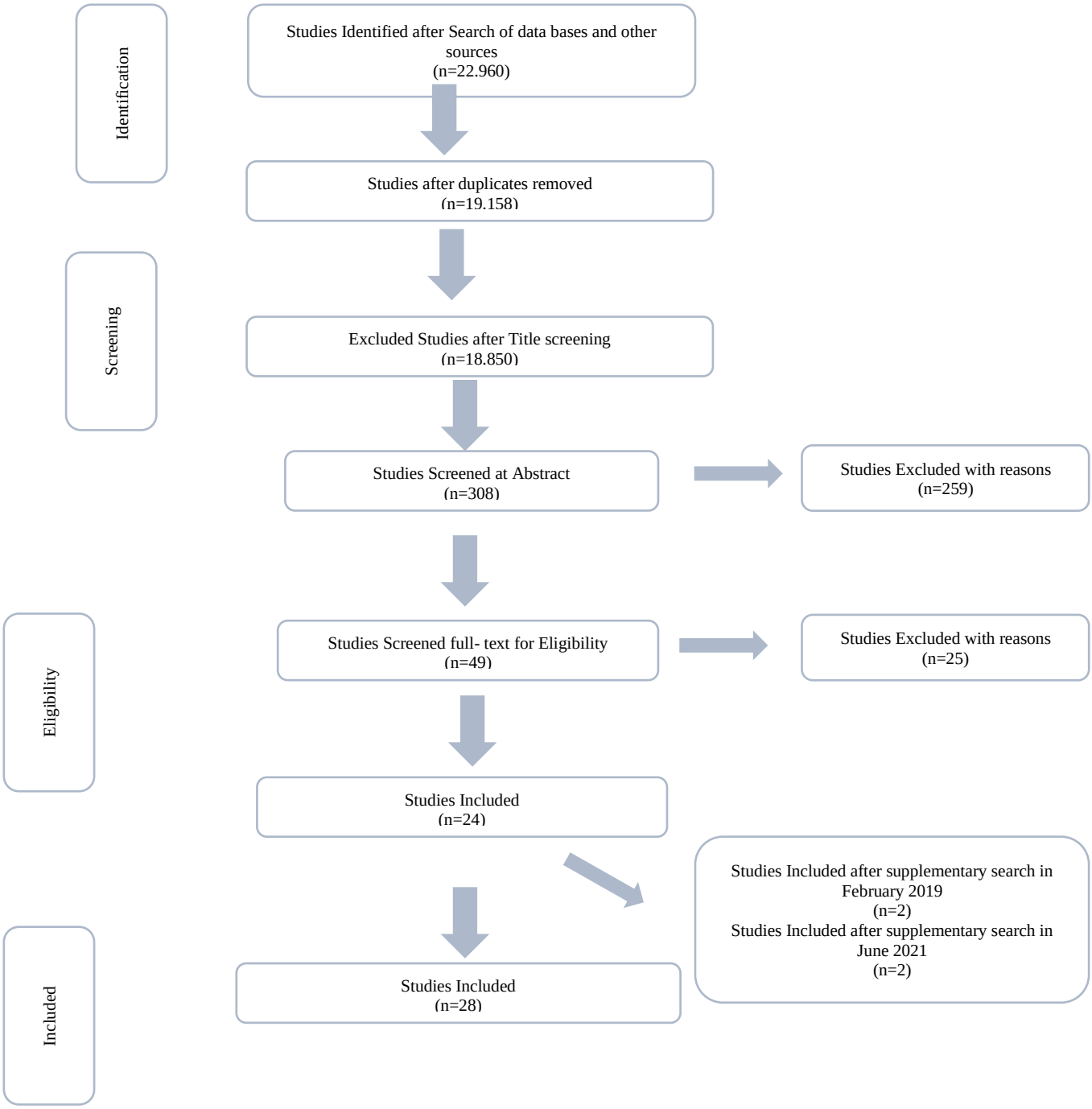

Table 1. Studies included in the Systematic Review 1

	Study	Sample Size	N of participants Patients	Diagnosis	Gender Female/male	MMSE mean (SD) [range]	Age (years) Mean (SD) [range]	Main Outcome Meaure	Residential status	Recruitment Source
1.	Addis et al. (2004)	40	20	probable AD	13/7	19.85 (3.15) [13-24]	75.45 (7.06) [66-90]	Autobiographical Memory Interview (AMI) (Kopelman et al., 1989) & Autobiographical Fluency (Dritschel et al. 1992)	5 in their own homes alone 15 in their own homes with family members 3 in residential care facilities.	Memory Clinic
2.	Bose et al. (2016)	160	60	30=AD 30=VD	8/22 12/18	20.5 ± 4.5 22.4 ± 3.4	64.36 ± 8.27 64 ± 8.93	Autobiographical Memory Interview (AMI) (Kopelman et al., 1989)	No information	Cognitive Clinic,
3.	Donix et al.(2010)	48	32	16 = aMCI 16 = early AD	7/9 11/5	28.56 (.81) 24.19 (2.95)	63.13 (5.78) 64.67 (7.3)	ABM task	No information	Memory Disorder clinic
4.	El Haj et al.(2015)	57	27	probable AD	17/10	21.89 (1.50)	71.85 (7.01)	Autobiographical and reliving assessment	Retirement homes	Retirement homes

5.	Eustache et al. (2004)	33	17	Unmedicated AD	11/6	22.2 (2.3)	72.8 (5.2)	Sophisticated novel personal event task derived from (AMI) Kopelman et al. (1989), Borrini et al. (1989) and Piolino et al. (2003a, b)	No information	no information
6.	Greenberg et al. (2011)	10	5	SD	4/1	27.6 (1.5)	61.2 (4.5)	AM test employed the Galton-Crovitz design	No information	Memory and Aging Center
7.	Hou (2005)	36	28	9 = AD 11 = FTD 8 = SD	no information	23.0 24.6 24.3	74.4 (9.6) 62.4 (9.4) 63.4 (9.4)	Autobiographical Memory Interview (AMI) (Kopelman et al., 1989)	No information	Memory and Aging Center
8.	Irish et al. (2018)	47	24	13=FTD 11=AD	13 9/2	no information	61.4 (5.8) 63.9 (8.2)	The EAMI (Irish et al., 2008) is a semi-structured interview		FRONTIER, frontotemporal dementia research group, at Neuroscience Research Australia, Sydney
9.	Irish et al. (2011a)	80	20	mild probable AD	9/11	MMSE ‘‘7s’’ =24.0 (2.4) MMSE ‘‘dlrow’’ =24.4 (2.4)	73.0 (74)	The EAMI (Irish et al., 2008) is a semi-structured interview	No information	Mercer’s Institute for Research on Ageing (MIRA)

10.	Irish et al. (2011b)	76	57	15 = (bv)FTD 25 = SD 17 = AD	2/13 7/18 3/14	26.0 (2.8) 25.0 (3.6) 24.5 (3.9)	61.6 (7.4) 62.6 (8.1) 66.6 (8.6)	Shortened version of the Autobiographical Interview (AI; Levine, Svoboda, Hay, Winocur, & Moscovitch, 2002).	No information	FRONTIER at Neuroscience Research Australia, Sydney. Cambridge Memory and Early-Onset Dementia Clinic, UK.
11.	Ivanoiu et al. (2006)	43	22	20 = Mild to Moderate AD 1=Mild SD 1=Moderate SD	8/12 1/1	22.15 (2.81) [16-26] 24.67 (1.22) [23-26] 20.09 (1.87) [16-22] 26 17	76 (.7) 77 (.6) 74 (.8) 72 80	The ABM questionnaire was constructed in two parts, a cued component using the basic principles of the AMI (Kopelman et al., 1990) together with a free recall part (higher in executive load) using the autobiographical fluency method (Dritschel, Williams, Baddeley, & Nimmo-Smith, 1992) to allow an evaluation of ABM under different executive demands.	No information No information No information Home/ spouse Home/ spouse	No information
12.	Ivanoiu e al. (2004)	41	21	9= minimal AD 11= mild AD 1=mild SD		77 (6) 74 (8) 72	9 10 12	Modified version of AMI (Kopelman et al., 1990)	No information	No information
13.	Kirk et al. (2018)	89	45	AD	24/19	19.89 (4.05)	80.67 (7.52)	AMI (Kopelman et al. 1990) The Galton- Crovitz cueing technique	Home	With the assistance of regional dementia works, who established the initial contact to the patients through their primary care takers
14.	Leyhe et al.(2009)	60	40	20 = aMCI 20 = AD	8/12 10/10	26.7 (3.3) 20.3 (5.9)	72.6 (6.8) 76.9 (5.5)	AMI (Kopelman et al., 1990).	No information No information	Memory Clinic

15.	Matuszewski et al. (2009)	14	14	7 = Mild SD 7 = Moderate SD	NI NI	26 (1.91) 21.29 (1.07)	63.71 (9.14) 66.68 (7.99)	a semi-structured questionnaire (TEMPau task, Piolino et al., 2003a, 2003b, 2006, 2007a, 2007b	No information	no information
16.	Matuszweski et al. (2006)	20	20	(fv)FTD	NI	24.3 (3.96)	67.9 (+/-9.1) [52-83]	a semi-structured questionnaire (TEMPau task, Piolino et al., 2003a, 2003b, 2006, 2007a, 2007b	No information	no information
17.	Meléndez et al. (2021)	59	33	17=MCI 16=AD	6/11 5/11	T1. 21.64 - T2. 21.35 T1. 17.57 - T2. 17.49	77.35 (4.76) 77.07 (4.54)	Autobiographical Memory Interview (AMI) (Kopelman et al., 1989)	No information	No information
18.	McKinnon et al. (2008)	46	30	8 = FTD 9 = FTD/SD 5 = PNFA follow up: [5=FTD, 1=FTD/SD, 2= PNFA]	3/5 7/2 3/2 3/5	25.9 (3.3) 28.0 (1.9) 27.8(1.5) 24.4 (3.4)	59 (6.0) 59 (9.4) 66 (10.4) 61 (6.2)	Autobiographical Interview [Levine, Svoboda, Hay, Winocur, & Moscovitch (2002).	No information	Dementia clinics
19.	McKinnon et al. (2006)	18	2	SD	2/0	Test 1=18 Test 2=10 25	62 67	Autobiographical Interview [Levine, Svoboda, Hay, Winocur, & Moscovitch (2002).	No information	No information
20.	Meeter et al. (2006)	42	21	probable AD	5/16	24.5 [16-29]	73.2 [61- 82]	Dutch version of the Autobiographical Memory Interview (AMI)	No information	Memory Clinic

21.	Meulenbroek et al. (2010)	43	21	early stage probable AD	9/12	24.8 (3.4)	72.4 (7.1)	Autobiographical Interview Scoring Manual (belonging to Levine et al., 2002)	No information	Memory Clinic
22.	Naylor et al. (2008)	30	30	20 = AD 8= mixed AD and vascular dementia 2 = vascular dementia	24/6	22.40 (3.61) [16-29]	78.20 (6.18) [64-91]	Autobiographical Memory Interview (AMI)	12= alone in their house 16 = with a spouse 2 = another family member	Memory Clinic
23.	Piolino et al. (2003)	1	1	SD	0/1	no information	69	Autobiographical fluency test / strictly episodic autobiographical test	No information	Neurological Unit
24.	Rauchs et al. (2013)	28	14	Unmedicated AD	8/6	24.9 (2)	77.1 (4.1)	TEMPau Piolino et al. (2003, 2009).	No information	Memory Clinic
25.	Sartori et al. (2004)	20	10	probable AD	4/6	11.8 (1.6) [9-15]	83.1 (9.0)	Autobiographical Memory Enquiry (AME; Borrini, Dall'Ora, Della Sala, Marinelli, & Spinnler, 1989)	no information	no information
26.	Seidil et al. (2011)	239	198	33 = MCI 35 = Mild AD 56 = Moderate AD 74= Severe AD	21/12 26/9 49/7 64/10	26.6 (2.3) 22.7 (3.4) 14.5 (5.1) 2.5 (3.8)	79.3 (6.0) 84.3 (7.8) 86.9 (6.1) 87.1 (7.0)	semi-structured interview (Erweitertes Autobiographisches Geda¨chtnis Inventar, E-AGI [26]) based on the AMI of Kopelman	Nursing homes	nursing homes
27.	Starstein et al. (2005)	58	38	AD	NI	23.0 (5.0)	74.5 (6.2)	Autobiographical Memory Scale.	No information	no information

28.	Thoman et al (2012)	53	29	15= MCI 14 -Mild AD	8/7 7/7	26.6 (1.7) 19.9 (4.5)	73.3 (3.8) 73.7 (5.2)	AM was assessed with a semi-structured interview (Er- weitertes Autobiographisches Gedächtnis Inventar, E-AGI) [29] trained raters/ blind to the diagnoses. is based on the AMI of Kopelmanet al.	No information	Memory Clinic

2.3 Quality Check

To assess the methodological quality of the studies included in the review, I was guided by the AXIS tool developed by the Delphi panel (Downes *et al.*, 2016). The tool was developed in order to assess design and research quality, as well as the risk of bias in cross-sectional studies (Downes *et al.*, 2016). The tool includes 20 questions relating to study design, sample, study population, measurements, methodological approach, all under the following sections: Introduction; Methods; Results; Discussion; and Other (Downes *et al.*, 2016). Table 2. presents the AXIS tool questions, and Table 3. presents the results of applying the AXIS tool to the included studies.

Table 2: AXIS tool Questions

AXIS tool (Downes *et al.*, 2016)

	Questions
Q1.	Were the aims/objectives of the study clear?
Q2.	Was the study design appropriate for the stated aim(s)?
Q3.	Was the sample size justified?
Q4.	Was the target/reference population clearly defined? (Is it clear who the research was about?)
Q5.	Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation?
Q6.	Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation?
Q7.	Were measures undertaken to address and categorise non-responders?
Q8.	Were the risk factor and outcome variables measured appropriate to the aims of the study**?**
Q9.	Were the risk factor and outcome variables measured correctly using instruments/ measurements that had been trialled, piloted or published previously?
Q10.	Is it clear what was used to determined statistical significance and/or precision estimates? (eg, p values, CIs)
Q11.	Were the methods (including statistical methods) sufficiently described to enable them to be repeated?
Q12.	Were the basic data adequately described?
Q13.	Does the response rate raise concerns about non-response bias?
Q14.	If appropriate, was information about non-responders described?
Q15.	Were the results internally consistent?
Q16.	Were the results for the analyses described in the methods, presented?
Q17.	Were the authors' discussions and conclusions justified by the results?
Q18.	Were the limitations of the study discussed?
Q19.	Were there any funding sources or conflicts of interest that may affect the authors' interpretation of the results?
Q20.	Was ethical approval or consent of participants attained?

Table 3: Assessment according to AXIS tool[1]

	Studies	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12	Q13	Q14	Q15	Q16	Q17	Q18	Q19	Q20
1.	Addis et al. 2004	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes
2.	Bose et al. (2016)	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes
3.	Donix et al. 2010	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes
4.	El Haj et al. 2015	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes
5.	Eustache et al. 2004	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes
6.	Greenberg et al.2011	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes
7.	Hou et al. 2005	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes
8.	Irish eta al. 2018	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes
9.	Irish et al. 2011a	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes
10.	Irish et al. 2011b	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes
11.	Ivanoiu et al. 2006	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes
12.	Ivanoiu et al. 2004	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes
13.	Kirk et al. 2018	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes
14.	Leyhe et al. 2009	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes

[1] Downes, M. J., Brennan, M. L., Williams, H. C. and Dean, R. S. (2016) 'Development of a critical appraisal tool to assess the quality of cross-sectional studies (AXIS)', *BMJ Open*, 6(12), pp. e011458. Answers: Yes; No; NA: Not Appropriate; U: Unkown

15.	Matuszweski et al. 2009	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes
16.	Matuszweski et al. 2006	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes
17.	McKinnnon et al. 2008	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes
18.	McKinnon et al. 2006	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes
19.	Meeter et al. 2006	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes
20.	Meléndez et al. (2021)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	U	Yes	Yes	Yes	No	Yes
21.	Meulenbroek et al. 2010	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes
22.	Naylor et al. 2008	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes
23.	Piolino et al. 2003	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes
24.	Rauchs et al. 2013	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes
25.	Sartori et al. 2004	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes
26.	Seidi et al. 2011	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes
27.	Starstein et al. 2005	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes
28.	Thomann et al. 2012	Yes	Yes	NA	Yes	Yes	Yes	NA	Yes	Yes	Yes	Yes	Yes	No	NA	U	Yes	Yes	Yes	No	Yes

2.4 Results

The review included 28 studies from 2003 until 2021. Regarding the participants, all the studies provide details regarding the recruitment of their participants and the diagnostic evaluation for the clinical criteria according to the NINCDS-ADRA (McKhann *et al.*, 1984) for the people with a type of dementia diagnosis. In the majority of the studies, participants who were defined as healthy controls were recruited either from the same community or from the patients' families or friends. The eligibility criteria for the participants were also well defined and evaluated with the same standardised diagnostic tools, and they all had neurological and neuropsychological evaluations prior to their participation in the study.

Control participants were also matched to the patients' age, gender and education to eliminate differences due to these factors in the study outcomes. Furthermore, all the studies had a detailed description of the procedure, and the methodological analysis, such as a description of statistics and the tests that were used. Overall, the studies in the review were of good quality and showed a low risk of bias. A total of 694 participants had a diagnosis of dementia. In Table 4. I present the total number of each type of dementia as it was reported in the studies.

The findings of this review are reported as a narrative synthesis. A meta-analysis was beyond the aim of the review and was not possible since studies used different measurement outcomes. Furthermore, the aim of the review was to understand how AM is affected in the different types of dementia, and for example, there was only one study included in the review where AM was assessed in vascular dementia (Naylor and Clare, 2008).

Table 4. Types of Dementia

Type of Dementia	**Participants (N)**
Probable AD	119
AD	211
Early/ mild AD	85
Moderate AD	102
Severe AD	74
Mixed AD & vascular dementia	2
Vascular dementia	30
FTD	32
fvFTD or bvFTD	35
PNFA	5
Mixed FTD & SD	9
SD	41
Mild SD	9
Moderate SD	8
Total	694

2.4.1 Findings

In this sub-section, I present the outcomes used in the included studies, and I describe how AM characteristics were assessed and evaluated in each outcome. I present how specifically AM was affected in the four different types of dementia: Alzheimer's disease, semantic dementia, vascular dementia and frontotemporal dementia.

i. Assessment of Autobiographical Memory

Scholars use a variety of measurements to evaluate AM. All of the assessments included in the reviewed studies were standardised or were derived from standardised assessments and modified for the purpose of each study. The difference was in use or not of probe stimuli (such as words or objects), in the definition of lifetime periods or the focus on phenomenological characteristics of AMs. Next, in this section, I give a detailed description of each test, describing the structure of each assessment, including how life periods were divided; I consider any implications for the conduct of the studies and the findings.

The assessments used in the studies were all well standardised and used appropriate measurements for the evaluation of AM. The majority of the studies used the Autobiographical Memory Interview (AMI) (Kopelman, Wilson and Baddeley, 1990), either a translation of AMI in another language or a shorter adaptation of the assessment (Addis and Tippett, 2004; Berna *et al.*, 2012; Leyhe *et al.*, 2009; Eustache *et al.*, 2004; Hou, Miller and Kramer, 2005; Ivanoiu *et al.*, 2004; Kirk *et al.*, 2018; Ivanoiu *et al.*, 2006; Kirk and Berntsen, 2018; Meeter, Eijsackers and Mulder, 2006; Naylor and Clare, 2008; Seidl *et al.*, 2011; Thomann *et al.*, 2012).

AMI is a research tool for investigating retrograde amnesia. During a semi-structured interview, participants are asked to recall general facts about their own earlier life (semantic memory) as well as specific autobiographical incidents (episodic memory), across three lifetime periods: childhood, early adult life and recent life (Kopelman, Wilson and Baddeley, 1990). According to the AMI scoring method, recall can be given a point score from zero to three, based on the types of details given in a recalled memory; for each life period, a maximum score of six can be obtained as two memories are described per each life period (Kopelman, Wilson and Baddeley, 1990).

The Autobiographical Interview (AI) by Levine and colleagues (Levine *et al.*, 2002) was used in four studies (Irish *et al.*, 2011a; McKinnon *et al.*, 2006; McKinnon *et al.*, 2008; Meulenbroek

et al., 2010b). During this assessment, participants are asked to describe in detail a personally significant event that happened in each of the following five time periods: early childhood (0-11 years); teenage years (11–17 years); early adulthood (18–35 years); middle age (35– 55 years); and the past year (Levine *et al.*, 2002). They are required to report the event with specificity in terms of time and place, and where needed, participants are provided with a list of events as prompts to assist them in the assessment (Levine *et al.*, 2002).

Two studies by Kirk and colleagues and Greenberg and colleagues included in the review used the Galton-Crovitz cueing task and the Galton-Crovitz design respectively (Kirk *et al.*, 2018; Greenberg *et al.*, 2011), developed by Galton (1879) and first introduced in contemporary psychology by Crovitz and Schiffman (GALTON, 1879; Crovitz and Schiffman, 1974). In this task, autobiographical memory is assessed by asking the participants to give a description of the first personal memory they recall in response to a cued word.

In the study by Kirk and colleagues (Kirk *et al.*, 2018), the test examined autobiographical memory recall under two different conditions, using an object-cue and a word-cue. For the first condition, each participant was presented with an object which had a personalised meaning and referred to the participants' past; in the second condition, a word equivalent to the object was given to the participants. In both cases, participants were asked to recall and give as many details as they could of the first autobiographical memory, prompted by both the object and the word.

Greenberg and colleagues (2011) used the same design as in the Galton-Crovitz cueing task; the cues they employed to retrieve AMs were words, simple pictures and odours. They tested the cues for three time periods: childhood (0–17 years); young adulthood (18–35 years); and recent life (36– to present). The instructions for each participant were to recall a specific memory of each period after the presentation of each cue. The scores were given by two blind

evaluators. The scoring of the test in both studies is on a scale from 0 to 5, which quantifies the level of detail and specificity of the memories recalled.

The Episodic Autobiographical Memory Interview (EAMI) is a semi-structured interview developed by Irish and colleagues (Irish *et al.*, 2008) and was used in two studies included in the review (Irish *et al.*, 2018b; Irish *et al.*, 2011b). EAMI contains categories across the life period, including childhood (0–15 years), early adulthood (16–30 years), middle adulthood (31–45 years), later adulthood (46 up to 5 years ago), and recent memory (in the last five years). The participants are given the instruction to recall and describe an incident that took place during these time periods, and give as many personal semantic details as they can, such as name the place or name other people involved in the event; participants are required to recall three events in total (Irish *et al.*, 2008; Irish *et al.*, 2018a).

The experiments that use phenomenological categories of autobiographical memory encourage and probe the participants to give more and specific information about the event (Irish *et al.*, 2010; Irish *et al.*, 2011a; Irish *et al.*, 2018a). The phenomenological categories are details of the event, specificity in time, perceptual details, spatial specificity and emotions and thoughts of the event (Irish *et al.*, 2008; Montebarocci, Luchetti and Sutin, 2014). The score is then formed from these seven phenomenological categories in terms of how many details participants can report for each category; one point is assigned for each type when the participant gives a detailed description of the event, half a point when the participant repeats information during the recall or cannot provide specific details, and zero points when participants cannot recall any personal memories (Irish *et al.*, 2008). The maximum score for each participant is 21 points (Irish *et al.*, 2008; Irish *et al.*, 2011b; Irish *et al.*, 2018b).

TEMPau task (*Test Episodique de Mémoire du Passé autobiographique*) (Piolino *et al.*, 2003a), was used in four studies (El Haj *et al.*, 2015; Matuszewski *et al.*, 2009a; Matuszewski *et al.*, 2006; Rauchs *et al.*, 2013). TEMPau task is a semi-structured questionnaire and is based on the previous work of Kopelman, Borrini, and Piolino (Kopelman, Wilson and Baddeley, 1990; Borrini *et al.*, 1989; Piolino *et al.*, 2003a). The test assesses participants' capability to report personal information of events from five different time periods: first period (0–17 years old); the second period (18–30 years old); the third period (more than 30 years old to the last five years); fourth period (last five years except for the last 12 months); and fifth period (the last 12 months).

One study (Eustache *et al.*, 2004) used a sophisticated novel personal task derived from combining the work of three research teams (Kopelman, Wilson and Baddeley, 1989; Borrini *et al.*, 1989; Piolino *et al.*, 2003a). In this test, participants are invited to report specific events in as much detail as possible for three time periods: period A (the previous five years except for the last 12 months); period B (middle age); and period C (teenage and childhood) (Desgranges *et al.*, 2002).

The Cue word Autobiographical Memory task was used in one study (Donix *et al.*, 2010). In this test, participants were instructed to report memory of a single event that occurred at a particular time and place, probed by a cue word. The test was translated into German and used ten cue words, divided as five positive and five negatives. The answers given by each participant were audio-recorded and were later rated by two individual examiners.

A strictly episodic autobiographical test associated with the Remember/Know procedure was used in one study (Piolino *et al.*, 2003a). The test is a semi-structured questionnaire based on previous work of Kopelman (Kopelman, Wilson and Baddeley, 1990; Borrini *et al.*, 1989; Piolino *et al.*, 2003b). The test assesses the ability to recall detailed specific events and give specific details about space and time and describe each event with as many details as they

could. The following instruction was given to the participants: "Describe, out loud and with as much detail as possible, what happened, as if you are able to relive it: What you did and felt, the circumstances, with whom, where and how it happened. If you recall, for example, holidays at the seaside, you must avoid general descriptions, giving precise memories of a particular event which happened on a day during these holidays". There was no time limit for their replies. The following five time periods were used: 0–17 years old; 18–30 years old; more than 30 years old except for the last five years; the last five years except for the last 12 months; and the last 12 months.

An autobiographical and reliving assessment was used in one study (El Haj, Antoine and Kapogiannis, 2015), which involved participants being tested individually in their homes or their rooms/apartments during two sessions. In one session, they were asked to recall and report on past events, and in the second session, they were invited to imagine future events. In this review, I extracted the data from the first session which is the assessment of AM.

The Autobiographical Memory Enquiry (AME) (Borrini *et al.*, 1989) was used in one study (Sartori *et al.*, 2004). This test assesses AM for three life periods: infancy up to 15 years; 16–40 years; and from 41 up to 2 years before the testing date. For each time -period, participants are asked five questions attached to specific autobiographical events, such as their first job or a childhood incident. Participants' responses are scored for how detailed and how rich the information is that they are able to provide, in a range of 0–15.

The Autobiographical Memory Scale was used in one study (Starkstein, Boller and Garau, 2005) and consists of 39 questions regarding five life periods: childhood, adolescence, youth, adult and recent events. The participants during the assessment are instructed to free recall and to give free answers. The second part of the assessment is a recognition section; in that section, participants need to choose among three different answers where one is the correct answer, and the other two are semantic foils. The correct answer is information provided by their families.

Assessing AM could be challenging since it involves different processes, such as the episodic and the semantic components of AM. Also, AM assessments and tests require access to specific and personal information for each participant; for example, participants' responses might need to be confirmed by a relative. Lastly, tests in a laboratory setting are difficult to apply for AM assessment (Sheldon *et al.*, 2018).

An element that can direct the selection of the assessments is the process researchers aim to explore: in AM research, there are different theoretical approaches for exploring and understanding AM in the healthy and patient population. One approach concerns the process of how people access AM information and is related to how AM is organised. Conway and Pleydell-Pearce developed a model related to this approach, with which they proposed that AM has a specific hierarchy. At the base of this hierarchy is the specific episodic knowledge (event-specific knowledge), followed by knowledge about general events and abstract information, and lastly by the lifetime periods (Conway and Pleydell-Pearce, 2000).

Another theoretical approach to AM memory evaluates three questions related to the knowledge of an event, “What was the event?”, “When and Where the event occurred?”, that approach was proposed by Tulving (1979, 2002). In this approach, the episodic component is accessed with these three questions, and the semantic component is related to how AM was experienced (Tulving, 1995; Tulving, 2002).

Yet another approach to understanding AM system is to assess the phenomenological qualities of the AMs, or how AM has been experienced by the individuals, including perceptual, emotional, spatial and linguistic systems. Along with the narrative process, which is differentiated from the elements of language in a linguistic system (Rubin, 2006), these basic systems interact and coordinate with the experience of AM.

The outcome measurements presented in this section for evaluating AM in dementia showed that there is a sufficient range of validated behavioural methods and specific tools to assess both how people access AM knowledge and the phenomenological components of AM. To evaluate how AM is accessed, researchers use cues as a methodological approach, whereas when phenomenological characteristics of AM are evaluated, researchers use interview assessments.

In dementia research, both approaches and the relevant assessments are important in exploring deficits in AM, but also in understanding how some AM components might be preserved in some types of dementia or how AM system might be affected across the dementia span. In both approaches, there might be some difficulties when AM is evaluated in people with a dementia diagnosis; one challenge might be the necessity to confirm participants' answers. In one of the included studies, researchers reported that they did not check for confabulation in participants' responses since it is not common among people with a diagnosis of dementia (Rose Addis and Tippett, 2004). Yet research has shown a relative confabulation in patients with FTD and AD diagnosis. People with an FTD diagnosis confabulate more in episodic and semantic memory, while people with an AD diagnosis confabulate more in provoked conditions and less spontaneously (Nedjam, Dalla Barba and Pillon, 2000; Lee *et al.*, 2009; Nedjam, Devouche and Dalla Barba, 2004; Barba, Nedjam and Dubois, 1999; El Haj and Larøi, 2017). Control for confabulation and the accuracy of AM memories could be challenging for people without any caregiver or close relative.

In most of the studies included in the review, veracity and accuracy of the recalled memories was verified either by retesting for the same memory or with a relative when possible (Eustache *et al.*, 2004; Hou, Miller and Kramer, 2005; Ivanoiu *et al.*, 2006; Leyhe *et al.*, 2009; Matuszewski *et al.*, 2009b; Matuszewski *et al.*, 2006; Meeter, Eijsackers and Mulder, 2006; Piolino *et al.*, 2003a; Rauchs *et al.*, 2013; Sartori *et al.*, 2004; Starkstein, Boller and Garau,

2005). One study by Kirk and colleagues (2008) reported the absence of systematic verification of the recalled memories as a limitation of their research. Nonetheless, they described that during the AM assessment, one caregiver was present for the majority of the participants. In the remaining studies, the veracity or not of the recalled memories was not reported.

ii. Autobiographical memory patterns in different types of dementia

From the 28 studies included in the review, seven studies compared AM function in participants with different types of dementia and control participants (Greenberg *et al.*, 2011; Hou, Miller and Kramer, 2005; Irish *et al.*, 2018a; Irish *et al.*, 2011a; Ivanoiu *et al.*, 2004; Ivanoiu *et al.*, 2006; Naylor and Clare, 2008); and 19 studies evaluated and compared the function of autobiographical memory in participants with only one type of dementia or compared participants with one type of dementia with control participants (Addis and Tippett, 2004; Donix *et al.*, 2010; El Haj, Antoine and Kapogiannis, 2015; Eustache *et al.*, 2004; Irish *et al.*, 2011b; Kirk and Berntsen, 2018; Leyhe *et al.*, 2009; Matuszewski *et al.*, 2009b; Matuszewski *et al.*, 2006; McKinnon *et al.*, 2008; McKinnon *et al.*, 2006; Meeter, Eijsackers and Mulder, 2006; Meulenbroek *et al.*, 2010b; Piolino *et al.*, 2003b; Rauchs *et al.*, 2013; Sartori *et al.*, 2004; Seidl *et al.*, 2011; Starkstein, Boller and Garau, 2005; Thomann *et al.*, 2012).

Different types of dementia have different symptoms. Semantic Dementia (SD) primarily affects speech, fluency, and comprehension (Kertesz *et al.*, 2010; American Psychiatric and Force, 2013). The definition of Frontotemporal Dementia (FTD) has been adjusted since its first description. FTD is now a diagnostic umbrella for three different syndromes: behaviour variant FTD (bvFTD); non-fluent variant primary progressive aphasia (nfvPPA); and semantic variant PPA (svPPA) (Olney, Spina and Miller, 2017; Bang, Spina and Miller, 2015). Symptoms of FTD are deterioration of behavioural and cognition, such as socially inappropriate behaviour and deficits in executive functions such as attention, working memory

(American Psychiatric and Force, 2013). In the studies included in this systematic review, the term FTD or bvFTD is used.

Alzheimer's disease (AD) is the most frequent diagnosis of dementia. AD symptoms include memory decline, difficulties in performing executive tasks, difficulties in speech and language, psychological and behavioural symptoms (American Psychiatric and Force, 2013; Bature *et al.*, 2017; Weller and Budson, 2018). Vascular dementia's primary symptoms include attention decline, deficits in executive functions such as difficulties in planning or comprehension, and psychological and behavioural symptoms. Memory decline is not to as common as in other types of dementia. (O'Brien and Thomas, 2015; American Psychiatric and Force, 2013). The diagnosis of the type of dementia is critical to determine the kind of symptoms and to develop more appropriate and effective interventions.

iii. Autobiographical memory in Alzheimer's disease

Across the studies, people with AD performed poorly in AM, regardless of which test was used (El Haj, Antoine and Kapogiannis, 2015; Addis and Tippett, 2004; Donix *et al.*, 2010; Eustache *et al.*, 2004; Hou, Miller and Kramer, 2005; Irish *et al.*, 2018b; Irish *et al.*, 2011b; Irish *et al.*, 2011a; Ivanoiu *et al.*, 2004; Ivanoiu *et al.*, 2006; Kirk and Berntsen, 2018; Leyhe *et al.*, 2009; Meeter, Eijsackers and Mulder, 2006; Meulenbroek *et al.*, 2010b; Naylor and Clare, 2008; Rauchs *et al.*, 2013; Sartori *et al.*, 2004; Seidl *et al.*, 2011; Starkstein, Boller and Garau, 2005; Thomann *et al.*, 2012; Meléndez *et al.*, 2021).

The majority of participants with a diagnosis of AD demonstrated a temporal gradient effect, meaning that they had an overall worse recall for events in their recent past and middle age, with a clear deficit in memories of the last 1-5 years, compared with events from the childhood period and/or early adulthood (Addis and Tippett, 2004; Eustache *et al.*, 2004; Irish *et al.*, 2018b; Irish *et al.*, 2011a; Kirk and Berntsen, 2018; Leyhe *et al.*, 2009). Only in the study by

Ivaniou and colleagues was there an absence of any clear temporal gradient effect for episodic AM; however, there was a medium gradient effect for the semantic AM component (Ivanoiu *et al.*, 2004; Ivanoiu *et al.*, 2006). In addition, people with AD reported less specific AM details related to personal memories; for example, they did not give details related to the time or the place (Donix *et al.*, 2010; El Haj, Antoine and Kapogiannis, 2015; Irish *et al.*, 2011b; Addis and Tippett, 2004).

In the study by Addis and Tippett (2004), participants with an AD diagnosis also recalled significantly less specific personal detailed memories compared to control participants, but there was a global deficit of AM across all life periods in recalling specific time and place details for personal events (Addis and Tippett, 2004). They also poorly recalled personal semantic memories for names or facts, such as the name of their school, when compared with healthy participants (Addis and Tippett, 2004). In this study by Addis and Tippet (2004), the main difference was in personal semantic memories for recent adulthood, where their recall was more affected when compared to the personal semantic memories recalled from their childhood period.

In Irish et al. (2011b), when the subcategories of the details were investigated further, participants were found to have preserved details on how they felt at the time of the event;, but emotional details of the event were less vivid in the recent period when compared to the remote periods (Irish *et al.*, 2011b).

In the study by El Haj and colleagues, the participants with an AD diagnosis produced fewer memories characterised as self-defining for past events compared to control participants (El Haj, Antoine and Kapogiannis, 2015); self-defining memories include events that are meaningful and significant to the person's life history and sense of self (Wood and Conway, 2006; Martinelli *et al.*, 2013). Reminiscence bump was found in two studies with people with AD diagnosis: in the study by Kirk and colleagues (2018) reminiscence bump was found in the

cueing task condition while in the study by Rauchs and colleagues (2003) it was found when the TEMPau semi-structured questionnaire was used.

Comparison among participants with different severity revealed no difference in recent recall, but people with a moderate AD diagnosis showed better recollection of semantic information from their childhood and early adulthood than recent life (Kirk and Berntsen, 2018; Meeter, Eijsackers and Mulder, 2006; Irish *et al.*, 2011a). In two of the studies reviewed, where participants had a diagnosis of "probable AD" (Meeter, Eijsackers and Mulder, 2006; Meulenbroek *et al.*, 2010a) when remote memories were recalled, they were reported with many incorrect answers. Furthermore, when compared with participants with a different diagnostic type of dementia such as SD, people with an AD diagnosis were able to recall more personal semantic events from their childhood and early adulthood but not from their recent life period, whereas people with SD, FTD and VD diagnoses showed better recollection of memories from their recent past, compared to participants with an AD diagnosis (Irish *et al.*, 2011a; Ivanoiu *et al.*, 2004; Hou, Miller and Kramer, 2005; Irish *et al.*, 2018b; Ivanoiu *et al.*, 2006)

iv. Autobiographical memory in semantic dementia

Participants with a diagnosis of SD generally demonstrated less specificity in their memories across all life periods when compared with control participants, using an AM assessment (Greenberg *et al.*, 2011; McKinnon *et al.*, 2006). Nonetheless, they could recall more details for AMs of the recent past (last five years) compared with detailed semantic information from their childhood and early adulthood. Semantic information was poorer regarding memories from childhood and early adulthood period. Furthermore, these participants were able to recall more incidents from their recent life period compared with the number of incidents recalled from other life periods. They also showed loss of semantic knowledge, but episodic AM, especially for remote events, were relatively well preserved.

Participants with SD showed a difference between free and probed recall conditions, wherein they recalled more internal details of an event from the recent period compared with the other periods, Childhood, Early Adulthood, and Middle Adulthood, in the probed condition (Irish *et al.*, 2011a). In the study by Irish and colleagues (2011a), the recalled details were characterised as internal when the details were specific for spatial and temporal information and when the information was "direct related" to the recalled event. They were charaterised as external when the details were not directly related to the event or the details were just repetitions (Irish *et al.*, 2011a).

Regarding the evaluation of the phenomenological characteristics in free recall conditions, SD participants recalled more perceptual, emotional and thorough details for the recent compared to the remote period (Irish *et al.*, 2011a). In studies where the participants were categorised by the severity of SD (mild vs moderate), there were differences in spontaneous retrieval as well as in terms of how specific recalled memories were, with the mild group performing better than the moderate group (Matuszewski *et al.*, 2009a; McKinnon *et al.*, 2006; Piolino *et al.*, 2003a).

People with a mild SD diagnosis showed preserved AM for the recent time -period up to the last 12 months and scored more highly in episodic memory tasks, whereas the moderate SD group showed a higher impairment across all time periods (Matuszewski *et al.*, 2009b). Between these two groups, there was also a difference in the specificity of the memories: the mildly severe group reported more specific memories compared to the moderate group, even though there was no difference between the groups in terms of generic memory recall (Matuszewski *et al.*, 2009b). Another difference between these groups was regarding reminiscence bump, which was found in the SD mild subgroup. Participants with SD also had less specificity in their memories across all life periods when compared with control participants and compared with people with AD or a diagnosis of FTD. In addition, when the number of details in free recall condition of the remote period were compared across

participants with a different type of dementia, SD participants could recall less perceptual details compared to participants with a diagnosis of FTD, and less perceptual and emotional details when compared with participants with AD (Irish *et al.*, 2011a).

v. Autobiographical memory in vascular dementia

People with a diagnosis of vascular dementia presented a temporal gradient effect similar to the participants with AD diagnosis. They had better recall for events from the earliest time periods compared to the recent period for both semantic and episodic memories (Naylor and Clare, 2008). In their study, Naylor and Clare reported no difference in the AMI scores participants with a vascular dementia diagnosis when compared to that of participants with mixed AD (Naylor and Clare, 2008), contrary to the results of Bose and colleagues which showed that the majority of the participants with VD (80%) performed better in the AMI when compared to participants with AD (Bose *et al.*, 2016). In the same study, the performance of people with VD was compared to the control group: according to this comparison, VD patients did not give details when they recalled episodic autobiographical memories, and they presented difficulties in the semantic section of AMI related to childhood memories (Bose *et al.*, 2016).

vi. Autobiographical memory in frontotemporal dementia

In the studies involving a diagnosis of FTD, participants could better recall personal semantic details such as names, and episodic details such as specific personal details or the emotional context regarding events from their recent life. However, they remembered fewer details, both episodic and semantic, when recalling events from remote periods when compared to other patient populations, such as people with an AD diagnosis (Irish *et al.*, 2018b; Irish *et al.*, 2011a; Hou, Miller and Kramer, 2005; Matuszewski *et al.*, 2006). In contrast, when their recall of internal episodic details was compared to healthy control participants, there was a significant difference, as presented in McKinnon *et al.* (2008).

Regarding the difference of recall across lifetime periods, there was an absence of temporal gradient in studies with people living with FTD (Matuszewski *et al.*, 2006), in contrast with the presence of temporal gradient in studies with people living with Alzheimer's disease, as was shown in the previous section. In a longitudinal study, memory for recent AM was better at baseline relative to follow-up (Irish *et al.*, 2018b). A subgroup of participants with a diagnosis of bvFTD had difficulties remembering and reporting specific and rich details of episodic AMs across all life periods, regardless of the condition (free or probed) (Irish *et al.*, 2011a). In addition, in this subgroup, there was an impairment in recalling phenomenological details such as emotion/thought as well as spatiotemporal details (Irish *et al.*, 2011a).

2.4.2 Findings Synthesis

This section provides a narrative synthesis of the outcomes from the current review with the current knowledge on the formation of the AM system. 28 studies met the inclusion criteria, with a total of 694 participants.

28 studies explored AM in people with a diagnosis of AD, FTD, SD, and vascular dementia. In these studies, regardless of the outcomes, participants present temporal gradients of AM, in which a pattern can be identified of recalling AM memories less well from the recent past, compared with remote AM memories from childhood and early adulthood. Furthermore, there was an over-generalisation in the memories when compared to the control group and in one study, compared to control participants.

Findings from the nine studies which reported on AM assessments with participants with a diagnosis of SD showed that memories recalled across all life periods were not specific, without providing information about the time or the place of the event, or who else might be present. In addition, participants with a diagnosis of SD could better remember events from their recent past (last five years) compared with remembering remote events. In the one study with participants with a vascular dementia diagnosis, results revealed the same pattern as that

found with people living with AD. The temporal gradient effect was also present in AM recall, whereby childhood and early adulthood memories were better remembered compared to the AMs from the recent past.

Five studies in the review explored the AM system in participants with a diagnosis of FTD and bvFTD. The synthesis of the findings from these studies shows that participants preserved personal events in terms of both episodic and semantic details from their recent life but remembering details from the remote period was affected by their condition. More specific semantic details, which includes general knowledge of the events from their childhood and early adult life, were also impaired.

Data were extracted from the studies to understand how AM is affected in different types of dementia. The findings of the included studies reveal differences in impairment of the AM system among the different types of dementia. The AM system is affected across the entire dementia spectrum, but the results of the findings show different patterns of impaired memories as well as preserved memories.

One main outcome of the review can be seen as the presence of a temporal gradient effect of AM recall in people with AD and vascular dementia and the reverse of this effect in participants with FTD and SD diagnosis. Participants with an SD diagnosis also showed a further impairment in the emotional and perceptual details of the recall event from the remote period and a relatively intact recall of these details from the recent period. FTD participants recalled relatively better, personal semantic and episodic details such as names and personal details or the emotional context from events of their recent life when compared to the remote life period. The sub-type of bvFTD showed difficulties in recalling rich specific details of episodic AMs across all life periods, in both free recall and probed conditions. This subgroup also presented impairment in recalling emotional/thoughts and spatiotemporal phenomenological details across all life periods.

The AM system in participants with AD diagnosis is affected, particularly in remembering memories of their recent past; furthermore, there was an over-generalisation of the recalled memories. The findings of the review demonstrate that AD participants have difficulties in accessing memories that are linked to the recent past and to the self-defining memories, which are essential to the construction of self and self-knowledge.

The findings from the studies which evaluated the phenomenological characteristics of AM showed impairment in the retrieval of emotional details of AM in all the types of dementia, even though there was a difference related to the life periods, with SD participants better able to recall these details for recent periods, and with no difference in the recalled details across the life periods for FTD and AD participants. The findings of this review did not show a significant effect related to the different types of assessments; for example, the temporal gradient effect on AD participants was present in both assessments, which used cues and assessments with semi-structured interviews.

In the study by Kirk and colleagues (2018), there was a further investigation regarding the reminiscence bump, where a reminiscence bump was found with the cueing task: in participants with AD, similar findings of a reminiscence bump presence in AD participants were reported in Rauchs and colleagues (2003). In addition, the reminiscence bump was found in the SD mild subgroup in the study of Matuszewski and colleagues (2009b), in both studies by Rauchs (2003) and Matuszewski (2009b), where the TEMPau semi-structured questionnaire was used. Finally, there were two more studies where the results were discussed related to the reminiscence bump (Ivanoiu *et al.*, 2006; Addis and Tippett, 2004). But in the majority of the studies, there was no further exploration of the reminiscence bump; this could be either due to the aims of each study or the result of the methodological assessments in the included studies. Since reminiscence bump was found to be present in some of the studies which were included in this review, future studies could further explore this phenomenon of AM in

different types of dementia, explain it and incorporate this knowledge into future interventions, such as personalised music intervention.

Some of the studies in the review evaluated if the memories reported from the participants were true or false, but there was no further discussion regarding the necessity to confirm participants' answers or relate them to the concept of memory accuracy. Thus, there are no outcomes in this review related to non- accurate memories or on how these memories provide a coherent sense of the world, and sense of self in people living with dementia. Evaluation of memory accuracy should not simply consist of a "right" / "wrong" marking system for reported memories. Conway & Loveday (2015) presented clinical evidence with a review of the current literature to explain the conception of memories as the "generating of personal meaning".

In previous work by Conway (2015), accuracy is described as a *"two dimensional space"* (Conway and Loveday, 2015), with one dimension being "correspondence", which means that a memory corresponds to the event being recalled, while the second is "coherence", which refers to the memory being consistent with previous memories and to the self. The model evaluates these two dimensions from low to high, which results in the following evaluations: (1) high correspondence-high coherence, (2) high correspondence-low coherence, (3) low correspondence-high coherence and (4) low correspondence-low coherence. Memory confabulation is when both correspondence and coherence are low. Conway & Loveday (2015) demonstrated how memories do not correspond to the actual lived experience and how even memories with low coherence serve the aim of reinforcing the "sense of the world" and maintaining the sense of self.

The study of correspondence and coherence on recalled memories might be an interesting future approach when AM function is evaluated in people living with dementia and might well inform the current assessments that we are using to evaluate AM in dementia care. These differences in AM impairment could contribute to the diagnostic criteria for different types of

dementia, but could also provide an important element of information for the design of interventions focused on the specific impairments and abilities of each type of individuals with dementia.

The findings of this review describe the differences in deterioration of the AM system in different types of dementia but more importantly, indicate that regardless of the differences in the impairment, elements of the AM are still preserved, even with a different pattern among the different types of dementia. Studies have demonstrated a positive effect on the recall of autobiographical memories when people with a diagnosis of Alzheimer's disease were listening to music (El Haj, Postal and Allain, 2012). An effect on mood was also reported when people living with Alzheimer's disease had music-evoked AMs (El Haj *et al.*, 2015). Music-evoked autobiographical memories have also been associated with an increase in positive mood, and a further positive emotional effect have been indicated specific to memories from the reminiscence bump in older adults (López-Cano *et al.*, 2020).

The next step would be to further explore the effect of personalised music, related to autobiographical memories, on the psychological and behavioural symptoms in people living with dementia and to explore the directionality of this potential correlation. For that, I did a second systematic review of the current literature, exploring the effect on the quality of life and psychological and behavioural symptoms when people living with dementia participate in personalised music interventions.

2.5 Chapter Summary

In this chapter, I have presented the results of a systematic review of how autobiographical memory is affected in different types of dementia. 28 studies, with a total of 913 participants, conducted over a period of 17 years in 14 countries were included in the review, focusing on exploring the outcomes of AM assessment across different types of dementia.

Chapter 3: Systematic Review

"The effects of personalised music on behavioural and psychological symptoms in patients with dementia"

Introduction

In this chapter, I present the background, methodology and the findings of a systematic review on the effect of personalised music interventions in psychological and behavioural symptoms in dementia. I describe how personalised music interventions are reported, using the Template for Intervention Description and Replication checklist (TIDieR) (Hoffmann *et al.*, 2014); I also discuss the effect of personalised music intervention on depression, anxiety, agitation and quality of life scales.

The systematic review was developed and published within the PROSPERO protocol, "an international database of prospectively registered systematic reviews" (https://www.crd.york.ac.uk/PROSPERO/) (Appendix 3). The search was designed with guidance from and collaboration of the review team, consisting of my two supervisors, and Guy Peryer and Toby Smith. The search and the screening of the titles and abstracts was done with my supervisors, Anne Killett, and Simon Horton who reviewed the selected studies according to the inclusion criteria. I exported the data for the included studies, analysed the findings and wrote the narrative synthesis presented in this chapter.

3.1 Music as a Therapeutic Approach

Music triggers and elicits autobiographical memories (Janata, Tomic and Rakowski, 2007; El Haj, Fasotti and Allain, 2012b; Jakubowski and Ghosh, 2019; Cady, Harris and Knappenberger, 2007). Research in the field has suggested a positive correlation of music and the autobiographical memory system in terms of cognition, memory retrieval and emotional

states in healthy populations as well as in people with a dementia diagnosis (Meilan Garcia *et al.*, 2012; Blais-Rochette and Miranda, 2016; Strollo and Romano, 2015).

Music has been considered to have therapeutic effects since ancient times, even among preliterate civilisations. For example, shamans used music in order to appease the spirits or the deity that was believed to be causing disease (Thaut, 2015). When the notion of disease changed, and the cause of disease and illness moved from a magical conceptualisation to a more rational one, the rationale for using music to heal the body and mind also changed. The aim of using music as a healing process was no longer to appease the spirits but directly targeted the person in need; since then, it has been used both to prevent disease and maintain individuals' health (Pelosi, 2010).

As evidence-based science has developed, so has our understanding of pathology, disease and therapeutic interventions. The use of music as an intervention has therefore progressed from spiritual healing to rational evidence-based science. It is now recognised as a very effective therapy for people with a wide variety of diagnoses and conditions. For example, it is used to reduce pain or anxiety and stress symptoms both during surgery and in recovery from surgery, as well as in heart disease (McCaffrey and Good, 2000; Kuhlmann *et al.*, 2018; Bradt, Dileo and Potvin, 2013) or in neurodegenerative diseases like dementia, for both behavioural and cognitive symptoms (Langhammer *et al.*, 2019; Onieva-Zafra *et al*., 2018; Perez-Ros *et al.*, 2019).

Music interventions in dementia care varies broadly in terms of the theoretical framework they draws on, the aim of the intervention and the people who carry out the intervention. Music therapy for example, is one branch of music intervention and has a specific protocol that only specialised music therapists can apply. Music therapy can be active or passive, meaning that it can involve the client creating the music and performing using musical instruments or singing

or passively listening to specific music, whether live or recorded (Vink *et al.*, 2004; Raglio *et al.*, 2016; Matthews, 2015).

Music interventions in dementia care that are not within the music therapy framework can be carried out by any professional involved in dementia care. Non-professional caregivers can also be trained to use music as an intervention or as a means to facilitate communication with people with a dementia diagnosis (Iyendo, 2016). In dementia care, both music therapy and other music-based interventions can have a broad range of objectives, either to improve cognition, memory retrieval or to affect specific symptoms such as depression, anxiety, and agitation (Ho *et al.*, 2011; Cuddy *et al.*, 2012; Meilan Garcia *et al.*, 2012; Ing-Randolph, Phillips and Williams, 2015; Jacobsen *et al.*, 2015). Besides behavioural, psychological, and psychiatric symptoms, music is used in dementia care to develop the general quality of life for those living with dementia and their caregivers. For example, it can create lines of communication, increase socialization and a sense of belonging within a social environment and "being part of the world" (Irish *et al.*, 2006; Hara, 2011; McDermott, Orrell and Ridder, 2014).

3.2 Psychological and Behavioural Symptoms in Dementia and their Connection with the Autobiographical Memory System

Agitation is one of the most common behavioural symptoms in people with a dementia diagnosis. The term includes physical and verbal behaviours, aggressive or not, which express discomfort and may be related to trigger events such as pain, lack of sleep or even hunger (Wolf, Goldberg and Freedman, 2018; Pelletier and Landreville, 2007). There are three types of agitation; the first type includes physical but not aggressive behaviour, such as wandering, mannerisms and restlessness.; the second type involves physical, aggressive behaviours, such as kicking; and the third type includes verbal agitation or vocal agitation, such as repetition of words or sounds and shouting (Okura *et al.*, 2010; Draper *et al.*, 2000).

Agitation not only affects the people with the dementia diagnosis but their caregivers as well as t health care staff, as it results in low quality of life and increased levels of anxiety, which might increase the burden on caregivers and cause depression (Ozel Kizil *et al.*, 2014; Alfakhri *et al.*, 2018). For people with a dementia diagnosis, agitated behaviour can also cause additional limitations on their communication and their everyday functions; they might also experience severe social isolation (Draper *et al.*, 2000).

Depression and mood symptoms alongside a dementia diagnosis are also prevalent; people might experience anxiety– the persistent feeling of worrying or being nervous and feeling fear (American Psychiatric and Force, 2013), have low mood and disturbed sleep. These symptoms can significantly affect their sense of self and motivation; furthermore, depression significantly affects people's quality of life (Kitching, 2015; Gutzmann and Qazi, 2015). Anxiety and anxiety disorders in dementia can result in behavioural problems, withdrawal from social activities and can affect sleep, leading to sleep disorders, that in turn can affect the perception of self-worth, leading to poor quality of life (Seignourel *et al.*, 2008; Badrakalimuthu and Tarbuck, 2012; Tales and Basoudan, 2016).

Symptoms such as depression and anxiety can affect the function of the autobiographical memory system. Autobiographical memory is the memory of personal events with emotional and social components, while the autobiographical memory system has a bidirectional correlation with psychological and behavioural symptoms. An example of this strong correlation was shown in a study by Holland and colleagues (2021), who evaluated the impact of active social environments (retirement villages) on autobiographical memory specificity in older adults, in association with their well-being. They reported an improvement in autobiographical specificity when people moved into supportive environments with social activities and social networks, compared with older adults, who did not change their living conditions (Holland *et al*., 2021).

Behavioural and psychological symptoms interfere with the daily lives of people living with dementia and the people caring for them (Kim, Noh and Kim, 2021; Feast *et al.*, 2016). In many cases, behavioural and psychological symptoms are the primary everyday symptoms clinicians encounter within dementia care. These symptoms can be better managed with appropriate interventions, thereby delaying the cognitive deterioration in dementia (!!! INVALID CITATION !!! (Braun et al., 2019a; Scales, Zimmerman and Miller, 2018) Zimmerman and Miller, 2018)). Thus, interventions in dementia care can aim to preserve quality of life and work through helping to maintain cognitive abilities (Sanjuán, Navarro and Calero, 2020). The hypothesis that personalised music interventions could improve psychological and behavioural symptom underpinned the systematic review question. As an extension to this hypothesis, positive management of these symptoms might give the space to further work with intact autobiographical memories, with possible improvements in quality of life.

There have been a number of systematic reviews on the effects of music therapy and music interventions on cognition, behavioural or psychological symptoms, and quality of life in dementia populations (Vink *et al.*, 2004; van der Steen *et al.*, 2017; Leggieri *et al.*, 2019; Moreno-Morales *et al.*, 2020). Most systematic reviews conclude that there are limitations in the quality of the interventional studies as well as in the way that they are reported. These systematic reviews highlight the need for future systematic research to investigate the effects of different types of interventions (van der Steen *et al.*, 2018; Pedersen *et al.*, 2017; Moreira, Justi and Moreira, 2018; Zhang *et al.*, 2017; Li *et al.*, 2019; McDermott *et al.*, 2013; Vink *et al.*, 2004). To the best of my knowledge, there has not been a systematic review on the type of music intervention discussed in this thesis (i.e. personalised music interventions), exploring the effect on behavioural and psychological symptoms and quality of life as a secondary outcome.

Furthermore, the TIDieR checkilist (Hoffmann *et al.*, 2014) has not been employed thus far in evaluating music interventions in the dementia discipline.

3.3 Systematic Review Question

The question in this systematic review was developed using the PICO framework (Population, Intervention/ Interest, Comparison, Outcomes) (Huang, Lin and Demner-Fushman, 2006). For this systematic review, the patient group comprises people with a dementia diagnosis such as Alzheimer's disease (AD), Frontotemporal dementia (FTD), or Semantic dementia (SD). The Intervention consists of personalised music interventions; the Comparison is care as usual, as well as non-music interventions; and lastly, the primary Outcomes are standardized measurements that evaluate the behavioural and psychological symptoms in dementia, such as agitation and depression; a secondary outcome is the quality of life for those living with dementia.

3.4 Search Strategy and Selection of Studies

A systematic search of the following electronic published literature databases was carried out between June 2019 and August 2019: Medline Ovid; CINAHL; PsycINFO; Cochrane Library (Cochrane Database of Systematic Reviews); Cochrane Dementia and Cognitive Improvement Group Specialized Register; and the ALOIS (https://alois.medsci.ox.ac.uk/). In addition, a hand search was carried out of reference lists of relevant reviews and journals and special issues. Multiple databases were used in order to increase the identification of all the relevant publications; the databases used in the systematic search are the most relevant to the field of dementia and autobiographical memory. Medline Ovid is the most relevant for medical sciences; PsycINFo is relevant for studies in the field of psychology; Cochrane Database of Systematic Reviews allowed me to identify relevant reviews and search further through their

references. Similarly, Cochrane Dementia and Cognitive Improvement Group specialised Registered, and ALOIS have collections of reviews and studies related to dementia.

Initial search terms were generated from terms observed in previous studies and literature. First, a focused question was developed for the systematic review. Key terms were identified from the different elements of the question i) diagnosis of the participants, ii) intervention, and ii) behavioural and psychological symptoms. Regarding the diagnosis of dementia, terms were used to ensure that all the different types of dementia were included. For the intervention, the aim was to identify and include all the terms which could describe the specific intervention (such as personalised, individualised, person-centred) without excluding eligible papers. Regarding the primary outcomes, the search terms were identified by studying the definition of psychological and behavioural symptoms in dementia. Terms were then synthesised with synonyms for the interventions, participants, and outcomes. The search terms were tested in a first search, and the outcomes from this search, along with a discussion with the supervisory team, trialed and redefined the final terms. The search strategy and search terms are shown in Appendix 4. The search syntax was adjusted according to the electronic databases.

The database search resulted in 565 records. After removing duplicates, 273 titles were screened. A further 84 studies were excluded because they were either reviews, conference papers or posters, responses to the editor or editorial comment/clarification papers or book chapters. Eight papers were excluded because they were not in English and there were no resources for translation, and an additional six were excluded because they were using a musical test in a laboratory environment. I continued with the full-text screening of the 181 remaining studies. Of these, 68 were excluded because their focus was on other outcomes such as cognition and memory, emotional recognition, brain imaging, outcomes related to mobility and physical activity, bathing or swallowing and nutrition, or neuroanatomical and blood biomarkers or social engagement.

Eight studies were excluded due to being mixed interventions that combined music with other activities such as physical exercise or walking. Ten studies were excluded due to the focus on either the caregivers' burden/stress or on the care staff perspective. 18 studies were excluded because there was no clear diagnosis of dementia, report of diagnostic criteria, or information regarding who diagnosed the participants. And finally, 48 studies were excluded because the intervention was not personalised: either the music was chosen by the therapist or researchers, or popular music from specific decades was used. In the second stage of the review, my primary supervisor additionally reviewed the studies for eligibility according to the inclusion and exclusion criteria; we jointly agreed to the final 30 studies that met the criteria; these were then assessed for quality, as presented in the next section.

Figure 2 shows the PRISMA flow chart with the search process which led to the thirty studies included in the review (Moher *et al.*, 2009), and Table 5 summarises the number of studies excluded with reasons. In Table 6 I present a summary of the characteristics of the 30 studies included in the review. The summary is organised as follows: first author and publication date; the aim of the study; the study design; the size of the sample; the gender of the participants; the age of the participants in years; the specific diagnosis of dementia; the intervention; the mechanisms of the intervention; the measurements/ outcomes used in each study.

Figure 2: PRISMA Flow chart of Systematic Review 2

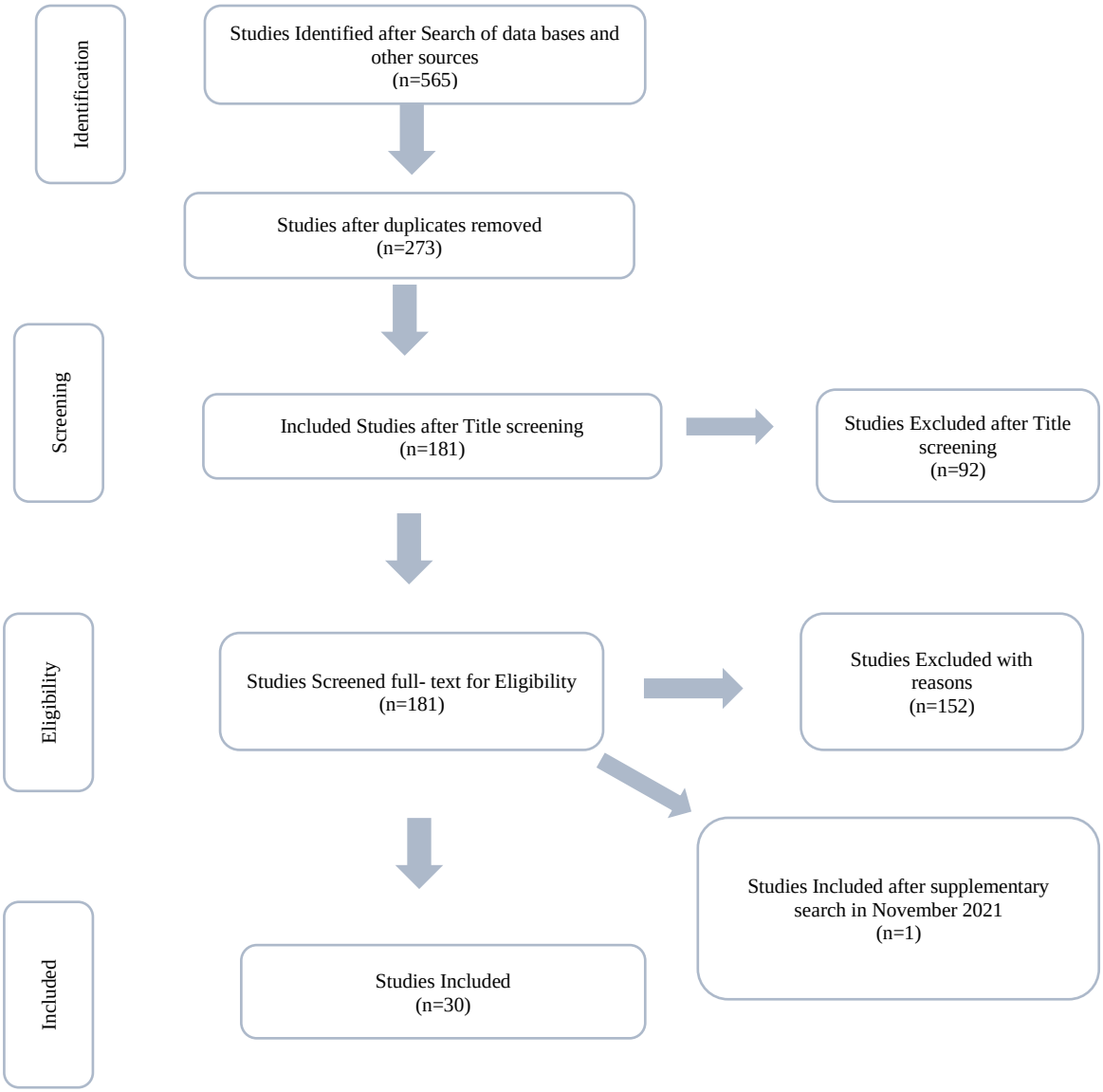

Table 5. Studies Excluded with Reasons

N (studies)	Excluded with reasons
68	The outcomes were evaluated for: cognition and memory; emotional recognition; brain imaging; outcomes related to mobility and physical activity; bathing or swallowing and nutrition; or neuroanatomical and blood biomarkers; or social engagement
8	Mixed interventions that combined music with other activities such as physical exercise or walking.
10	Focus on either the caregivers' burden/ stress or on the care staff perspective
18	No clear diagnosis of dementia, report of diagnostic criteria, or information regarding who diagnosed the participants
48	The intervention was not personalized: either the music was chosen by the therapist or researchers, either they used popular music from specific decades

Table 6. Characteristics of the studies included in Review 2

Study (first author, year)	Aim	Design	Participants		Intervention	Mechanisms of the intervention	Measurements
			Intervention group (n), age (mean years), gender (female/male), diagnosis Intervention received	**Control group (n), age (mean years), diagnosis Intervention received**			
1. Camic et al. (2011)	Seek to determine if participation had a positive impact in PWD (and the caregivers)	Phase I exploratory study	n=10 75 years (68-88) Female=5/ Male= 5 2= diagnosis of Alzheimer's disease 2= vascular dementia 1= Mixed Dementia 1= MCI		Singing group for people diagnosed with dementia and their caregivers.	Singing as group participation "a positive approach to mental health". Positive wellbeing is thought to be derived from participation in activities that are personally meaningful, especially informal social activities.	GDS[2], NPI[3], Dem-QoL-4[4], Dem-QoL-proxy[5] Non-standardized measurement: Semi-structured interview Observational scale. Satisfaction rating experience
2. Chu et al. (2014)	''To determine the effectiveness of group music therapy for improving depression and delaying the deterioration of cognitive functions in	Parallel-group design with permuted-block randomization.	n=52 complete the study =49	n=52 complete the study =51 The control group received usual nursing home care, watching television, afternoon tea, and taking walks.	Group music therapy intervention in 30-min sessions conducted twice a week for 6 weeks.	Music therapy interventions may promote psychological and physical well-being is by lowering stress levels (levels of plasma cortisol)	C-CSDD[6] Salivary Cortisol
			82 years, (65-97) Female= 53 /Male= 47				

[2] GDS: Geriatric Depression Scale (Sheik &Yesavage, 1986)
[3] NPI: Neuropsychiatric Inventory (Cummings et al., 1994)
[4] Dem-QoL-4: Dementia Quality of Life scale (Smithet al., 2005)
[5] Dem-QoL-proxy: Dementia Quality of Life proxy (Brod, Stewart, Sands & Walton, 1999)
[6] C-CSDD: Chinese Version of the Cornell Scale for Depression in Dementia (Alexopoulos, Abrams, Young, & Shamoian, 1998)

Study (first author, year)	Aim	Design	Participants		Intervention	Mechanisms of the intervention	Measurements
			Intervention group (n), age (mean years), gender (female/male), diagnosis	**Control group (n), age (mean years), diagnosis Intervention received**			
	elderly persons with dementia''		17=mild dementia 62= moderate dementia 21= severe dementia				
3. Cooke et al. 2010a	Investigate the effects of intervention on quality of life, and depression	Randomised controlled cross-over	n= 47 Age range = 65-95+ Female= 33/ Male=14	Reading control sessions, reading local news stories, short stories, telling jokes and undertaking quiz activities	40 minutes, live group music programme	It is thought that as the person's ability to understand language diminishes, the ability to process music is retained. Music interventions are reported, as successful with a wide range of positive outcomes and, seemingly, a lack of side-effects. Promote greater feelings of belonging. Music produce a number of positive physiological effects including, increased melatonin levels, decreased levels of the stress indicator salivary chromogranin.	DQOL[7] GDS
4. Cooke et al. 2010b	Study the effect of intervention			Reading control sessions, reading local news stories,	40 minutes, live group music programme	Reduces stress levels, as measured	CMAI-SF 14 item short form[8]

[7] DQOL: Dementia Quality of Life (Brod, Stewart, Sands &Walton, 1999)
[8] CMAI-SF: Cohen-Mansfield Agitation Inventory-Short Form (Werner, Cohen-Mansfield, Koroknay, & Braun, 1994)

Study (first author, year)	Aim	Design	Participants		Intervention	Mechanisms of the intervention	Measurements
			Intervention group (n), age (mean years), gender (female/male), diagnosis	**Control group (n), age (mean years), diagnosis Intervention received**			
	on agitation, and anxiety	Randomised cross-over design		short stories, telling jokes and undertaking quiz activities		by salivary Chromogramin A (CgA). Live music sessions can alleviate anxiety-related symptoms	RAID[9]
			n= 47 Age range = 65-95+ Female= 33/ Male=14				
5. Cox et al. 2011	Investigate the effect of intervention on agitated behaviour	Quasi-experimental on group repeated measures design.	n=7 77 years (70-85) Female=4/ Male=3		18 minutes of live one-to- one violin recital	No clear reported mechanism for the intervention. "Music and music therapy have emerged as promising tools in the management of agitation"	Video recordings Modified C-MAI[10]
6. Gallego et al. 2017	Explore clinical improvement profile	Within - subjects design.	n= 42 77.5 years Female= 27/ Male=15 Mild dementia=25 (CDR1) Moderate dementia=17 CDR2)		Music listening (no head- phones) 45 minutes, 2 weekly sessions of music therapy (welcome song, active music playing, music quiz, moving to background music, farewell song)	Improve communication, learning, mobility, and other mental and physical functions	NPI HADS[11] BI[12]
7. Garland et al., 2007	Compare the effectiveness of individualized psychosocial treatments in	Head-to-head study of two plausible therapies with		Control conditions: Usual care Placebo condition: nonpersonal and non-emotive neutral audiotape	1st intervention: 15 minutes audiotapes of simulated family presence. 2nd intervention: 15 minutes audiotapes of preferred music	Treatments will work best if they are personalized to residents' physical, psychological,	Participants behaviours were observed unobtrusively, by experienced

[9] RAID: Rating Anxiety in Dementia Scale (Shankar et al., 1999)
[10] Modified C-MAI: Modified Cohen-Mansfield Agitation Inventory (Werner, Cohen-Mansfield, Koroknay, & Braun, 1994)
[11] HADS: Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983)
[12] BI: Barthel Index (Mahoney and Barthel, 1965)

Study (first author, year)	Aim	Design	Participants		Intervention	Mechanisms of the intervention	Measurements
			Intervention group (n), age (mean years), gender (female/male), diagnosis	**Control group (n), age (mean years), diagnosis Intervention received**			
	reducing the frequency of physically and verbally agitated behaviours.	a placebo condition.		(psychologist reading in neutral tones from a gardening book).		social, and cultural circumstances	trained researchers, who recorded at two minutes interval before, during and after exposure to the 15 minutes tape.
			n= 30 79 years (66-93 years) Female= 19/ Male=11				
8. Gerdne, 2005	Investigate the reduction in agitation as was measured by visual analog scale & Cohen - Mansfielf Agitation Inventory	Pre-test/ post test pilot study	n=8 83.3 (77-95) Female=8 AD or Related disorder=8		IMIA Gerdner / Assessment of Person Music Preference (completed by a family member) Every participant had their own CD, and music was played on the portable CD player for 30 minutes daily at a time selected to precede the resident's peak level of agitation.	Receptive and expressive musical abilities are preserved long after their ability to process or express verbal language diminishes. Remote memory usually remains relatively intact. Presentation of selected preferred music may stimulate remote memory. Music changes the focus of attention, and provides an interpretable stimulus, overriding meaningless or confusing stimuli. Elicitation of memories associated with positive feelings has a soothing	Global Deterioration Scale (GDS)[13] Cohen - Mansfield Agitation Inventory (CMAI) Agitation Visual Analog Scale (VAS)[14] Staff and Family Interviews.

[13] GDS: Global Deterioration scale (Reisberg et al., 1982)
[14] VAS: Agitation Visual Analog Scale (McDowell & Newell, 1996)

Study (first author, year)	Aim	Design	Participants		Intervention	Mechanisms of the intervention	Measurements
			Intervention group (n), age (mean years), gender (female/male), diagnosis Intervention received	**Control group (n), age (mean years), diagnosis Intervention received**			
						effect, which alleviates agitation.	
9. Guetin et al. 2009	Investigate the effect of the intervention on anxiety and depression	Randomised, controlled, comparative, single- centre design.	n=15 85.2 years (75-93) Female=13/ Male=2	Reading Sessions n=15 86.9 years (74-92) Female=9 / Male=6	Individual receptive music therapy, music was streamed via headphones	It may allow patients with cognitive disorders to stimulate, use and discover their remain abilities. Encourages emotional and self-enhancing support. Triggering emotions and help to express themselves verbally. Stimulate memory of evoking autobiographical events.	HAS GDS
10. Ibenthal et al. (2021)	The effect on Neuropsychiatric symptoms in residential care and the effect on the caregivers	Control design Pre and post-intervention assessment	n= 14 80 years (5) Female=10/ Male=4	n=14 88 (6) Female=7/ Male=7	Personalised music during personal care for eight weeks. (individually)	The discomfort or disorientation can be alleviated by directing their attention to positively-linked familiar music	NPI-Q Log files captured the date and time Closed-ended questions for the activities that took place
11. Ihara et al. 2018	Effect of the intervention on mood, agitation, and social engagement	Quasi-experimental design	n=31 81.27 years (57-93) Female= 19/ Male =2	Daily planned activities, such as exercises and games n=20 83.79 years (68-94) Female=15/ Male=5	MUSIC & MEMORY program, an individualized music listening system where individuals are given an iPod programmed with their personalized playlist	Music stimulates multiple areas of the brain that oversee emotions, mood control, motor skills,	CSDD CMAI Behavioural observations 20 min before,

Study (first author, year)	Aim	Design	Participants		Intervention	Mechanisms of the intervention	Measurements
			Intervention group (n), age (mean years), gender (female/male), diagnosis Intervention received	**Control group (n), age (mean years), diagnosis Intervention received**			
						attention and memory. Preferred music changes the focus of attention, access remote memory, elicit positive memories, and promotes relxation.	during, and after for total =1 h.
12. Kwark et al. 2018	Examine the effect of intervention on agitation, behavioural problems, and use of psychotropic medication	Randomised control crossover design	6 weeks M& M programme/ washout / no M&M n=30 88.92 years Female=21/ Male=9	Treatment as usual/ washout/ Treatment as usual combined with M&M n=29 84.88 years Female= 25/ Male=4	MUSIC & MEMORY program, an individualized music listening system where individuals are given an iPod programmed with their personalized playlist	Music familiarity may activate cognition, establishing an emotional connection with the autobiographical past.	CMAI NPI
13. Maseda et al. 2018	Explore the effect of 2 interventions on mood, behaviour, and biomedical parameters	Randomised trial design	n=11 88.7 years (77-97) Female= 9/Male=2	MMSE intervention (Snoezelen room) n=10 89.1 years (81-102) Female=6/ Male=4	Music sessions according to their musical preferences, the intervention, including the main specifications of the Gerdner guideline	Music interventions stimulating communication and verbal non-verbal expression. Helping recover memories by evoking autobiographical events. Use of music has shown a decrease in respiratory rate and an increase in temperature and oxygen saturation.	Interact Scale

Study (first author, year)	Aim	Design	Participants		Intervention	Mechanisms of the intervention	Measurements
			Intervention group (n), age (mean years), gender (female/male), diagnosis	**Control group (n), age (mean years), diagnosis Intervention received**			
14. Hicks-Moore et al. 2008	Investigate the effect of the interventions on Agitation	Randomised design	n=41 84. 5 years (67-92) Female = 32/ Male=9	Compared intervention: Hand massage Hand Massage and Favourite Music	Favourite Music: Music was played on a portable compact disc player at a volume that was slightly higher than environmental noise level and low enough to allow conversations to be heard. The musical selections were based on information gathered from the family members specific to type of music that the participant enjoyed, favourite artists and songs	Music abilities appear to remain even in the later stages. Familiar music may be a viable strategy to arouse memories connected with positive feelings.	CMAI observational checklist
15. Park et al. 2013	The effect of Intervention on agitation	One- group pre-test / post-test design	n= 26 84 years Female=19/ Male=7		30 minutes of Music on CD	No clear reported mechanism for the intervention. "Many previous studies have reported the positive effects of music intervention on agitation in persons with dementia"	Modified CMAI peak Agitation time Modified CMAI Agitation Level

Study (first author, year)	Aim	Design	Participants		Intervention		Mechanisms of the intervention	Measurements
			Intervention group (n), age (mean years), gender (female/male), diagnosis Intervention received	**Control group (n), age (mean years), diagnosis Intervention received**				
16. Raglio et al. 2013	To assess the effects of active Music Therapy (MT) with those of Favourite and individualized music (ML) on Behavioural and psychological symptoms	Randomised Crossover study design	n= 17 (ML+ MT) n=9 (MT+ML) n=8		30 individual biweekly sessions of ML and MT (30 minutes per session) ML based on individualized music playlist, during ML participants were alone		No clear reported mechanism for the intervention.	NPI Cornell Scale for Depression in Dementia (CSDD) Cohen Mansfield Agitation Inventory (CMAI) Cornell–Brown Scale for Quality of Life in Dementia (CBS-QoL) [15]
17. Raglio et al. 2015	Assess the effect of active Music Therapy (MT), Listening to Music (LtM) and Standard Care (SC) on behavioural and psychological symptoms	Randomised controlled trial	LtM n=40 Evaluation Completed by 32 81.7 years Female=32	MT n=40 Evaluation Completed by 31 81.0 years Female= 29/ Male=2	SC n=40 Evaluation Completed by 35 82.4 years Female= 33/ Male=2 Standard Care= educational, occupational and physical activities)	MT= 20 individualized 30-minute sessions, twice a week for 10 weeks. LtM= 20 individualized 30-minute sessions, twice a week for 10 weeks. During the session participants listened to music from a preferred play list without any interaction with a music therapist or for- mal caregiver.	No clear reported mechanism for the intervention	Neuropsychiatric Inventory (NPI) Cornell Scale for Depression in Dementia (CSDD) Cornell-Brown Scale for Quality of Life in Dementia (CBS-QoL)

[15] CBS-QoL: Cornell Brown Scale- Quality of Life (Ready et al., 2002)

Study (first author, year)	Aim	Design	Participants		Intervention	Mechanisms of the intervention	Measurements
			Intervention group (n), age (mean years), gender (female/male), diagnosis	**Control group (n), age (mean years), diagnosis Intervention received**			
18. Rangeskog et al. 2001	Investigate the effect of individualised music intervention on symptoms of agitation	Systematic observational study, within subjects' design.	n=4 Participants 1st 77 years, male, Alzheimer's Disease late onset 2nd 80 years, female, vascular dementia 3rd 84 years, vascular dementia, Parkinson disease aphasic symptoms 4th 84, male, Vascular dementia, aphasic symptoms Control period= No music Control period= General music (Pachebell) Individualized music period 1 Individualized music period 2		Individualised music was chosen after discussion with the patients, the patients' next of kin and the nursing staff	Music may be used to alter the sound environment in long-term care facilities. Soothing music during dinner time could reduce irritability, fear-panic and depressed mood. Music can be an alternative management strategy for confused and agitated patients.	Video recordings analysed by Systematic Observations Facial Action Coding System
19. Ray et al. 2017	The use of MT for treatment for symptoms of depression, agitation, and wandering	Explanatory design, each individual was his own control	n= 132 89.6 years (59-101) Female= 112/ Male= 20 Alzheimer' s Disease =31 Vascular = 12 Parkinson disease= 3 Mixed=28 Other/ Unspecified= 58 Control=treatment as usual		Music Therapy Intervention for 2 weeks/ 3 times a week= 6 sessions the therapists obtain information for the participants preferences from family members, social workers and recreation staff, also from the participants themselves where that was possible	Music may be the only activity where residences of nursing homes can experience social interactions. Can help in experience fewer psychological symptoms.	Cornell Scale for Depression (CSD) Algase Wandering Scare (AWS)[16] Cohen Mansfield Agitation Inventory (CMAI)

[16] AWS: Algase Wandering Scale (Algase, Beattie, Bogue & Yao, 2001)

Study (first author, year)	Aim	Design	Participants			Intervention	Mechanisms of the intervention	Measurements
			Intervention group (n), age (mean years), gender (female/male), diagnosis		Control group (n), age (mean years), diagnosis Intervention received			
20. Sakamoto et al. 2013	Would Music intervention have beneficial effects on behavioural and psychological symptoms compared to no-music? Compare the effect between interactive music intervention and passive music intervention.	Randomised control trial	Passive Music n=13 Female=10 81.1 years Ale=3 78.7 years severe Alzheimer's Disease	Interactive Music n=13 Female=11 81.2 years Male=2 76 years severe Alzheimer's Disease	Control group n=13 Female=11 81 years Male=84.5 years severe Alzheimer's Disease Control group = spent time with one caregiver in their own room as usual	Passive music intervention group= passively listened to the selected music via a CD player. Interactive music intervention group= not only listened to the selected music via a CD player but also participated in interactive activities (e.g., clapping, singing, and dancing) guided by a music facilitator. Each intervention was performed for 30 min once a week for 10 weeks (10 sessions in total). Individualised music in both groups: After closely interviewing each participant and their family, we selected individualized music that was related to special memories for each participant.	Familiar individualised music evokes positive emotions, eliciting recall of pleasant memories. Autonomic nervous system becomes activated when listening to self-selected music to evoked joy, resulting the release of dopamine. Autobiographical memories are elicited by popular music that evokes emotions.	Blind evaluation Autonomic Nerve Index Facial Scale Behavioural Pathology in Alzheimer's Disease (BEHAVE-AD) Rating Scale [17]
21. Sanchez et al. 2016	To compare the effects of multisensory stimulation environment (MSSE) and individualised music sessions on agitation, emotional, and cognitive status	Randomized control trial	n=11 88.73 years (77-97) Female=6/ Male=5		n=11 88.09 (78-102) Female=9/ Male=2 MMSE Sessions lasted 30 min	The individualized music group participated in music sessions according to their musical preferences. The intervention occurred in a quiet room away from others. Each music intervention session was presented in a "free field" on a computer, and the volume of the music was set at an appropriate level for each participant. In this group, the therapist followed a directive approach, selecting the music for each session and taking into account the preferences and interests of the participants. Sessions lasted 30 min	Sensory stimulation as the primary form of psychological intervention to reduce neuropsychological symptoms. Imbalances in the pacing of sensory-stimulation and sensory-calming activities affect behaviour and instrumental and social functioning. noncontingent	Cohen-Mansfield Agitation Inventory, CMAI) Cornell Scale for Depression in Dementia (CSDD) Rating Anxiety in Dementia (RAID)

[17] BEHAVE-AD: Behavioural Pathology in Alzheimer's Disease Rating Scale (Reisberg et al., 1987)

Study (first author, year)	Aim	Design	Participants		Intervention		Mechanisms of the intervention	Measurements
			Intervention group (n), age (mean years), gender (female/male), diagnosis Intervention received	**Control group (n), age (mean years), diagnosis Intervention received**				
							sensory reinforcement which evokes states of reward and the relaxation response. Personalised music stimulates memories of remote events. Eliciting memories may have a soothing effect.	
22. Särkämö et al. 2013	Explore the efficacy of Music Intervention	Randomised control study	Dyads of PWD and caregivers Singing Group n=27 78.5 years Female=16/ Male=11 AD=12 Vascular=6 Mixed=4 Other=5	Dyads of PWD and caregivers Music Listening group n=29 79.4 years Female=26/ Male=3 AD=14 Vascular=7 Mixed=4 Other=4	Dyads of PWD and caregivers Control group n=28 78.4 years Female= 18/ Male=10 AD=14 Vascular=6 Mixed=3 Other=5 CG was not given any additional activities and were instructed to continue with their normal everyday activities and hobbies throughout the follow-up	Singing Group Music Listening group The singing and music listening sessions were held weekly (1.5 hr/session) at each centre for a group of 10 participants (5 PWDs, 5 caregivers), and they were led by a trained music teacher or music therapist, respectively.	Musical activities can contribute to positive aging, reducing social isolation. Psychologically contributes in self-regulation, communication and social interaction. Neuroimaging studies have shown that music engages a large-scale bilateral network of brain areas. Music can temporarily enhance attention	Cornell-Brown Scale (CBS) Quality of Life in AD (QOL-AD)[18]

[18] QOL-AD: Quality of Life in Alzheimer's Disease (Logsdon, Gibbsons, McCurry, & Teri, 2002)

Study (first author, year)	Aim	Design	Participants		Intervention	Mechanisms of the intervention	Measurements
			Intervention group (n), age (mean years), gender (female/male), diagnosis	**Control group (n), age (mean years), diagnosis Intervention received**			
					In MLG, the sessions consisted primarily of listening to songs from CD and dis-cussing about the emotions, thoughts, and memories (e.g., personal events, people, and places) that they evoked The songs were selected based on the individual musical preferences of the PWDs and were, thus, highly familiar and autobiographically and emotionally important to them.	and memory and have related to well-being.	
23. Sole et al. 2014	To evaluate the effect of group music therapy on Quality of Life. Identify and analyse changes in affect	Pre-test/ post test design. Randomly selection of participants.	n=16 87.5 years (76-91) Female=15/ Male=1 Possible Dementia=5 MCI=4 AD=3 Vascular dementia=1 Mixed =1 Normotensive Hydrocephaly=1 Parkinson's disease=1		12 weekly music therapy sessions, which always took place in the morning. The duration of the sessions ranged from 45 to 60 min. Music was chosen according to patients' expressed preferences identified through initial evaluations.	Music Interventions promote participation, which appears to have an influence to reduce negative emotions. Nonparticipation can significantly worsen the symptoms. Listening to music	GENCAT scale on Quality of life[19] Sessions were video recorded for post-hoc analysis of facial affect and participation behaviours

[19] GENCAT (Verdugo, 2008)

Study (first author, year)	Aim	Design	Participants		Intervention	Mechanisms of the intervention	Measurements
			Intervention group (n), age (mean years), gender (female/male), diagnosis Intervention received	**Control group (n), age (mean years), diagnosis Intervention received**			
						has been rated as pleasant experience, also as an activity allows older people to interact, share aspects of their lives and it is an opportunity to connect with others.	
24. Sung et al. 2010	Evaluating a preferred music listening intervention for reducing anxiety	Quasi-experimental pre-test and post est	n= 29 78.10 years Female=11/ Male= 18 Severe Dementia=13 Moderate-severe=8 Moderate=8	Control group: usual standard care with no music. n= 23 82.65 years Female=12/ Male=11 Severe Dementia=13 Moderate-severe=3 Moderate=7	The participants listened to their preferred music via CD players for 30 minutes in mid- afternoon twice a week, giving a total of 12 sessions over six weeks. Preferred music listening intervention involved determining participant's music preferences with the assistance of family or caregivers, implementing the music based on participant's music preferences in a familiar setting and regularly monitoring participant's responses to the music intervention.	Music can facilitate feelings of physical and mental relaxation by masking environment noises and refocusing individual's attention on a more pleasant state. Listening to preferred music can induced pleasant and positive feelings and that was correlate with activation of the limbic system. Listening to relaxing music was found to decrease cortisol.	Rating Anxiety in Dementia (RAID) tool
25. Sung et al. 2012	evaluate the effects of a group music intervention on	Experimental study	n=27 81.37 years	Control group only received usual care and did not attend the group music interventions.	A collection of music and songs familiar to the participants was used with the music session. The participants' music preferences were assessed by asking the participants, caregivers, families or nursing staff prior to the intervention, so the music selection used was based on the majority of	No clear reported mechanism for the intervention. "Music therapy or music intervention, as one approach, has been studied	Cohen-Mansfield Agitation Inventory (CMAI)

Study (first author, year)	Aim	Design	Participants		Intervention	Mechanisms of the intervention	Measurements
			Intervention group (n), age (mean years), gender (female/male), diagnosis Intervention received	**Control group (n), age (mean years), diagnosis Intervention received**			
	anxiety and agitation			n=28 79.5 years	the participants' preferred or familiar music, which were Taiwanese and Chinese songs from the 1950–1970s with pleasant moderate rhythm and tempo.	and suggested as one of the non-pharmacological interventions to manage behavioural and psychological symptoms of those with dementia.	Rating of Anxiety in Dementia (RAID) scale
26. Suzuki et al. 2004	Investigated the effectiveness of music therapy for dementia patients using endocrinological and behavioural evaluations	Experimental study	n=10 82 years Female=6/ Male=4 AD=6 Vascular dementia=4	n=13 85.23 years Female=9/ Male=4 AD=6 Vascular dementia=7	Music therapy was provided to all 10 patients, twice a week for 8 weeks, for a total of 16 sessions. The old Japanese songs came from earlier periods of the patients' lives and were based on personal references.	Rhythm, harmony, melody of music, and singing familiar nostalgic songs induced an emotional reaction and stimulated cognitive and psychological function. Increased levels of melatonin following music therapy contribute to the relaxed and calm mood, also music has an effect on serum cortisol and salivary cortisol levels.	Multidimensional Observation Scale For Elderly Subjects (MOSES) [20]
27. Tamplin et al. 2018	Examine the Anxiety, apathy, agitation, and Quality of life	Feasibility study pre-post design	n=12 (9 completed the sessions) 77.9 years (57-89) Female=7/ Male=4		20-week therapeutic group singing protocol and home-based music program.	Areas of the brain responsible for processing music are retained until	Anxiety in dementia Scale (RAID)

[20] MOSES: Multimensional Observation Scale for Elderly Subjects (Helmes et al., 1987)

Study (first author, year)	Aim	Design	Participants		Intervention	Mechanisms of the intervention	Measurements
			Intervention group (n), age (mean years), gender (female/male), diagnosis Intervention received	**Control group (n), age (mean years), diagnosis Intervention received**			
					Contacted a music assessment with dyads at baseline to identify personal salient music for the construction of 3 playlists 1. Reminiscence, 2. Relaxation, and 3. Agitation reduction/ calming down	late in dementia. Memories and lyrics are relatively preserved. Music interventions can increase engagement and stimulate successful social interaction.	Apathy Evaluation Scale Cohen-Mansfield Agitation Inventory-Short Form (CMAI-SF) Quality of Life-Alzheimer's Disease (QoL-AD) (PHQ-9)[21] Post-intervention Interviews
28. Thomas et al. 2017	*compare resident outcomes before and after implementation of an individualized music program, MUSIC & MEMORY (M&M), designed to address the behavioral and psychological symptoms*	Experimental pre-test/ post-test study	n=6.298 84.4 years Female= 4.627	n=6.278 84.6 years Female=4.554	*M&M is a facility-level quality improvement program that provides residents with music specific to their personal histories and preferences.* To implement M&M, caregivers (e.g., health-care providers or family members) create music playlists tailored specifically to each resident's personal history of music choices and preference	No clear reported mechanism for the intervention. "Music intervention have the potentials to reduce agitation, aggression, anxiety, and behavioural symptoms and improve mood"	Use of anxiolytic medication Aggressive Behaviour Scale (ABS) [22] (PHQ-9) -mood

[21] PHQ-9: 9-item depression scale of the Patient Health Questionnaire (Kroenke et al. 2001)
[22] ABS: Aggressive Behaviour Scale (Perlman & Hirdes, 2008)

Study (first author, year)	Aim	Design	Participants		Intervention	Mechanisms of the intervention	Measurements
			Intervention group (n), age (mean years), gender (female/male), diagnosis Intervention received	**Control group (n), age (mean years), diagnosis Intervention received**			
29. Thornley et al. 2016	The aim is to determine the feasibility and effectiveness of Music Therapy on Behavioural Psychological Symptoms in patients with dementia in an acute psychiatric inpatient setting.	Pilot Randomised controlled study	n=10 83.5 years AD=11 Vascular dementia=3 Dementia with Lewy Bodies= 2	Control = Active Engagement Intervention (AEI) n=6 68.4 years	The music was selected in accordance with participant preferences and was of a calming nature. The music therapist indicated that most participants engaged in a meaningful way. All MT and AEI sessions were completed individually. The participants were encouraged to actively engage in the musical process and to follow the music therapist's lead.	No clear reported mechanism for the intervention. "Music Therapy may be an effective non-pharmacological treatment for BPSD as it has been shown to reduce aggressive behavioural symptoms and anxiety, while improving mood and quality of life.	NPI-C[23] CMAI
30. Zare et al. 2010	Examine the various methods of MT on reducing agitation	Experimental	n=16 4 subgroups 1. Preferred music individually 2. Preferred music 3. Non-preferred music 4. Singing	n=10	Preferred music was chosen by participants, their family, and their caregivers and non-preferred music which were chosen by experimenter were similar to Vivaldi's four seasons (Thompson and Moulin, 2005) with minor scale and slow theme.	No reported mechanism for the intervention	CMAI

[23] NPCI-C: Neuropsychiatric Inventory-Clinician version

3.5 Results

3.5.1 TIDieR Checklist Assessment

To assess the quality of the reported interventions of each of 30 studies, a template was used consisting of a checklist of intervention description and replication (TIDieR) (Hoffmann *et al.*, 2014). Hoffmann and colleagues identified a lack of quality and consistency in reports of clinical trial intervention studies in the literature, and this tool, developed by an international team of experts, aimed to provide a checklist and guide to improve the reporting of such interventions, including the control intervention received from comparisons groups (Hoffmann *et al.*, 2014).

The TIDieR checklist has 12 items: the 1st item assesses the presentation and how precise the name given to the intervention is, as well as the phrase used to describe it. The 2nd item answers the question "Why?" and examines whether the authors provide any theory or mechanism related to the intervention. The 3rd item refers to the "What?" regarding the materials, whether physical or informational, examining the presence or not of a full description of what happened during the intervention and what materials were used for it. The 4th item refers again to the "What?" but focuses on the specific procedures that were used in the intervention. Item 5 examines the question "Who?" - who provided the intervention and any information about their occupation and expertise. The 6th item answers the question "How?" - how was the intervention delivered; for example, whether it was delivered to an individual or in a group. The 7th item of the checklist examines the question "Where?" and refers to the location where the intervention took place, whether it was a hospital, participants personal space or somewhere else. The 8th item examines "When and how much?", looking at the information provided in the report regarding how many times the intervention was delivered to the participants, including the specific schedule, duration and number of total sessions, as well as the dose if applicable. The

10th item explores whether any modifications of the intervention were made during the study and how these are reported by the authors. The last two items of the TIDier checklist examine "How well" the intervention was planned (Item 11) and carried out (Item 12). Table 4 presents the assessment of the studies using the TIDieR checklist. The studies are then reviewed, addressing each item of the TIDieR checklist.

Item 1. Brief name: provide the name or a phrase that describes the intervention.

This item examines whether the studies in the review report a name or phrase that is sufficiently clear to describe the intervention. This item was found in all the studies included in the review and fell under the following categories: "**music therapy**"(Chu *et al.*, 2013; Gómez Gallego and Gómez García, 2017; Gerdner and Schoenfelder, 2010; Guetin *et al.*, 2009; Raglio *et al.*, 2013; Raglio *et al.*, 2015a; Ray and Mittelman, 2017a; Solé *et al.*, 2014; Suzuki *et al.*, 2004; Thornley, Hirjee and Vasudev, 2016; Zare, Ebrahimi and Birashk, 2010; Tamplin *et al.*, 2018); "**music intervention**"(Camic, Williams and Meeten, 2013; Cooke *et al.*, 2010b; Cooke *et al.*, 2010c; Cox, Nowak and Buettner, 2011; Garland *et al.*, 2007; Gerdner, 2005; Ihara *et al.*, 2019; Kwak, Anderson and O'Connell Valuch, 2018; Maseda *et al.*, 2018; Hicks-Moore and Robinson, 2008; Ragneskog *et al.*, 2001; Sakamoto, Ando and Tsutou, 2013; Sánchez *et al.*, 2016; Särkämö *et al.*, 2014; Sung, Chang and Lee, 2010; Sung *et al.*, 2012; Tamplin *et al.*, 2018; Thomas *et al.*, 2017).

The main categories differentiate the role and implication of music in the intervention, between music therapy provided by a qualified trained music therapist, and music interventions provided outside of the theoretical framework of music therapy by a healthcare professional or a caregiver, with no specialization in music therapy.

Further characteristics were included in the description such as **"live music"**(Cox, Nowak and Buettner, 2011); "**active group music therapy/ music intervention**"(Raglio *et al.*, 2013;

Raglio *et al.*, 2015b; Ray and Mittelman, 2017a; Sakamoto, Ando and Tsutou, 2013; Solé *et al.*, 2014; Sung *et al.*, 2012; Suzuki *et al.*, 2004); "**passive group music therapy/ music intervention- music listening**" (Gómez Gallego and Gómez García, 2017; Sakamoto, Ando and Tsutou, 2013; Raglio *et al.*, 2013; Raglio *et al.*, 2015a; Sánchez *et al.*, 2016; Särkämö *et al.*, 2014); "**group music therapy/ music intervention**" (Chu *et al.*, 2013; Cooke *et al.*, 2010b; Cooke *et al.*, 2010c; Solé *et al.*, 2014); "**group singing**" (Camic, Williams and Meeten, 2013; Tamplin *et al.*, 2018); "**individualized music therapy/ music intervention- music listening**" (Garland *et al.*, 2007; Gerdner, 2005; Guetin *et al.*, 2009; Ihara *et al.*, 2019; Kwak, Anderson and O'Connell Valuch, 2018; Maseda *et al.*, 2018; Hicks-Moore and Robinson, 2008; Raglio *et al.*, 2013; Ragneskog *et al.*, 2001; Sung, Chang and Lee, 2010; Thomas *et al.*, 2017; Thornley, Hirjee and Vasudev, 2016; Zare, Ebrahimi and Birashk, 2010).

Item 2. Why: describe any rationale, theory, or goal of the elements essential to the intervention

The majority of the studies provided a full description of a theory or mechanism that supported the aims of the intervention. Some theories and proposed mechanisms of the studies suggest that singing is a "positive approach to mental health", which derives from activities that are tailored to the individuals and are meaningful. In addition, they propose that music therapy interventions promote well-being by lowering levels of stress indicators, or by increasing melatonin levels, and also that the person's ability to process music and musical capacity, is retained. The mechanisms and theories presented in the studies, also propose that music interventions benefit the feeling of belonging, improve communication, stimulate social interaction and have a greater effect if interventions are personalised and take into consideration participants' individual psychological, social and cultural backgrounds.

A theoretical perspective regarding remote memories proposes that these remain relatively intact in people with dementia, and that of music evokes autobiographical memories. Furthermore, familiarity with music is proposed to provide an emotional connection with

peoples' life history and enables people to re-experience positive autobiographical events. It is suggested that familiar nostalgic songs might induce emotional reactions and has a positive effect on behavioural and psychological symptoms.

Another theoretical perspective in some studies focusing on psychological and behavioural symptoms, posits that music might trigger emotions and help participants to express verbally, thereby reducing agitation. The majority of the studies which proposed the emotional effect of personalised music intervention, focused on the experience of mainly positive emotions and on music interventions reducing negative emotions.

Masking of environmental noise in the care facilities was also proposed by some of the studies, as well as the absence of side effects of the personalised music interventions. Only seven studies did not report a clear mechanism or a background theory supporting their intervention (Cox, Nowak and Buettner, 2011; Raglio *et al.*, 2013; Raglio *et al.*, 2015a; Sung *et al.*, 2012; Thomas *et al.*, 2017; Thornley, Hirjee and Vasudev, 2016).

Item 3. What (materials): describe any physical or informational materials used in the intervention, including those provided to participants or used in intervention delivery or in training of intervention providers. Provide information on where the materials can be accessed (for example, online appendix, URL).

For the present study, this question was considered to be addressed when researchers reported using materials relevant to the intervention, in this case: **musical instruments** (Chu *et al.*, 2013; Cooke *et al.*, 2010b; Cooke *et al.*, 2010c; Cox, Nowak and Buettner, 2011; Gómez Gallego and Gómez García, 2017; Raglio *et al.*, 2015a; Raglio *et al.*, 2013; Ray and Mittelman, 2017a; Särkämö *et al.*, 2014; Solé *et al.*, 2014; Sung *et al.*, 2012; Suzuki *et al.*, 2004; Tamplin *et al.*, 2018; Thornley, Hirjee and Vasudev, 2016); **printed-out song lyrics** (Camic, Williams and Meeten, 2013); CDs/ CD players (Gerdner, 2005; Hicks-Moore and Robinson, 2008;

Sakamoto, Ando and Tsutou, 2013; Särkämö *et al.*, 2014; Sung, Chang and Lee, 2010), audiotapes (Garland *et al.*, 2007); **headphones** (Ihara *et al.*, 2019); **computers or other audio devices** (Guetin *et al.*, 2009; Kwak, Anderson and O'Connell Valuch, 2018; Maseda *et al.*, 2018; Raglio *et al.*, 2013; Raglio *et al.*, 2015b; Ragneskog *et al.*, 2001; Sánchez *et al.*, 2016; Thomas *et al.*, 2017). As can be seen in Table 4., all but one study included in the review presented the related materials used for the intervention.

Item 4. What (procedures): describe each of the procedures, activities and/or processes used in the intervention, including any enabling or support activities.

The 4th item of the TIDieR checklist was considered to have been addressed when the authors described all the procedures used in the intervention, including identification or not of personalised music, as well the outline of the protocol of the intervention followed for both groups, the group exposed to the intervention and the comparison group or condition. In some studies, the procedure of the protocol and study design were presented using a flow chart (Chu *et al.*, 2013; Cooke *et al.*, 2010a; Cooke *et al.*, 2010c; Guetin *et al.*, 2009; Kwak, Anderson and O'Connell Valuch, 2018; Ragneskog *et al.*, 2001; Sánchez *et al.*, 2016; Särkämö *et al.*, 2014). The majority of studies had an extra section to include this information or presented it under the methodology section. Only two studies (Thornley, Hirjee and Vasudev, 2016; Zare, Ebrahimi and Birashk, 2010) did not provide this information.

Item 5. Who provided: for each category of intervention provider (for example, psychologist, nursing assistant), describe their expertise, background and any specific training given.

The majority of studies reviewed included this item. The provider of the interventions in the majority of the reviewed publications was either a qualified music therapist or a healthcare professional trained for the specific intervention, such as nurse, psychologist, occupational therapist and research assistant. In some studies, the intervention was provided by family

members/ caregivers. In three studies, this item was missing (Guetin *et al.*, 2009; Ihara *et al.*, 2019; Zare, Ebrahimi and Birashk, 2010).

Item 6. How: describe the modes of delivery (such as face to face or by some other mechanism, such as internet or telephone) of the intervention and whether it was provided individually or in a group.

All studies reported on item 6, which in all cases was face to face. In addition, the studies were described as individual or group interventions.

Item 7. Where: describe the type(s) of location(s) where the intervention occurred, including any necessary infrastructure or relevant features.

This item was considered present if the authors reported the location of the intervention. All the studies in this systematic review provided information about the location of the intervention. In the majority of studies, the location was a long-term facility for people with a diagnosis of dementia such as a nursing home or a special unit. In one study, the intervention occurred at the participants' homes (Park, 2013).

Item 8. When and how much: describe the number of times the intervention was delivered and over what period of time, including the number of sessions, their schedule, and their duration, intensity or dose.

Information regarding when and for how long the intervention was delivered was present in the majority of the studies, but there was no information about "When" with regards to the onset of the symptoms, as suggested in the checklist. The majority of the studies reported on the "when and how much" in relation to what time of day the intervention took place, reported as "during late afternoons" (Camic, Williams and Meeten, 2013) or "morning" (Cooke *et al.*, 2010b). In some studies, that information was even more general, such as "after 2 pm" (Cox, Nowak and Buettner, 2011). Other studies delivered the intervention in relation to the

individual's peak agitation time (Gerdner, 2005; Park, 2013). The duration of the intervention also varied from ten minutes (Hicks-Moore and Robinson, 2008) to up to two hours (Tamplin *et al.*, 2018); in studies with longer duration, breaks were also included (Camic, Williams and Meeten, 2013). The interventions also differed in terms of the overall number of sessions, ranging from four sessions to thirty-two sessions (Sanchez *et al.*, 2016). In the relevant studies, a washout period between five and six weeks was also reported.

Item 9. Tailoring: if the intervention was planned to be personalised, titrated or adapted, then describe what, why, when and how.

This item was not applicable to any of the studies included in the review, so was excluded from Table 4, the presentation of the TIDieR checklist.

Even though the music used for the intervention was personalised as described in this chapter, the delivery of the intervention was not personalised. The studies did not describe any tailoring regarding the amount or the duration of the intervention, nor did they refer to the place or how the intervention was administrated.

Item 10. Modifications: If the intervention was modified during the course of the study, describe the changes (what, why, when, and how).

This item was not applicable to the studies included in the review and so was also excluded from the assessment and Table 4.

Items 11 and 12 were not reported in any of the studies and therefore not represented in Table 4. However, I do address the questions under items 11 and 12 because they contribute to understanding how well interventions were planned and delivered.

Item 11. How well (planned): if intervention adherence or fidelity was assessed, describe how and by whom, and if any strategies were used to maintain or improve fidelity, describe them.

This item of the TIDieR checklist is considered as present if the studies describe adherence and fidelity of the intervention. More particularly, this item refers to whether or not the intervention followed a standardised procedure protocol, whether there was a trained and qualified person to carry out the intervention, as well as if the person evaluating the measurements was trained, and/ or blinding was used.

In Cox, Nowak and Buettner (2011), fidelity was assessed by playing the songs of the intervention in the same order for each participant (Cox, Nowak and Buettner, 2011). In Sakamoto, Ando and Tsutou (2013), all the participants' assessments were implemented individually in a familiar room (Sakamoto, Ando and Tsutou, 2013). In two studies by Cooke et al. (2010b, 2010c), fidelity was explicitly reported and assessed by developing "treatment fidelity" with a standardised procedure manual for the intervention. The person who delivered the intervention was trained and a practice session of the intervention was carried out in another facility. The research team then carried out random checks on the sites (Cooke *et al.*, 2010a; Cooke *et al.*, 2010c). In Ihara *et al*. (2019), fidelity was also ensured by including training for the researchers involved in the study.

Suzuki *et al*. (2004) reported that their intervention program was based on a protocol for people living with dementia (Clair and Bernstein, 1990) and that the intervention was delivered by a specialized music therapist and nurse staff (Suzuki *et al.*, 2004). In several publications, authors reported that the intervention was facilitated either by a qualified musician or specialized music therapist with experience in the field of dementia ((Camic, Williams and Meeten, 2013; Raglio *et al.*, 2015a; Raglio *et al.*, 2013; Sarkamo *et al.*, 2014; Solé *et al.*, 2014; Ray and Mittelman, 2017b); or trained and certified nursing staff, psychologist, occupational therapist or social workers (Gerdner, 2005; Kwak, Anderson and O'Connell Valuch, 2018; Maseda *et al.*, 2018;

Sakamoto, Ando and Tsutou, 2013; Sanchez *et al.*, 2016; Sarkamo *et al.*, 2014; Sung *et al.*, 2012; Suzuki *et al.*, 2004; Sung, Chang and Lee, 2010).

In the intervention reported in Gerdner (2005), the researcher facilitated a training programme for the staff and families of the people with dementia, with a focus on the construct of agitation (Gerdner, 2005), whereas the training in the study by (Kwak, Anderson and O'Connell Valuch, 2018) was delivered by nurses trained in the intervention. The training was offered by the research team for the specific intervention, and as in other studies, the research team carried out several fidelity checks at the facilities to ensure the quality of the intervention. However, in that study, the authors reported low levels of fidelity and a high level of variation in implementation.

In Sakamoto, Ando and Tsutou (2013), the evaluators were not the ones who implemented the intervention. The facilitators of the intervention were qualified occupational therapists and nurse experts in dementia care who were trained by the researchers. In their publication, Thomas *et al.*, (2017) reported that they trained at least one member of staff in each facility and provided online and ongoing access to resources on a website, including one-on-one consultation and coaching calls.

The majority of the publications described the randomization of the participants in the relevant studies. In some studies, a member of the methodology team or a biostatistician did the randomization using a computer-generated programme or an online randomization programme (Chu *et al.*, 2013; Cooke *et al.*, 2010a; Cooke *et al.*, 2010c; Sung *et al.*, 2012; Thornley, Hirjee and Vasudev, 2016; Garland *et al.*, 2007; Maseda *et al.*, 2018; Guetin *et al.*, 2009).

In addition, this item was considered as present if authors reported who carried out the assessment of the measurements, who evaluated the intervention both in terms of quantitative and qualitative outcomes, and whether the raters were trained for it or the rating procedure was

blind (Chu *et al.*, 2013; Camic, Williams and Meeten, 2013; Raglio *et al.*, 2015a; Raglio *et al.*, 2013; Tamplin *et al.*, 2018; Thornley, Hirjee and Vasudev, 2016; Garland *et al.*, 2007; Gómez Gallego and Gómez García, 2017; Guetin *et al.*, 2009; Ray and Mittelman, 2017b). In the two studies by Raglio *et al.* (2015b; 2013), evaluation of the measurements was blind in all the phases: baseline, beginning and end of the intervention, and the washout and follow-up periods. In these studies, the evaluation was assessed by a music therapist who had not been involved in the intervention and had been trained to carry out the specific assessment. Sole et *al*. (2014) reported that the professional caregivers had undergone a training session by the site's specialized neuropsychologist and that the video recordings were evaluated by a professional music therapist who had not been involved in the intervention. The interventions reported by Hicks-Moore and Robinson (2008), were delivered to the groups by the same researcher who also evaluated the outcomes, although the coding for five out of the 41 participants was carried out by the primary author with the help of a research assistant to "ensure consistent" rating. Nonetheless, this was reported as a limitation of the study. No mention was made of a fidelity check. Similarly, in the study by Maseda *et al*., 2018, both data collection and interventions were carried by the same researcher.

Item 11 was not found to be present in studies by Park (2013), Zare, Ebrahimi and Birashk, (2010);and Ragneskog et *al*. (2001). In Ragnseskog and colleagues' study, the publication simply reported that two of the authors analysed the same randomly selected samples of the video recordings to ensure agreement in the analysis.

Item 12: How well (actual): if intervention adherence or fidelity was assessed, describe the extent to which the intervention was delivered as planned.

This item was not present in most of the studies. Instead, the majority of the publications included in the review contained a section describing the limitations or the strengths of the overall study. In this section, I describe how these studies presented the limitations and general

evaluation of their intervention as an overview of "How well (actual)" the intervention was delivered.

Camic, Williams and Meeten (2013) identified a limitation with the standardised measures they used in detecting changes over the period of the intervention. Similarly, Gómez Gallego and Gómez García (2017) acknowledged some concern about whether the test assessment had an influence on the results. Cox, Nowak and Buettner (2011) modified an existing standardised test (Cohen-Mansfield Agitation Inventory, with the permission of the author) and noted that this modification was not standardised.

Sanchez et al. (2016) noted a limitation regarding the quantitative assessment tools they used with the participants, given the severity of their symptoms, proposing that this limitation could be overcome with the use of qualitative methods in future studies. (Solé *et al.*, 2014) also raise questions about how appropriate the measurement tests they used were while Sung *et al.* (2012) were cautious about the tools they used to measure the symptoms of interest.

In the study by Chu et *al*. (2014), the duration of the intervention period was described as a limitation. They state that it was too short and that a longer follow-up period was needed. The need for a longer follow-up period was also identified in (Särkämö *et al.*, 2014) and Sung et *al*. (2012).

Cooke et *al*. (2010b) suggest that in future studies, a control group that receives the usual care should be built into the design, describing the need for a baseline that provides a more "in-depth" evaluation of agitation and assessment. Regarding the time of day when the intervention is delivered, they suggest that future interventions could be delivered at times when agitation is most present, although they acknowledge that it can be difficult to coordinate this within the daily schedule of the facilities (Cooke *et al.*, 2010c). In discussing the limitations of their study,

Sakamoto, Ando and Tsutou (2013) also referred to the timing of the intervention, stating that there was no prior testing that would have allowed them to optimise it.

In Cox *et al*. (2011), the limitation was that the findings are potentially biased because the intervention was rated by the same researcher who also delivered the intervention. A similar limitation was reported in studies by (Hicks-Moore and Robinson, 2008), (Sung, Chang and Lee, 2010; Sung *et al.*, 2012). Ray *et al*., (2017b) suggest the need for a wider variation in socioeconomic status and racial groupings in future studies, while lack of site variation was emphasized in Sung et al. (2012). Some studies focused on the dementia diagnosis, stating that not controlling for the specific type of dementia nor the severity of the symptoms was a limitation (Särkämö *et al.*, 2014). The need to evaluate future interventions in groups according to dementia type and homogeneity of severity was also described in (Solé *et al.*, 2014) and Tamplin *et al*. (2018).

Many studies describe the small number of participants due to the difficulties of recruitment as a limitation for generalisation of their outcomes (Cox, Nowak and Buettner, 2011; Maseda *et al.*, 2018; Sakamoto, Ando and Tsutou, 2013; Sanchez *et al.*, 2016; Solé *et al.*, 2014; Sung, Chang and Lee, 2010; Suzuki *et al.*, 2004; Tamplin *et al.*, 2018; Thornley, Hirjee and Vasudev, 2016; Zare, Ebrahimi and Birashk, 2010).

Table 7 . TIDieR Checklist Assessment

Studies	Item 1. Brief name	Item 2. Why	Item 3. What (material)	Item 4. What (procedure)	Item 5. Who	Item 6. How	Item 7. Where	Item 8. When & how much
1. Camic et al. (2011)	√	√	√	√	√	√	√	√
2. Chu et al. (2014)	√	√	√	√	√	√	√	√
3. Cooke et al. 2010a	√	√	√	√	√	√	√	√
4. Cooke et al. 2010b	√	√	√	√	√	√	√	√
5. Cox et al. 2011	√	X	√	√	√	√	√	√
6. Gallego et al. 2017	√	√	√	√	√	√	√	√
7. Garland et al., 2007	√	√	√	√	√	√	√	√
8. Gerdner, 2005	√	√	√	√	√	√	√	√
9. Guetin et al. 2009	√	√	√	√	X	√	√	√
10. Ibenthal et al. (2021)	√	√	√	√	√	√	√	√
11. Ihara et al. 2018	√	√	√	√	X	√	√	√
12. Kwark et al. 2018	√	√	√	√	√	√	√	√
13. Maseda et al. 2018	√	√	√	√	√	√	√	√
14. Moore et al. 2008	√	√	√	√	√	√	√	√
15. Park et al. 2013	√	X	√	√	√	√	√	√
16. Raglio et al. 2013	√	X	√	√	√	√	√	√
17. Raglio et al. 2015	√	X	√	√	√	√	√	√

Table 7 . TIDieR Checklist Assessment

Studies	Item 1. Brief name	Item 2. Why	Item 3. What (material)	Item 4. What (procedure)	Item 5. Who	Item 6. How	Item 7. Where	Item 8. When & how much
18. Rangeskog et al. 2001	√	√	√	√	√	√	√	√
19. Ray et al. 2017	√	√	√	√	√	√	√	√
20. Sakamoto et al. 2013	√	√	√	√	√	√	√	√
21. Sanchez et al. 2016	√	√	√	√	√	√	√	√
22. Sarkamo et al. 2013	√	√	√	√	√	√	√	√
23. Sole et al. 2014	√	√	√	√	√	√	√	√
24. Sung et al. 2010	√	√	√	√	√	√	√	√
25. Sung et al. 2012	√	√	√	√	√	√	√	√
26. Suzuki et al.2004	√	√	√	√	√	√	√	√
27. Tamplin et al. 2018	√	√	√	√	√	√	√	√
28. Thomas et al. 2017	√	X	√	√	√	√	√	√
29. Thornley et al. 2016	√	X	√	X	√	√	√	√
30. Zare et al. 2010	√	√	X	X	X	√	√	√

3.6 Findings Synthesis

3.6.1 Studies Quality Assessment

In this section, I will present the methodological quality of the included studies, including the procedures of randomization, blinding, participants withdrawing, and presentation of the aims and theoretical framework of the study.

A total of 30 intervention studies were included in the review. Eight studies described the process of randomization of the participants (Chu *et al.*, 2013; Cooke *et al.*, 2010a; Cooke *et al.*, 2010c; Sung *et al.*, 2012; Thornley, Hirjee and Vasudev, 2016; Garland *et al.*, 2007; Maseda *et al.*, 2018; Guetin *et al.*, 2009).

13 studies described explicitly who carried out the assessment of the measurements, who evaluated the intervention both in terms of quantitative and qualitative outcomes, and whether the raters were trained for it or the rating procedure was blind (Chu *et al.*, 2013; Camic, Williams and Meeten, 2013; Raglio *et al.*, 2015a; Raglio *et al.*, 2013; Tamplin *et al.*, 2018; Thornley, Hirjee and Vasudev, 2016; Garland *et al.*, 2007; Gómez Gallego and Gómez García, 2017; Guetin *et al.*, 2009; Ray and Mittelman, 2017b; Sakamoto, Ando and Tsutou, 2013; Ibenthal, Kehmann and Backhaus, 2021).

In two studies, it was reported that rating was blinded for all the phases of the evaluation (Raglio *et al.*, 2015a; Raglio *et al.*, 2013), and in one study professional caregivers were trained for the process by the sites' neurologists (Raglio *et al.*, 2015b; Raglio *et al.*, 2013; Solé *et al.*, 2014). Two studies did not follow any blinding method, and both the intervention and evaluation of the measurements were carried out by the same researchers (Hicks-Moore and Robinson, 2008; Maseda *et al.*, 2018).

Regarding who delivered the intervention, the majority of the studies reported that either the intervention was delivered by a certified trained nursing staff, occupational therapist,

psychologist or social worker (Gerdner, 2005; Kwak, Anderson and O'Connell Valuch, 2018; Maseda *et al.*, 2018; Sakamoto, Ando and Tsutou, 2013; Sanchez *et al.*, 2016; Sarkamo *et al.*, 2014; Sung *et al.*, 2012; Suzuki *et al.*, 2004; Sung, Chang and Lee, 2010; Thomas *et al.*, 2017); or the intervention was facilitated by a qualified musician or specialised music therapist with experience in the field of dementia (Camic, Williams and Meeten, 2013; Raglio *et al.*, 2015a; Raglio *et al.*, 2013; Sarkamo *et al.*, 2014; Solé *et al.*, 2014; Ray and Mittelman, 2017b) In one study, the intervention was delivered by the caregivers (Ibenthal, Kehmann and Backhaus, 2021).

In studies by Park (2013); Zare, Ebrahimi and Birashk (2010) and Ragneskog et *al*. (2001), participants were recruited with no random methods, and the rating procedure was not blinded.

Regarding participants withdrawal, two studies reported in their "flow chart of study participation" the number and the reasons of dropouts which were mainly due to deterioration (Raglio *et al.*, 2015a; Chu *et al.*, 2013). In 23 studies, aims were well reported and related to a theoretical framework while in seven studies, no clear mechanism or theory supporting their intervention was reported (Cox, Nowak and Buettner, 2011; Raglio *et al.*, 2013; Raglio *et al.*, 2015a; Sung *et al.*, 2012; Thomas *et al.*, 2017; Thornley, Hirjee and Vasudev, 2016; Ibenthal, Kehmann and Backhaus, 2021). A potential bias due to the non-blind rating process was found in seven studies ((Cox, Nowak and Buettner, 2011; Carcaillon *et al.*, 2009; Sung, Chang and Lee, 2010; Sung *et al.*, 2012; Park, 2013; Zare, Ebrahimi and Birashk, 2010; Ragneskog *et al.*, 2001).

Nonetheless, the majority of the studies included in the review are considered of good quality, and the sample sized for most of the studies was sufficient to achieve the aims of each study.

3.6.2 Findings

i. Personalised music interventions

This review focuses on personalised music interventions, the key factor being that music is selected because it is meaningful and personal to the participants, rather than being chosen by the researchers who designed the intervention for its relaxing, tonal or other musical characteristics. All the studies in the review reported that the selection of music was made after interviewing the participants and whenever that was not possible, from information provided by relatives, caregivers or health care staff members. That information included favourite artists or songs or music linked to autobiographical memories.

In the studies where the intervention was applied in a group setting and was reported as a group intervention, the process of selecting the music was the same: music therapists or researchers collected information on peoples' meaningful and personalised music either directly from the participants or the relatives, caregivers and staff members. The personalised music preference selected by each participant was incorporated in the programme of the group intervention.

ii. Study designs

The studies included in the review adopted different designs: 15 studies consisted of a randomized cross over design; five studies followed a pre-test and post-test design; two studies were explanatory; two studies adapted a within-subjects design, and six studies described their design as experimental[24] or quasi-experimental[25].

iii. Participants' diagnosis

All the participants in the studies had a diagnosis of dementia, although the type and severity of the symptoms varied within and across the studies, and not all the studies provided

[24] Where a set of variables are kept constant while the other set of variables are being measured.

[25] An interventional study used to estimate the effect of an intervention on target population without randomization.

differentiation between different types of dementia. One finding was the absence of the reporting of specific dementia diagnoses, in the majority of the studies. In four studies, the participants had a diagnosis of Alzheimer's disease (Cox, Nowak and Buettner, 2011; Gómez Gallego and Gómez García, 2017; Guetin *et al.*, 2009; Zare, Ebrahimi and Birashk, 2010). In their study, Suzuki and colleagues (2004) differentiated between types of dementia diagnosis, Alzheimer's disease (six participants) and vascular dementia (four participants). Regarding the diagnosis, they only reported an improvement on behavioural assessments in people with a diagnosis of Alzheimer's disease, without any further evaluation regarding the diagnosis (Suzuki *et al.*, 2004). Similarly, in the study by Sole *et al*. (2014), different diagnoses of dementia are reported: Alzheimer's disease (three participants), vascular dementia (one participant), mixed dementia (one participant), but the outcomes are not evaluated in relation to the diagnosis. A differentiation between dementia types was also reported in Ray *et al.*'s study (2017) (Alzheimer's disease, vascular dementia, Parkinson's disease, mixed and unspecified) but there was no correlation made between the outcomes and the different types of dementia. By contrast, in studies irrespectively of the diagnoses, the effect of the intervention was reported in correlation with the level of the severity. In addition to severity, it is possible to identify a difference in the effect personalised music intervention had on psychological and behavioural symptoms according to the type of dementia, as there is a difference in severity.

iv. Comparison conditions

15 studies had a control group or a control condition to compare the music interventions with (Chu *et al.*, 2013; Garland *et al.*, 2007; Ihara *et al.*, 2019; Kwak, Anderson and O'Connell Valuch, 2018; Raglio *et al.*, 2015b; Ragneskog *et al.*, 2001; Ray and Mittelman, 2017a; Sakamoto, Ando and Tsutou, 2013; Särkämö *et al.*, 2014; Sung, Chang and Lee, 2010; Sung *et al.*, 2012; Thomas *et al.*, 2017; Hicks-Moore and Robinson, 2008; Suzuki *et al.*, 2004;

Ibenthal, Kehmann and Backhaus, 2021). These studies described as control condition or group, standard care or treatment as usual, such as normal daily planned activities, taking walks, physical or occupational activities, watching television, having afternoon tea, or drawing. The music interventions described in these studies were also compared to other treatments/ interventions such as reading activities (Cooke *et al.*, 2010a; Cooke *et al.*, 2010c; Guetin *et al.*, 2009); listening to recorded audiotapes which simulated family presence, or listening to a neutral audiotape book (Garland *et al.*, 2007); a Multisensory Stimulated Environment (MMSE) (Maseda *et al.*, 2018; Sánchez *et al.*, 2016); hand massage and the combination of hand massage and favourite music listening (Hicks-Moore and Robinson, 2008); Active Engagement Intervention (AEI) (Thornley, Hirjee and Vasudev, 2016).

Other comparisons made in these articles were between: passive music listening and music therapy (Raglio *et al.*, 2013); interactive music listening and singing (Sakamoto, Ando and Tsutou, 2013); individual music listening and group music listening and listening to non-preferred music (Zare, Ebrahimi and Birashk, 2010).The remaining eight studies adopted a pre-test and post-test design so there was no comparison or control treatment.

v. Outcome measurements

Validated measurements for agitation, depression and quality of life were used in the majority of the studies except for one study (Cox, Nowak and Buettner, 2011) in which a modified version of a validated measurement was used with the permission of the author. The assessments used for behavioural and psychological symptoms were:

Geriatric Depression Scale (GDS) (Sheik &Yesavage, 1986); NPI: Neuropsychiatric Inventory (Cummings *et al*., 1994); C-CSDD: Chinese Version of the Cornell Scale for Depression in Dementia (Alexopoulos *et al*., 1998); CMAI-SF: Cohen-Mansfield Agitation Inventory-Short Form (Werner *et al*., 1994); RAID: Rating Anxiety in Dementia Scale (Shankar *et al*., 1999); Modified C-MAI: Modified Cohen-Mansfield Agitation Inventory (Werner *et al*.,1994);

HADS: Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983); BI: Barthel Index (Mahoney and Barthel, 1965); AWS: Algase Wandering Scale (Algase et al., 2001); BEHAVE-AD: Behavioural Pathology in Alzheimer's Disease Rating Scale (Reisberg *et al*., 1987); GENCAT (Verdugo, 2008), MOSES: Multimensional Observation Scale for Elderly Subjects (Helmes *et al*., 1987); PHQ-9: 9-item depression scale of the Patient Health Questionnaire (Kroenke *et al*. 2001); ABS: Aggressive Behaviour Scale (Perlman & Hirdes, 2008), NPCI-C: Neuropsychiatric Inventory-Clinician version.

To assess quality of life, the following scales were used: Dem-QoL-4: Dementia Quality of Life scale (Smith *et al*., 2005); Dem-QoL-proxy: Dementia Quality of Life proxy (Brod *et al* , 1999); DQOL: Dementia Quality of Life (Brod *et al*, 1999); CBS-QoL: Cornell Brown Scale-Quality of Life (Ready *et al*., 2002); QOL-AD: Quality of Life in Alzheimer's Disease (Logsdon *et al*., 2002).

Qualitative methods were also used, such as video tape recordings, qualitative behavioural observations and semi-structured interviews. Lastly, one study also tested for salivary cortisol levels (Chu *et al.*, 2013).

vi. Effects of the interventions

The primary question of the review was whether personalised music interventions had an impact on behavioural and psychological symptoms in people with a dementia diagnosis. The secondary question regarded the quality of life and sought to establish whether personalised music interventions in dementia care improve the quality of life of people living with dementia. The next section presents the findings of the included studies, in the light of these two questions.

Effects on Depression and Anxiety Symptoms Evaluation

Regarding the effects on depression symptoms, the majority of studies reported a positive effect of personalised music interventions. In particular, participants in group music interventions

showed a tendency to have reduced depression scores on the depression scale (Chu *et al.*, 2013). Individual personalised music intervention also had a significant positive effect, with a decrease in the majority of participants compared to control groups receiving standard care or reading activities (Cooke *et al.*, 2010a). Guetin *et al*. (2009) also found a decrease in depression and anxiety levels following individually personalised music interventions compared to the reading group intervention; in their study, the effect lasted up to two months after the end of the intervention.

Similarly, positive feelings such as enjoyment, and sense of satisfaction were present as themes in the qualitative analysis (Camic, Williams and Meeten, 2013) as a result of music engagement, when people with dementia participated in a group personalised music intervention. In the same study, when depression symptoms were evaluated in a follow-up period after the end of the intervention (ten weeks post-intervention), there was an increase in scores, underlining the effect on depression during the intervention (Camic, Williams and Meeten, 2013).

The positive effect of personalised music was also noted in the study by Gallego *et al*. (2017) where a decrease in depression scales as well as anxiety scales was reported. When the authors tested the effect within the subgroups (participants were placed in subgroups according to the severity of the dementia), the effect on depression symptoms was noticeable for the mild group but not the moderate dementia group (Gómez Gallego and Gómez García, 2017). In mood comparison before and after the session, Maseda *et al*. (2018) found that the individual personalised music group was happier and connected better to others. Although there was no difference in mood when they compared the two interventions (personalised music and MMSE), they reported that participants in the MMSE were rated to be more relaxed.

Raglio et *al.* (2013) found that the music therapy intervention had an effect on the psychological and behavioural symptoms of the participants, but they could not demonstrate

the same for the participants in the personalised music listening group. This was explained as being due to the interaction and the relationship that developed between the participants and the music therapist, and the lack of it in the personalised music listening group. In a later study by Raglio *et al.* (2015), however, improvement of depression symptoms occurred in both the personalised music group and the music therapy group. The absence of any significant difference in depression symptoms was explained by the authors as being due to the fewer number of sessions compared to the previous study (20 sessions vs 30 sessions) and by the high number of dropouts.

Ray and Mittelman (2017a) also reported that depressive symptoms were reduced following the personalised music therapy intervention. In a study comparing a passive music group intervention with an interactive music group intervention; the mood in the passive group was described as "more comfortable" post -intervention while a similar but greater effect was found in the interactive group (Sakamoto, Ando and Tsutou, 2013). Särkämö *et al.* (2014) found a reduction of depressive symptoms and improvement of mood in their music intervention group when compared to the control group (Särkämö *et al.*, 2014) while in the study by Sanchez *et al.*, (2016), no difference was found in the mood scores of the MMSE group, but scores were worse in the individualised music group, even though not statistically significant. Using the Emotional Well-being subscale from the beginning to the end of the intervention, Solé *et al.*, (2014) reported positive changes, especially in the subgroups where participants had mild and moderate dementia.

In the study by Sung, Chang and Lee, (2010), scores in ratings of anxiety were significantly decreased in the preferred music listening group when compared to the control group who received standard care. Similar results for anxiety scores were reported in a later study by Sung *et al* (2012). Tamplin *et al*. (2018) reported a difference in anxiety evaluation when compared

to the baseline assessment in the mid-intervention and post intervention assessment, with a drop in anxiety scores.

Thomas *et al.*, (2017) evaluated the effect of a Music & Memory (M&M) intervention according to the need or not of anxiolytic and antipsychotic medication, and by assessing a behavioural scale. Their study showed that facilities where an M&M intervention was employed administered less anxiolytic and antipsychotic medication when compared to the control facilities. Participants in the M&M programme also showed improvement in terms of behavioural symptoms, but there were no statistically significant changes in mood when participants from M&M were compared with patients in the control facilities (Thomas *et al.*, 2017).

The results from two more studies that explored the effect of the same protocol M&M intervention were different from the Thomas *et al*. (2017) study and from the other studies where depression and behavioural symptoms were evaluated. Using the evaluation scales CMAI and NPI, Kwark *et al*. (2018) found no significant effect on the depressive symptoms of people who participated in the M&M intervention. Thomas *et al*. (2017) evaluated the behavioural and mood changes using different outcomes, namely (PHQ-9)-mood, Aggressive Behavioural Scale and observation, on changes in the use of anxiolytic and antipsychotic medication and that might be one reason why these two studies reported different results.

Another study where no significant difference was found on depression and agitation scales (CDSS, CMAI) after a M&M intervention is the study by Ihara *et al*. (2019). However, the authors did identify effects of the intervention based on behavioural observation. More specifically, they reported an increase in expressions of joy, eye contact, engagement, verbal communication and a decrease in agitated physical behaviour such as rocking. These findings changed after the end of the intervention and did not carry over (Ihara *et al.*, 2019).

Effects on Agitated Behaviour

I will now describe how the studies report the effectiveness of personalised music interventions regarding agitated behaviours. Using CMAI to measure agitated behaviour, Cox, Nowak and Buettner (2011) reported a significant reduction following a personalised music intervention, as did the study by Gallego *et al*. (2017). In both cases, the participants had both mild and moderate dementia. Garland *et al.* (2007) found a significant reduction of agitated behaviour in all intervention groups, the preferred music listening group and in the simulated family presence group, when compared to the placebo. A similar reduction of agitation was reported in semi-structured interviews with the health care staff and family members; only one family member reported that they could not evaluate the presence or absence of agitation. When evaluating agitated behaviours using the CMAI measurement, Raglio *et al*. (2013) found significant improvement in agitation for both types of intervention (music listening and music therapy) but this result was not replicated in a later study by Raglio *et al*. (2015) using the NPI scale, which reported a significant improvement on agitation for the music therapy intervention group but not for the music listening participants.

To show the effectiveness of such interventions, however, agitation levels also need to be subjected to follow up evaluations, for example, ten weeks after the end of the intervention. The follow-up evaluation conducted by Camic, Williams and Meeten (2011) revealed that agitation levels increased. Similarly, while Park (2013) found a reduction in the levels of agitation during the music intervention period, when the intervention ended, there was an increase, although there was still an overall decrease in agitation post intervention compared to the pre-intervention test. (Ray and Mittelman, 2017a) found agitation levels to be reduced significantly immediately following the music therapy but could not report any significant impact of the intervention when they tested for wandering behaviours.

In other comparisons, personalised music intervention was found to have a clear effect when compared to classical music sessions in the study (Ragneskog *et al.*, 2001): observations of video recordings showed that personalised music sessions improved the agitated symptoms for all the participants, as well as reducing the amount of shouting in the case of two participants. No such effect was observed during the classical music sessions.

The study by Sakamoto, Ando and Tsutou (2013) comparing a passive personalised music intervention group and an interactive personalised music intervention group found a reduction of anxiety in both groups, but in the interactive group, there was also a reduction in aggressiveness. In Suzuki et *al*. (2004), authors reported a positive change on irritability for the music therapy group compared to the control group who participated in the usual activities and care (Suzuki *et al.*, 2004). Finally, Zare *et al*. (2010) found a significant decrease in agitation in all four intervention groups (group singing preferred music, group listening to preferred music, group listening to non-preferred music, individual listening to preferred music), compared to the control group.

In some studies, the analysis showed no significant effect of the music intervention on agitation symptoms as compared to control activities (Cooke *et al.*, 2010c) or when compared to interventions such as MMSE (Sanchez *et al.*, 2016), hand massage intervention (Hicks-Moore and Robinson, 2008) and Active Engagement Intervention (Thornley, Hirjee and Vasudev, 2016). A small or non-effect of the intervention was reported in M&M interventions in studies by Kwak, Anderson and O'Connell Valuch (2018) and (Kwak, Anderson and O'Connell Valuch, 2018; Sung *et al.*, 2012).

Effects on Quality-of-Life Evaluation

The secondary question of the systematic review was to explore if personalised interventions had an effect on Quality of Life (QOL). When QOL was compared between participants attending individual music interventions and group activities without music (reading), there

was a significant difference in favour of the non-music activities (Cooke *et al.*, 2010b). This can be explained by the absence of interaction and communication, and the feeling of isolation in individual music activities; for example, in some studies, apart from the participant being alone in the room, an eye mask was also offered to minimize any additional stimulus.

When QOL was post-tested in the intervention group, there was no significant change in the scores (Cooke *et al.*, 2010b). Raglio et *al*. (2013) found that quality of life was significantly improved in the music therapy group compared to the music listening group (Raglio *et al.*, 2013). But in a later study by Raglio *et al*. (2015) there was improvement in terms of QOL for all the participants, regardless of the music intervention. In Särkämö *et al*.'s study (2014) there was an effect on the QOL scale among participants in the music listening group compared with the singing group and the control group who received standard care.

In Tamplin et *al*. (2018), the QOL scale was administered to participants with a dementia diagnosis and their family caregivers; interestingly, the QOL for people living with dementia, was perceived as lower by the family caregivers, compared with what people with the dementia diagnosis reported (Tamplin *et al.*, 2018). In another study (Solé *et al.*, 2014) assessing QOL, outcomes showed a decrease from pre-test to post-test, but the authors reported in their paper that "this decrease was not clinically meaningful" (Solé *et al.*, 2014, p. 120).

3.7 Chapter Summary

In this chapter, I have presented a systematic review of the literature on how personalised music interventions have an impact on behavioural and psychological symptoms in dementia such as agitation, depression and anxiety, as well on peoples' quality of life. To my knowledge, this systematic review is the first to review the effects of personalised music interventions on agitation and depression as primary outcomes, and on quality of life as a secondary outcome.

I have presented the characteristics of each study and assessed the quality of the reported interventions using the TIDieR checklist. The majority of the included studies were of good quality and any limitations were well explained by the authors. Finally, I have synthesized the findings in relation to the primary and secondary questions of this review.

Chapter 4: Discussion of Systematic Reviews Findings

Introduction

In this chapter I discuss the findings of the two systematic reviews. The aim of the current PhD thesis was to conceptualize the mechanisms of autobiographical memory in using music to facilitate sharing personal events in terms of approaches to dementia care.

Two research questions were developed to address this aim

1. What are the characteristics of the autobiographical memory system in people with dementia?
2. What is the effect, if any, of personalised music interventions in dementia care regarding the autobiographical memory and sense of self?

I addressed this question by conducting a separate systematic review for each question, then integrating the outcomes to have a better understanding of how music intervention can be conceptualised and applied in dementia care. In this chapter I outline, contextualise and synthesise the main findings of the reviews and discuss them in relation to the current literature.

4.1 Summary of main findings

The first systematic review explored the AM characteristics in people with different types of dementia diagnosis; Alzheimer's disease, vascular dementia, semantic dementia and frontotemporal dementia. A total of 26 studies were included in the systematic review. One of the main findings when AM assessment was compared between people with a diagnosis of dementia - irrespective of the specific type- and the control participants, was that they reported general facts about their recalled memories compared to a richer more detail account of recalled memories by the control groups. When each type of dementia was assessed for AM function, participants with a diagnosis of vascular dementia and AD, recalled more autobiographical

memories from their childhood and early adulthood life, compared to the memories from their recent past, an effect known as temporal gradient, as compared to the two other types of dementia, FTD and SD.

Participants with an SD diagnosis showed that the recalled memories where not specific, across the entire life span, with no difference between remote memories and memories from their recent past, when compared to control participants. The AM assessment in these participants also revealed that the AMs that were more preserved were those from their recent past (last five years). Similarly, in the studies with participants with a diagnosis FTD and (bv)FTD, semantic details of the remote memories were impaired as compared with the semantic details the same participants recalled from their recent past. On the contrary, participants with a vascular dementia diagnosis and AD diagnosis, recalled more childhood and early adulthood memories compared to the number of AMs from the recent past. Also, the participants with an AD diagnosis produced less memories, characterised as self- defining, for past events compared to the control participants. Memories characterised as self-defining include memories of events which are meaningful and significant to the person's life history and sense of self (Wood and Conway, 2006). The findings of this review did not show a significant effect related to the different types of assessments; for example, the temporal gradient effect on AD participant was present in both assessments, which used cues and assessments with semi-structured interviews.

Regarding the reminiscence bump, there were three studies which further investigated it and showed it to be present in participants with an AD diagnosis in a cueing task, in a TEMPau semi-structured interview and in the SD mild subgroup in a semi-structured questionnaire (TEMPau). Two additional studies discussed their findings in relation to the reminiscence bump but in the majority of studies, there was no further exploration of the reminiscence bump;

this could be because it was beyond the scope of the studies or a result of the methodological assessments in the included studies.

The second systematic review investigated the personalised music interventions and the effects on behavioural and psychological symptoms in patients with dementia. The main difference of this definition "personalised music interventions", is that music selected was meaningful and personal to the participants, and it was not chosen by the researcher or the caregivers to aid relaxation.

For that reason, I only included studies where it was reported in their method section that prior to the intervention the selection of music was made after interviewing the participants, and in the cases that was not possible, on information provided by relatives, caregivers or health care staff members. Although the autobiographical meaning for the participants is likely to be greater in self-identified music than in music suggested by someone who knows them, the scope of that information was to identify music with autobiographical and emotional meaning for the individuals.

The main findings from the 30 studies included in the systematic review, can be summarized as follows.

Regarding the effects on depression symptoms, the majority of studies reported a positive effect of personalised music interventions compared with care as usual, other interventions such as walking, and reading activities, and non- personalised music interventions. However, even though there was an overall positive effect on depression (as evaluated by depression scales, and qualitative observation), the effect in the majority of the studies did not last after the end of the intervention, and it varied across participants, according to the severity of the diagnosis. A positive effect was also described when evaluating the agitation and anxiety symptoms but again, the effect did not last beyond the period of the intervention.

Quality of Life (QOL) was the secondary outcome explored in the systematic review. Regarding this outcome, there were no clear results. Even thought there was a borderline significant effect of the personalised music intervention in group interventions, there was no significant improvement in QOL when participants were listening alone to their personalised music with no other interaction. By contrast, when participants actively listened to music and interacted with caregivers or other people, a clearer effect of positive improvement was present in the QOL scales.

4.2 Discussion of the Findings

The aim of this thesis was to further develop our understanding of how personalised music can engage AM functioning; an additional aim was to conceptualize the mechanisms of AM in sharing personalised music in terms of approaches to dementia care. Dementia is a complex syndrome and an umbrella term that includes a series of subtypes of neurodegeneration diseases. Each sub-type of dementia diagnosis has its own cognitive characteristics and symptoms, and as was explored in the first review, in the AM system as well. These different characteristics of the formation of the AM system need to be considered in the development of interventions for specific populations.

Music interventions are very popular in the field of dementia, as a continually growing evidence base from research with healthy populations, as well as with people with a dementia diagnosis demonstrates how music can be an effective means to evoke AMs (Janata, Tomic and Rakowski, 2007; El Haj, Fasotti and Allain, 2012b; El Haj *et al.*, 2015; Cuddy *et al.*, 2017; Jakubowski and Ghosh, 2019; Blais-Rochette and Miranda, 2016). The result of the systematic review on AM characteristics in different types of dementia showed that even though there is impairment of AM in the patient population compared to the control participants, there are

elements of AM which are still preserved. Furthermore, the findings of the review demonstrated a different pattern of the preserved elements among the different types of dementia, such as the difference in recalling memories from childhood and early adulthood and memories from the recent past.

In a study by Basaglia-Pappas and colleagues, people in the early stage of Alzheimer's disease, showed no difference compared to the healthy population in recalling AMs about specific songs (Basaglia-Pappas *et al.*, 2013b). Also, both groups recalled equally more memories related to the reminiscence bump time period. This study shows that semantic information and phenomenological details of autobiographical memories, such as vividness, coherence, time perspective, emotional intensity and valence, can be better preserved in AMs linked to music compared with the AMs not linked to music (Basaglia-Pappas *et al.*, 2013b).

In another study by Cuddy and colleagues (2017), participants with AD showed no significant differences compared to the control group of "older adults" in recalling AMs after listening to familiar music excerpts. Both groups reported less specific AMs compared with the "young adults" group, but no differences could be correlated with the diagnosis, in terms of the amount of memories, the vividness or the selection of the memory topics (Cuddy *et al.*, 2017). In addition, the "older adults" group and the group with an AD, produced more memories from the reminiscence bump. The main difference between these groups was found to be only in the specificity of the recalled memories, where "older adults" could provide more details and be specific about the events described in their memories (Cuddy *et al.*, 2017).

People with Alzheimer's disease diagnosis have difficulties in recalling AMs, but there is ongoing growing evidence from studies that the use of music can help to minimize these difficulties, and to help people to recall vivid autobiographical events (Foster and Valentine, 2001; Jacobsen *et al.*, 2015). The period between 10-30 years encompass self-defining memories, which are memories of significant events meaningful to the person's sense of self

(Wood and Conway, 2006; Martinelli *et al.*, 2013), and the phenomenological dimensions of these memories are significant to the construction and sense of self. In addition, the reminiscence bump component is present in music linked memories where they seem to be preserved in neurodegenerative diseases, such as AD.

Another finding from this review is that the reminiscence bump was preserved in participants with AD and mild SD diagnosis. There is a strong connection between music evoked self-defining AMs within the reminiscence bump. People with an AD diagnosis in one study were exposed to personalised meaningful music; they reported significantly more self-defining memories compared to the conditions where the recall was done with music selected by the researchers or in silence (El Haj *et al.*, 2015). Future research could further explore this phenomenon of AM in different types of dementia and apply the findings to develop personalised interventions such as personalised music interventions, taking into consideration how the reminiscence bump is formed in the different types of dementia.

Self-defining memories may help in preserving or reconstructing a sense of self and identity. This connection for people with dementia diagnosis is related to the social- emotional area of the sense of self; personalised music interventions link people with their environment, promote interactions with others, and provide a sense of sharing of their life history and belonging through this active process. Narration of autobiographical events and the interaction during this process, has been reported to influence autobiographical memory. Elmi, Bartoli and Smorti (2019) explored this influence in a study with healthy young adults and identified the importance of the empathic listener in the narrative process of AMs, compared to the same interaction with a detached listener. The social interaction between the participants, the narrator and the active listener, is a dynamic process and all the members share a role in recalling the memories, thereby reinforcing the narrative. This has an effect on the phenomenological

characteristics of the recalled memories: in the presence of an empathic listener, narrators recalled more details of the events (Elmi, Bartoli and Smorti, 2019).

In another study (Bavelas, Coates and Johnson., 2000) the characteristics of narration were tested in relation to the listeners' responses. The researchers set up two conditions: in one, the listeners gave a "specific response" and in the other, they had a "generic response". In the "specific response" condition the listeners engaged more in the process of narration and their responses were directly connected to what the people were saying, while in the "generic condition", the listeners did not make direct comments or responses. The effect of these two condition in the narration was that given a "generic response", narrators told their narratives 'less well', as evaluated by how they ended their stories and if they completed their sentences, compared to the "specific response" condition (Bavelas, Coates and Johnson, 2000). As the authors of these studies elaborated, the results indicate that the social interaction component of the narration is what significantly improves the recall. Another study exploring the effect of personalised music in autobiographical narration demonstrated that narration of an AM event in the personalised music condition was significantly better in terms of linguistic characteristics compared with narration under the silent condition (El Haj *et al.*, 2013). The process of *sharing* personalised music seems to be the key component for people with dementia in recalling AMs. It results in a re-establishment of self and a sense of belonging in their environment; this might have a direct effect on psychological and behavioural symptoms and on quality of life.

The studies included in the review report an overall beneficial effect of personalised music interventions on depression symptoms and agitated behaviour in people with a dementia diagnosis. Nevertheless, the significance of this effect in the long term is still in doubt. This finding can be a result of the way results of interventions are evaluated. Without wishing to underestimate the importance of neuropsychological assessments, it is equally important to think about different ways to measure the benefits of personalised interventions. We might

need to measure the positive responses during the intervention, such as aspects of engagements, how interactions and connections are enabled, how and if emotions are expressed, along with physical responses and facial gestures. Outcomes could also be evaluated individually, by listening to the views and feedback of the carers regarding any changes they noticed.

In people with a dementia diagnosis, there is a link of the sense of self and the loss they might experience and its projection to behavioural and psychological symptoms (Caddell and Clare, 2010). A future implementation might be to include outcomes related to the sense of self and identity in the studies to evaluate the effect of personalised music intervention in behavioural and psychological symptoms. A recent review by Dowson, McDermott and Schneider (2019) also suggested additional outcomes to evaluate the positive responses to music, besides measuring the decrease of negative symptoms such as depression and agitation, to additional interventions (Dowson, McDermott and Schneider, 2019). Developing measurements to evaluate changes in the self could be more informative in ascertaining the effect of the interventions. These could be in the form of qualitative interviews, observation-based measurements or outcomes that evaluate the recall of self-defining memories. Qualitative research approaches do not need to recruit large sample size, which is always an objective difficulty in dementia research. Using and further developing this set of measurements could overcome the limitations reported in many of the studies in the review regarding sampling size.

Nevertheless, better controlled studies are needed to clarify why in some cases this effect is either small, insignificant or absent. One main finding of the review was the importance of interaction in music interventions: studies where participants were isolated when listening to preferred music did not report improvement in terms of measurement scales or observations, on the contrary. A similar conclusion can be drawn from the results pertaining to quality-of-life scales, where music listening had no positive effect when compared with active music interventions.

The interventions differed across the included studies in the way they were delivered, whether involving group or individual activities; passive or active listening; and live or recorded music. A main reflection on the findings is in relation to active or passive interventions. When the intervention was active, either active music listening or active music playing, participants could better engage, and the interaction had a positive effect on the outcomes. When personalised active music interventions were compared to other activities, however, there was no consistent evidence to indicate that music had a greater effect (even live music). The effects were also similar for one-to-one active personal music interventions (music listening, live music interventions). The findings indicate that active interventions that engage the attention and communication can have a similar effect irrespective of the stimulus they use. This is particularly true for quality of life: "passive music listening" resulted in a decrease in quality of life as assessed by the standardised measurements. Listening to music in an isolated environment or other activities in dementia care (such as bathing, dressing), might be beneficial for relaxation but not for behavioural and psychological symptoms and the quality of life. Music is a very powerful stimulus for interventions in dementia care but as has been reported in many of the studies in this review, music has a greater effect when it links people with the dementia diagnosis with their environment and promotes interaction with others, such as music therapists or caregivers; when these conditions are met, it can provide a sense of sharing and belonging through this active process.

As discussed in Chapter 3 regarding the effect of personalised music interventions, few studies included participants with a specific diagnoses, and in these studies the outcomes of the personalised music intervention were not reported in correlation with the diagnosis. Yet autobiographical memory is differently affected in different types of dementia; therefore, a future implementation could be to further explore the effects of personalised music interventions in correlation with the specific dementia diagnosis.

A very common limitation in studies with participants who have a medical diagnosis, and especially in the field of dementia, is the small number of participants. This was also found in the current review. An outcome of the review was that most interventional studies did not evaluate their outcomes in relation to the different types of dementia. The findings of the review indicated that this was mainly due to the lack of a specific diagnosis of dementia in most of the papers, where in the majority of the studies the diagnosis was usually reported under the umbrella term of dementia.

This finding might be related to a general absence of a specific diagnosis in people living with dementia, but it can also be related to another limitation reported from many of the studies, that of the small sample size. Difficulties of recruitment might have as a result to not subgroup according to the diagnosis. This can also reflect the issue of the assessments we are using to evaluate the outcomes of the interventions. This finding also points towards the need to re-examine the use of assessments that need a big sample size to evaluate the outcomes of personalised interventions. One way to overcome the difficulties of recruitment would be to better inform health care staff and caregivers to encourage them to support the research. Another way to address this limitation would be to adapt and develop more qualitative methodologies that do not require large samples. This would also address the limitation of quantitative measurements with regards to capturing the intervention's impact on participants with severe dementia.

4.3 Outcomes of systematic reviews on the importance of personalised music and the link with autobiographical memory.

The two systematic reviews were designed to explore (i) the characteristics of autobiographical memory in people with different diagnosis of dementia; (ii) the effect of personalised music interventions in psychological and behavioural symptoms in dementia care; and (iii) how music

interventions are currently implemented in dementia care. The reviews sought to describe AM in dementia and to explore why and how music interventions have meaning for people living with dementia, and thus why personalised music may have a very particular impact on wellbeing.

Studies have shown a temporal distribution (10-30 years) of the preferred music ((Janssen, Chessa and Murre, 2007; Hemming, 2013). Musical choices were also found to be from the self -defining period and to relate to an important event or person , when Loveday and colleagues analysed narratives of musical choices and life history from a radio broadcast (Loveday, Woy and Conway, 2020). Memories recalled with a music cue from the self - defining period are described in great details and tend to be more vivid (Rathbone, O'Connor and Moulin, 2017). Music-evoked autobiographical memories tend include more emotionally-charged content (El Haj, Fasotti and Allain, 2012b), and are recalled spontaneously, and more easily, including by people with Alzheimer's disease (El Haj, Fasotti and Allain, 2012a).

Analysis of the second review showed that personalised music used in the interventions, was mainly identified as preferred music or what music participants enjoyed. A question that arises from this finding is: what constitutes personalised music is? Preferred music to listen to might not be as meaningful or might not have the elements that connect to the important autobiographical events of our lives. There is a need therefore to identify and describe what are the qualities of the music that people define as meaningful to them, music that can be used as a stimulus to cue autobiographical memories, meaningful experiences and self- defined memories.

In this regard, prior to the design of personalised music interventions for people living with dementia, there is a need to understand what music people choose to share when they narrate their life history, and to explore if personally meaningful music shares specific components for everyone, regardless of any known diagnosis of a neurodegenerative disease. A better

understanding and description of this characteristic would help to further develop the aims and the design of personalised music interventions for people living with dementia. Questions that arise in this regard are (i) how do people use music to narrate their past experiences?; (ii) does music enable the sharing of life history?; (iv) is there a commonality in the AMs they link with music?; (v) does the sharing of meaningful music influence the expression of emotion and social connections?

To further investigate these questions, examining the qualities and relationships between the AM system and personally meaningful music in people not knowingly affected by dementia and of a range of ages seemed to be a fruitful next step. This is what led me to analysing interviews from Desert Island Discs, a radio programme in which people are invited to choose and share eight music tracks that they would take with them if they were cast away on a desert island. I posited that an analysis of Desert Island Discs interviews might help to understand how people use music to express, identify and describe their self through important AMs linked with music, and to define what makes music so important and personal. DIDs interviews focus precisely on these elements and the interviewees narrate their life stories through meaningful music.

4.4 Limitations of the reviews

As reported in Chapter 2, the limitation of the first review was that the data was extracted from the included papers without a second reviewer. To overcome this limitation, my first supervisor Anne Killett reviewed all the included papers and I was continuously advised throughout the review process. In the second review, there was no distinction between different types of dementia. This can also be seen as a but at the same time, served to indicate a gap in the research and the need for a more refined description of people living with dementia participants in interventional studies. Finally, a limitation of both reviews was that I might have missed

relevant papers, although I did a second search in February 2019 to ensure that the search was updated.

4.5 Chapter Summary

In this chapter I summarised the results of the two reviews and explored the connections of the findings with the literature. The findings showed a lack of investigation regarding the direct correlation of specific diagnoses and the effect of personalised music interventions. This is due to the difficulties of the clinical populations and because the studies aimed at sampling sizes for the purpose of generalization rather than to investigate the interventions for different types of dementia. Yet the majority of authors commented on the small number of the participants that had been recruited and the consequent limitations of their results.

As I have suggested in this chapter, adapting supplementary qualitative approaches might overcome this limitation and also allow the focus to be on exploring the effect of interventions in the different sub-types of dementia. The behavioural and psychological symptoms we often used as outcome measurements in dementia are directly intertwined with the decline in AM and the loss of sense of self or self-defining memories. Focusing on developing music interventions in that direction and using outcomes related to the re-construction of the self and identity, might reveal a greater impact in terms of the behavioural and psychological symptoms of dementia.

Chapter 5: Qualitative analysis of Desert Island Discs interviews

Introduction

The overall aim of the thesis was to explore the way personalised music enables people to share autobiographical memories, and how this may lead to applications in dementia care. In Chapters 2 and 3, I presented the findings of two systematic reviews: the first review aimed to describe autobiographical memory in different types of dementia, and the second, the effects of personalised music interventions on behavioural and psychological symptoms in people with dementia diagnosis.

The first review highlighted how the autobiographical memory system declines in different types of dementia and the second review evaluated current research on the effects of personalised music interventions in dementia care, compared to other types of interventions or standard care, with a specific focus on behavioural and psychological symptoms. The outcomes of these reviews set the context for this thesis's objectives and its methodological choice: to qualitatively analyse interviews of Desert Island Discs broadcasts, with the aim of exploring what are the core processes in sharing personally meaningful choices of music and understanding how music is used to represent and support a sense of self.

In this chapter, I present the qualitative study and the methodological approach adopted. The first section begins with an overview and brief history of Desert Island Discs (DIDs). I then discuss the methodological approach that was applied to the selection, analysis and discussion of the data set. More specifically, the thematic analytic framework that guided the analysis is introduced within an overarching phenomenological approach in the discussion of the findings. The chapter continues with a discussion of the data set and a justification of the sample chosen for analysis.

5.1 Qualitative Analysis of Desert Island Discs

The present study used as a dataset broadcasts from the popular BBC Radio 4 show, Desert Island Discs (DIDs), a weekly show that has been on air since January 29th, 1942. DIDs has been described as "Britain's longest-running radio show" (Sean, 2012), with more than 2800 episodes recorded thus far. DIDs was devised by Roy Plumley and presented by him from January 1942 until his death in May 1985. Since then, the show has had a number of presenters. In the sample broadcasts used for the purposes of this analysis, Kirsty Young is the presenter. The idea of the show is to invite well-known people each week and ask them the following question: "If you were to be cast away alone on a desert island, which eight gramophone records would you choose to have with you, assuming of course, that you had a gramophone and an inexhaustible supply of needles?" (BBC and 4., c 2019). Castaways present eight music tracks and explain why they chose to take these particular discs with them to a desert island. In the course of the programme, and aligned with their choices, they discuss significant moments of their life stories.

More than 1500 DIDs broadcasts are available online through the BBC's efforts to create an archive for the show. For this study, online data from this archive were used; one category of qualitative data are qualitative audio and visual materials in digital archives (Clandinin, 2007) and DIDs radio broadcasts fall within this category. In their study, Smith and Waters (2018) also used DIDs as a source of data, and they described the kind of show as having a "(…) biographical chat show register, since a retrospective focus on the guest's life is routinely prominent*"* (Smith and Waters, 2018 p.171). By using this unique data set, I explore how people choose personalised music to present significant autobiographical aspects of their life.

The interviewees on DIDs present aspects of their life story to the audience by choosing music that is meaningful to them. Particular pieces of music may be chosen because they bring back

specific autobiographical memories, related to different time periods or related to significant people. They may also be chosen because of a unique and specific meaning that the interviewee wants to carry with them and convey as part of who they are, as a sense of self. In DIDs, music is used as a means of presenting different and significant aspects of their life history.

Implicit in the question ("If you were to be cast away alone on a desert island…") that is the basis of the show, is that the guests are asked to choose music to accompany them in an environment where we as the audience assume that they will not have communication with other individuals and there will be an absence of social life activities. Implicit to DIDs question is that social interaction on the desert island will be entirely absent and interviewees will try to replace it with these eight discs which carry moments, events and people, meanings that they want to maintain, as they want to maintain their sense of self. In other words, music stands for all the other things in life that will not be available on the desert island. Interviewees may choose to engage with this concept in different ways: they could be reflective, or they might be more concerned with how they are representing themselves.

The DIDs broadcasts on BBC Radio 4, have inspired other academics and have been used in other studies as a source of data for linguistic studies (Smith and Waters, 2018), social sciences studies (McDonald, 2014) and studies that are interested in the show's setup and aim to examine specific questions, such as Dr Loveday, who is also interested in understanding the connection between autobiographical memory and music (Loveday, 2016; Loveday, 2017).

5.2 Methodology

This qualitative research study aimed to explore the processes in the autobiographical memory system that are involved in the sharing of personally meaningful choices of music, and how music is used to represent and support a sense of self. In order to provide a detailed and nuanced

examination of these autobiographical memory processes and personal music choices, the data corpus for the study consists of individual interviews from the DIDs online archive.

I will describe and justify my use of thematic analysis as described by Braun and Clarke (2013), showing how I deepened the discussion through following a phenomenological philosophical perspective (Smith, 2018) .Thematic analysis, following the six-phase guide described by (Braun *et al.*, 2019) (see below in Section 5.2.1) was used to initially move from the data corpus to the specific data set and coding, and to develop the key analytic themes.

5.2.1 Thematic analysis

Thematic analysis is a qualitative research method in which the researchers capture and identify patterns, "themes", in the data-set, and interpret that information and their meaning in the context of the research aim and research questions (Braun *et al.*, 2018). In order to address the key aim of the study, I chose thematic analysis using an inductive approach. A thematic inductive approach involves staying close to the data throughout the analytic process so that the experiences of the participants and their personal meanings can be unravelled, leading to a detailed description and to new understandings and meanings of the data (Braun *et al.*, 2019).

Adopting this approach begins by considering and acknowledging any theoretical presumptions and then works with the analysis as free as it can be of any preconceptions. As such, the inductive approach is described as a bottom up process, where the starting point is the data set, instead of being theory driven (deductive approach) (Braun *et al.*, 2019). There is flexibility in the analysis process and often the researchers are both informed by the data as well by their research questions that drive the analysis.

Thematic analysis is described as consisting of specific stages (Braun and Clarke, 2006). The first stage involves familiarization with the data; this is followed by the generation of codes by identifying initial patterns and categories within the data; from the collection of codes, the

researcher searches for themes which are reviewed in terms of the codes and each specific data-set; following this stage, the final themes are generated and defined by giving a name and description to each theme. (Braun *et al.*, 2019). Clarke (2017) makes a distinction between two categories of themes: a "domain summary", where the researcher summarises what participants said in the light of the research question and the "storybook theme", charaterised by being interpretive and underlined by a central concept that unifies the data (Clarke, 2017).

In thematic analysis, before themes are developed, the data must undergo a process of coding. Saldaña (2016) describes a code as a "word or short phrase" (p.4) that captures the information and what may be of interest in the raw data. At a second level, coding can consist of longer phrases from the original transcripts (Saldaña, 2016). In this step, a list of codes is generated which later collapses into themes (Braun *et al.*, 2019). With interview data, codes are generated by what the participants say in their interviews at a semantic level; in Braun and Clarke's thematic analysis approach, the semantic level is when the researcher presents the meaning of what the participants said "close to the participants language" (Braun *et al.*, 2019). The process of the analysis then moves from a detailed description of the data to an interpretation, where patterns from the meanings and descriptions from the semantic level start to materialise into a developing theory. In this study, in order to give a detailed description of the themes that were identified in the data set, the themes generated during the analysis pertained to participants' own meaning-making as they talked about their music choices.

5.2.2 Phenomenological philosophy

To uncover and describe the structures which appear in the process of sharing aspects of life history with the use of music, phenomenological philosophy has been incorporated in the discussion of the findings. Phenomenology is a philosophical discipline first introduced by Edmund Husserl (1859-1938) and later developed by other philosophers such as Maurice

Merleau-Ponty (1908-1961) and Jean-Paul Sartre (1905-1980) (Smith, 2018). The starting point of phenomenological philosophy is the study of subjective experience and how it is shaped. The interest is focused on phenomena as experienced from each individual's point of view, and conclusively is the reflective study on how the world appears to us in terms of our subjective experience (Smith, 2018).

Phenomena derives from the Greek verb "phainesthai" (φαίνεσθαι), which means "to appear"; phenomena can be then described as the object or the experience of the world as it appears to us, prior to our judgments and preconceived thoughts and ideas (Britannica, 2017). In short, phenomenology is a philosophy that seeks to describe the phenomena of experience (Finlay, 2012; Applebaum, 2012; Smith, 2018). According to Husserl, experience is directed towards the phenomena in order to find and make the meaning of our experience (Smith, 2018). That direction is the intentionality of our experience of the phenomena. Intentionality can be both active and passive. Passive intentionality is all the already given meanings of our experience in an emotional-embodied reflection on the phenomena, which is already there, before our reflection (Applebaum, 2014). Active intentionality occurs as soon as we reflect on our experience; as we are naming the perceived object of our experience, and we start making interpretations (Applebaum, 2014), objects are the entities we observe and we are aware of when we perceive the world (O'Brien; Crane and French, 2017). Our life and experience of the world is charaterised by both these qualities, the passive experience of the world as its given, and the interpretative, active intentionality of our experience, as formed by our previous knowledge and our reflections of the world in our experience (Applebaum, 2014).

In psychology, phenomenology is both a descriptive and interpretive method with which one can explore and describe the phenomena of interest, and study how people experience them. A principle of phenomenology is that description is a form of interpretation: when we observe a phenomenon or someone experiences a phenomenon, our observation is our approach to

interpreting peoples' meanings and the structures of their experience. Phenomenological researchers aim to investigate personal concepts for the phenomenon of interest, as it is unfolding in a particular context (Finlay, 2014). Within that context, phenomenology as a philosophy and research method in psychology can be informative in studying the phenomenon of sharing personalised music. Music as an experience is generally unique for each individual. The way that people relate to music at a personal and social level can be seen from a phenomenological philosophy perspective as an experience between the person and the world that is bidirectional, characterised by both active and passive intentionality (Dura, 2006; Parr Vijinski, Hirst and Goopy, 2018).

In the work by Thomas Clifton "Music as Heart: A study in Applied Phenomenology", feelings are essential components of the music experience, and Clifton relates the feelings as an action of the body; he further describes music listening as an active ongoing process (Clifton, 1983). Incorporating phenomenological philosophy in the discussion of the findings can further contribute to understanding and contextualising the use of music in intervention for people with a dementia diagnosis, for example by describing the structures in musical experience of the participants in relation to the environment, such as the persons delivering the interventions.

5.3 Data collection and considerations of ethics

5.3.1 Ethics in online data

As in any other study where people are involved, studies where online data are used need to address the question of ethics (Snee, 2013; Whiteman, 2012), to establish whether these data can be considered public or personal and whether, therefore, ethical approval is needed. For the current study, I used online recorded broadcasts from the BBC internet archives; these online data were intended to be public even before being uploaded onto the internet. Furthermore, the interviewees in the broadcasts are public figures and well known to the public.

However, while the interviewees had agreed to take part in the broadcast for entertainment purposes, they did not agree to take part in research; for this reason, protecting their identity has to be considered as in any other research involving humans.

Given these considerations, I made the following decisions regarding ethics: I present the participants' demographic characteristics (Table 8) without any direct reference to their name and I allocated numbers for presentation purposes such as I1, I2 (interviewee 1, interviewee 2 etc.). Furthermore, I present their occupation in general rather than specific terms. For example, in the case of one participant, I present his occupation under the general term of 'physician', without giving information about his specialization that could lead to identification. One action I took prior to the analysis of the data was to send an email out of courtesy to inform the producers of the show that I would be analysing a sample from the content of DIDs radio broadcasts for my PhD research project (Appendix 5). That decision was made to enable comments of anyone involved in the DIDs programme.

Another decision related to ethical considerations was to include interviews only from people who were alive at the time of sampling. Using deceased peoples' data is not straight forward and has been described as a 'grey zone' for the Research Ethics Committees (*Manual for Research Ethics Committees: Centre of Medical Law and Ethics, King's College London*, 2003). Even though approval was not required from a Research Ethics Committee for these online data, that decision was made because there was not in my knowledge relevant guidance regarding online data pertaining to deceased people.

5.3.2 Sampling

For qualitative research, decisions about sampling need to be made in relation to the research question, the resources available for identifying eligible participants and the method of analysis

(Wilmot, 2005). Following this guideline, I sampled eligible DIDs interviews from the available online broadcast from 1/10/2006 to 23/09/2018. For thematic analysis as for other methods in qualitative research, there is no specific ideal number of total participants (Braun *et al.*, 2019). One main criterion for sampling is how rich the data is in relation to the phenomenon of interest. A way to encounter rich information is to sample purposively to ensure diversity in the characteristics of the participants, thus allowing the researcher to capture and understand the different aspects of the research question (Palinkas *et al.*, 2015).

Another consideration in qualitative research is the principle of saturation; saturation is a term first used in grounded theory (Glaser and Strauss, 1967) to describe and justify that the sample size is sufficient to answer the research aims and questions (Guest, Bunce and Johnson, 2006; Mason, 2010). When saturation is reached it means that additional sampling will not provide new codes and in addition new themes in the analysis. For this thesis, I aimed to have an equal number of participants in terms of sex, and a broad variation in terms of occupation, ethnicity and age. Taking into consideration this principle of variation but also saturation and the time available to analyse the data, my aim was to sample up to eighteen interviews from the online available broadcasts.

Since the interviews were not conducted for research, I wanted to have a constant element in the data, and so I decided that the interviews should be carried out by the same person. The total number of available online DIDs broadcasts with the same presenter (Kirsty Young) is 505, from 1/10/2006 to 23 September 2018. Therefore, I chose to sample from that period.

The first step in sampling was to enter all the interviewees from the online data into an excel table and to add demographic information for each interviewee. Since the sampling strategy I followed was purposeful nonrandomised sampling, I selected the eighteen participants in order to have variation in occupational background, musical background and to represent a broad

range of age and ethnicity. In Table 8 I present the demographic characteristics of the participants.

5.3.3 Data transcription

The DIDs interviews were downloaded from the BBC Radio 4 online archive. After listening to the interviews, I used an online transcription software, "Happy Scribe" (https://www.happyscribe.co/). I then checked the manuscript myself, while listening to the audio files, to ensure accuracy and made corrections where needed; this step also gave me the opportunity to further familiarize myself with the data. Since these interviews were not conducted for research purposes and I was not involved in the interview process, re-reading and re-listening to the broadcasts was an essential part of my analysis. The transcriptions had a specific format that included the timestamps, speakers' names and comments, which included moments of silence, laughing, crying, exclamations and descriptions of non-verbal communication.

5.4 Data analysis process

Analysis of the data followed specific steps. As I did not have any involvement in the interviewing process itself, the first step after sampling the broadcasts was to listen to each interview and to keep notes regarding initial thoughts about the data. I included this step so as to reflect on the data, recognise and record any pre-conceptions that might influence subsequent analysis, in a procedure referred to as bracketing (Tufford and Newman, 2010). Bracketing is the process of actively working with the data in order to acknowledge previous beliefs, hypotheses and biases regarding the research question (Roberts and Priest, 2006). The use of field notes is a common practice in qualitative research generally. It provides, among other things, a systematic method of recording personal assumptions and preconceived notions

regarding the data and the research question and therefore, helps to reduce bias (Phillippi and Lauderdale, 2017; Maharaj, 2016).

The second step was to transcribe the data as described in section 5.3. The third step was the initial coding which was done within the Microsoft Word document of each transcribed interview. I underlined participant quotations and labelled them with a word or a phrase referring to the meaning. This step generated the initial codes. I then transferred the codes from each interview into a Microsoft Excel document, organised into three columns: in the first column was the code; in the second column was the original extract from the text, and lastly, the third column contained my comment and notes. After this step was completed, the fourth and last step of the analysis involved reviewing all the codes and categorizations, generating the sub-themes and the final overarching themes. These overarching themes were reviewed by both of my supervisors (AK and HS) and feedback was provided.

The findings were further presented and discussed using thematic analysis (Braun *et al.*, 2019) and the discussion of the findings was informed by phenomenological philosophy and phenomenological psychology (Smith, 2018; Applebaum, 2014), as will be described in Chapter 6.

Analysis Note

To end this section, I report on one choice by an interviewee that was not a musical piece but an excerpt from a poem. Because it is not music, I have chosen to separate it from the main analysis. Poems share elements with music such as rhythm, rhyme and tonality; moreover, one could argue that lyrics are simply poems set to music. However, the interviewee chose the recitation of poetry and while it can provide another system of information and analysis, such as the research of sounds, it is beyond the current scope of my research questions.

Table 8 Participants Demographic Characteristics

	Gender	**Occupation**	**Date of birth**	**Age at time of Interview**	**Nationality**
1.	Female	Scientist	1968	42	British
2.	Female	Physician	1960	50	New Zealand
3.	Female	Athlete	1956	56	Czechoslovak-born American
4.	Female	Writer	1962	51	British
5.	Female	Farmer	1961	54	British
6.	Female	Chief Executive	1943	72	British
7.	Female	Novelist	1971	46	Turkish-British
8.	Female	Artist	1985	29	British
9.	Female	Nurse	1953	61	Anglo-Swiss
10.	Male	Designer	1964	51	British
11.	Male	Athlete	1980	35	British
12.	Male	Artist	1962	54	British-Nigerian
13.	Male	Scientist	1956	61	Italian
14.	Male	Farmer	1960	58	British
15.	Male	Physician	1950	68	British
16.	Male	Scientist	1948	70	American
17.	Male	Athlete	1977	39	British
18.	Male	Artist	1969	46	German

5.5 Results

The analysis of the eighteen interviews initially generated a total of 157 codes (development of codes Appendix 6), which were then synthesized into eight overarching themes: (1) Emotional effect; (2) Autobiographical memories; (3) Healing; (4) Inspiration; (5) Motion; (6) Social connection; (7) Spirituality; (8) Timelessness. These themes, sub-themes and related comments are set out in Table 9. The process of analysis was discussed with the supervisory team in order to ensure precision of the analysis and the findings, and both supervisors reviewed the themes and the codes. In the following sections of this chapter, I present each overarching theme and sub-theme in relation to the research questions set out above and illustrate the findings with selected interview excerpts.

Table 9. Themes & sub-themes from DIDs Interviews

Themes	Sub-themes	Comments	Illustrative Quotes
Emotional effect	• Emotions evoked by music • Feeling of freedom/ liberty • Feeling carefree • Feelings of happiness • Distraction • Music as mood-setter/ regulation of emotion • Emotional autobiographical memories • Romantic love emotions • Nostalgia	All the interviewees described how music had an emotional effect on them that was either solely evoked by the music piece, or by the associated memory.	*"So, this is a piece from that wonderful film The Thomas Crown Affair. Glider, Bill Conti. It's such a playful piece and I think we're all at our best when we are in slightly more playful and relaxed mode. And for this bit of music sort of symbolizes that for me if you remember the film when they're sort of coming in on the little biplane and zipping in and zipping out and it just feels light and I want some lightness in my life.*" (Int 5) *"Noir Desir, Le Vent Nous Portera, however when I hear this song, I think it takes me back to this other connection that I have and maybe I was never able to build, I felt connected to France mostly through French literature. There's something in this song that makes me very emotional"* (Int. 7)
Autobiographical Memories	• Childhood • Adolescence • Family	All eighteen interviewees linked at least one music choice to childhood or early adulthood memories or to memories with their family or significant relationships. These episodic memories were also characterised by the effect of the "reminiscence bump".	*"Yes, this is the Best thing that ever happened to me by Gladys Knight, and the reason I picked this is because it's for my hubby [name of the husband]. And that's what he is, He's the best thing that ever happened to me."* (Int. 4) *"Chosen Chopin's ballad number four in F minor because my mother was a gifted pianist but she didn't become a concert pianist because she followed my father who was a civil engineer all over Africa, but wherever they went she had a piano carried with her and at sundown every night wherever they were she would play the piano and her favourite composer was Chopin."* (Int.6)
Healing and Coping with Loss	• Loss • Illness • Recovery • Reconciliation	The majority of the interviewees chose to bring music in DIDs which was related to memories of loss or them dealing with illness and associated with the very strong emotions they had experienced. They also selected this music because that experience was a core element of their sense of self.	*"Genesis and Genesis was my first big musical love introduced to me by my brother [name of the brother]. This was in my sort of mid-teens. He was a Madcap, but he was a real countryman and I spent all of my childhood out with him ferreting to earn our pocket money (..). And I adored him, and he introduced me to Genesis, and it was like opening a window on the world for me. (…) I was 18 and he was married and great celebrations and two weeks later he went into hospital and didn't come out and he died aged 23 of a very rare disease*." (Int. 5)
Inspiration	• Motivation • Reinforcing • Energy	Music was described by many interviewees as a means of motivation and inspiration, or as a source of empowerment during significant events in their life.	

Motion	• Movement • Dance • Embodiment	Embodiment of music was present in a few of the interviews, where musical choice was related to the physical effects of music.	*"Speaking of the happiness and the joy and the next record I've chosen is the Weather Girls- it's raining men, and I chose this because it reminds me of the times at medical school when we would dance. Dancing has been a very important part of my enjoyment of my life and this was great fun to dance to."* .(Int. 1)
Social connection	• Professional self • Music as a gift • Music to send a message • Connecting with the world	All of the participants found that at least some of their musical choices had either a very powerful message that they want to send to the world and have with them on the DI, or that the music piece was referring to their social connections. The latter was reported through their professional characteristics and how they placed themselves in the world with their professional identity.	"*Well my second is Pablo Casals playing Bach's first cello suite. It's just one of the most perfect pieces of music, I give this music to people that I care for, I don't know who it was who said that the cello is the voice of the heart. But I think there's no doubt that it is."* (Int.1)
Spirituality	• Resolution • Key to the soul • Faith • Redemption • Forgiveness • Hope	Spirituality was a theme present in the majority of the interviews, regardless of personal religious beliefs.	*"Well I think the last Maria Callas I couldn't just do one song of Maria Callas had to do two and this is a beautiful Puccini opera of Madame Butterfly. It's just it's sad but it's the same time just kind of give you a sense of spirit and hope."* (Int. 3)*"*
Timelessness	• Continuation of life • Is very timely	This theme was presented in some of the interviews as a unique characteristic of music. Music was presented as a constant in the lives of the interviewees, and one which they can always refer to.	*"(...) it fades over time, but Schubert quintet does not fade with time"* (Int 15).

5.5.1 Emotional effect of music

"Emotional effect" was an overarching theme present in all the DIDs interviews. This theme comprised two main categories: the emotions evoked exclusively by listening to their music choices, and emotionally evoked autobiographical memories.

i. Emotions evoked by music

Interviewees described how some of their music choices evoked emotions related purely to the experience of the music itself. Listening to music can trigger different emotions: one can feel happy by listening to a major key piece of music or have a feeling of melancholy when listening to a minor key, a soft piece of music. In DID interviews, some of the castaways' selections were based only on the emotional experience they invoked when listening to a particular music piece. The emotions triggered by these musical choices were very powerful and the castaways wanted to take these discs with them to the desert island for that reason:

"(…) this is the first song I remember listening to on the radio that made me laugh howl with laughter and even now I can't listen to this song and not have a smile on my face." (Int 4, Music: Bernard Cribbins, Right Said Fred).

Emotions perceived by music were described as very unique, and in some cases, interviewees described their admiration for how music, through its simplicity, influenced such a robust emotional experience:

"To me this was sort of like a voyage of discovery because I got the record for some reason from the library and I was amazed that something that was purely instrumental could conjure up that much emotion and it made me cry. And this was probably as I was 15 or angst-ridden teenager but to be able to put a few notes together and invoke emotion like that to me is just amazing" (Int 4, Music: Johann Sebastian Bach, Brandenburg Concerto No2 in F major).

Listening to music can also evoke contrary emotional experiences. In the following excerpt, an interviewee talks about a music piece that touched him to the point of bringing tears to his eyes; in the same sentence, he says that having this music with him on the island would made him feel very happy:

"(…) perfectly beautiful piece that always on the edge of tears every time I hear it, and I will be very very happy to be sitting there enjoying that as part of my experience of being alone" (Int 10, Music: Jeff Buckley, Corpus Christi Carol).

Emotional states were also indicated as a quality of the instruments used in some music choices, as illustrated in the next excerpt:

"(…) there's a sort of weepy guitar in it that I really identify with and just watch out for how he says woman. It's very good" (Int 8, Music: Gerry Rafferty, Right Down the Line).

The "emotional effect" of music as a theme was also described by the interviewees with regards to how it could affect their mood. Listening to music could not only induce an emotional reaction in the listener but could also alleviate peoples' mental and emotional states, ease a challenging feeling, or determine and regulate their emotions, as illustrated by the following excerpts:

Induce positive emotions

"(…) is one of those songs that I hear, and it just brings a sense of calm and peace over me" (Int 4, Music: Leo Delibes, The Flower Duet - from Lakmé).

"It is such a playful piece and I think we're all at our best when we are in slightly more playful and relaxed mode" (Int 5, Music: Bill Conti Glider Pt. 1).

"I mean I think is an extremely good mood setter. It has the key to our soul for some reason (…)" (Int 18, Music: Johann Strauss II, The Overture to Die Fledermaus).

Distraction

Interviewees also talked about how music might act as a distraction when people faced difficult situations:

"(…) be distracted and is to forget about their sorrows and the reason why this song and many others written in these in the 20s and 30s are so persuasive and really pull you into this other world are because people were in misery and needed something to get distracted from" (Int 18, Music: Robert Stolz, Im Traum hast du mir alles erlaubt).

The feeling of freedom and liberty

The feeling of freedom was also described as being induced by some of the music choices. Interviewees reported that some of the musical choices for the desert island evoked feelings of freedom and liberty:

"(…) this wonderful string sequence that sweeps you away and allows you to be lost and it's a beautiful song" (Int 10, Music: Nick Drake, River Man).

"it is a song that represents I think more than anything else the music of my life. It is about liberty it is about freedom it is about breaking out and it is about taking a risk taking thing all the way through" (Int 13, Music: Janis Joplin, Me and Bobby McGee).

ii. Emotional autobiographical memories

The overarching theme, the "emotional effect" of music, had emotions characterizing autobiographical memories as a sub-theme. In this sub-theme, interviewees recalled musical choices that evoked emotions associated with an autobiographical event. These memories differ from the "autobiographical memories" evoked by music, which will be described in section 6.3 (below), due to their emotional intensity.

The music interviewees chose to take with them because of their link to autobiographical memories were defined by vivid and strong emotions. As can be seen in the following excerpt, in describing what music means to her, this interviewee distinguishes between music that make her wants to dance and music that induces emotions. She describes her selection in relation to two autobiographical events: one relates to her profession and the other to her wedding, and she brings these two significant emotional autobiographical events together with the music she chose:

"I think music for me comes into different categories, music that evokes strong emotion in me and music I like to bop to, and when I was up on the mountain I was very isolated and I really missed my husband and that's our song we played it at our wedding. When I hear it, I think of us dancing in the moonlight" (Int 2, Music: Van Morrison, Moondance).

In the eighteen broadcasts analysed here, a very common finding was that almost all interviewees referred to a musical choice associated with a rich emotional autobiographical memory that related to a significant other, such as their siblings, partner or children. Their musical selection helped them to recapture the memory:

"It reminds me of a very happy time where I met someone that was the first proper girlfriend and that was to spend the rest of my life with her and that was it. I asked her to marry me after a week, so it was sort of love at first sight and we are still together. She is part of me all these years" (Int 11, Music: The Rolling Stones, Sympathy for the Devil).

"(…) it brings back to me how being madly in love is wonderful" (Int 15, Music: Franz Schubert, String Quintet in C major, Adagio [2nd movement]).

Interviewees did not only choose music associated with positive and happy emotional autobiographical memories. Interviewees chose to take music with them to the desert island that was meaningful for them and represented an important autobiographical event or period of their life, even when challenging emotions were associated with the autobiographical. These choices and associated autobiographical memories were meaningful and therefore perceived to be an important part of their life history:

"(…) and I used to sing this song (…) quite a lot. And it was at a time when my first marriage was probably starting to fall apart, so it seems very poignant to me. (…) I love its simple directness and I can be a bit soppy as well" (Int 14, Music: Kenny Rogers, Lucille).

iii. Nostalgia

The complex emotion of nostalgia was also very commonly alluded to by interviewees when they were talking about the music they selected, either explicitly using the word nostalgia or referring to their listening experience of the specific music as transporting them to a place or an era in their life. During their recall, they described in much detail the place or the time period

to which they were brought back, but they also described in depth how they were feeling during that period:

"(…) this very much reminds me of my childhood in [my country of origin], and I am bilingual, so he sings in Europe. And I just like the mixture of traditional African drums with the guitar and also the Uruguay language. And this is just pure nostalgia for me" (Int 12, Music: King Sunny Adé, Synchro System).

"It takes me back to an era that I very much enjoyed, watching from the sideliners which was kind of Britpop and my dad being his most sort of anarchic, and although that was painful at the time in retrospect it looked like quite a lot of fun and I was very attracted to songs that paint pictures (…)" (Int 8, Music: Pulp, Common People).

The music that they chose because of its nostalgic quality was meaningful to them due to the recollection, and to the association that they made with elements of their past self, which they wanted to incorporate, and take with them into the future:

"It is just a very simple song. It is a story about going into a garden which is overgrown with ivy and it always reminds me of the cottage, this wonderful place that we were brought up in, the place that was my place of discovery" (Int 10, Music: Kate Bush, Under the Ivy).

5.5.2 Autobiographical memories

"Autobiographical Memories" was the second overarching theme. All the interviewees elected to take musical pieces to the desert island that were linked to or evoked an autobiographical memory. The autobiographical memories under that theme were not emotional in the sense that is described in sub-section 6.2.2 (above). Interviewees' reminiscences through these music choices were either specific autobiographical events from their childhood, adolescence and family, or were linked with autobiographical events related to significant people in their lives, such as family members.

The contrast with the sub-theme "emotional autobiographical memories" is that these "autobiographical memories" are about the sense of self and personal history and do not always have an explicit emotional context; instead, they are purely significant autobiographical events.

i. Childhood

Some interviewees chose a piece of music associated with their childhood; it might evoke an autobiographical memory of a first experience of listening to music, as described in the following excerpts:

"(...) this is the first piece of music I remember thinking. I like that, this was released in 1986, so I don't know if I was six or seven. It just struck me those opening chords Marr's guitar in through it and it is just stayed on me ever since. Whenever I hear it, I have to turn it up and it is it is just an incredible song" (Int 11, Music: The Smiths, The Queen is Dead).

"I was a little boy you know probably about 5 - 6 years old, Walt Disney had this movie about Davy Crockett and I really loved that, and I liked the song" (Int 16, Music: Fess Parker, The Ballad of Davy Crockett).

The recall of these autobiographical memories was very detailed, including the place where events occurred, who was present at those events and the specific sequence of events. As described in Chapter 1, these are the phenomenological characteristics of autobiographical memories. This finding provides support for the idea that music does not only evoke autobiographical memories but also elicits lucid and vivid autobiographical memories, accompanied by many details and the specific recall of its phenomenological characteristics:

"(...) it reminds me of my childhood this song and being in my nan's house some Christmas, with all the family around and after to watch the Queen on the telly going down the British Legion and playing darts and things like that and playing cards for entertainment as a family, it seems that times have changed and it's not like that anymore and Chas & Dave kind of sum up for me a little bit and they're rock royalty and I love them" (Int 11, Music: Chas & Dave, That's What I Like).

"Well my my next choice of record is ah, is a piece of me that means an enormous amount to me. It's James Taylor, Shower the People and I used to listen to this all the time at school. James Taylor's Greatest Hits was our record that we played in the juniors' common room all the time, and my children like him and this is a song which I think really exemplifies everything that I think is important about relationships" (Int 1, Music: James Taylor, Shower the People).

ii. Adolescence

Interviewees in DIDs are asked to choose music that will accompany them in circumstances that are mostly entirely different to their current, everyday life: that of being isolated on a desert island. Interviewees make their choices based on what they would like to take with them during these very unique circumstances. It is often music that they like due to personal preferences, either because of the linked memories, or because of what music represents for them. In the next excerpt, one interviewee wanted to take with him a music piece that he does not like at all; the music is only meaningful because of the autobiographical memory he attaches to it. He describes an autobiographical memory from his adolescence, with rich information about the situation, how he perceived himself and his friends, what outfit he was wearing and how that related to who he was as a teenager. He provides details about the event they went to and how he perceived and felt about it. Even though this music is not something he would like to listen to now as an adult, he chooses it as a result of the associated autobiographical memory and what that memory represents about his image of self, and what he wants to preserve. This autobiographical memory appears to be a significant element in his image of Self, and likewise the music it is linked to:

*"***Int 14:** *I was not at all a cool teenager but some of my friends were and they heard that the Sex Pistols were playing, at Plymouth and I've just got my driving licence and had a car. So, we all piled into the car. I had no idea what to expect, I was probably way* ***impaired****, flared jeans and a roll neck sweater I might even have had a tweed jacket. And we went down to this club Yeah and then there they were Johnny Rotten and Sid Vicious, and all these go going, spitting, you know in the mosh pit the front. It was pretty extraordinary and pretty dreadful music really, I think. But anyway, here we go Sex Pistols, Anarchy in the UK.*

Kirsty Young*: That was the Sex Pistols and Anarchy in the UK. I just looked at you during the playing of that (his name) and I said: You're not loving this are you? You said: No, I'm not really. I brought you back to that maybe"* (Int 14, Music Sex Pistols, Anarchy in the UK).

iii. Family

The musical choices under the theme "Autobiographical Memories" were also associated with significant others in interviewees' lives. In most cases, these were members of their parental

family or the family they later created themselves. Interviewees picked music that was played in their home or a song that was strongly related to the musical preference and background of their parents:

"I mean I was constantly surrounded by music because my, my parents and grandparents they all love classical music, they had a huge collection of LPs and tapes, so the first thing in the morning was to put on some music that was quite heavy stuff also we had Wagner, Shostakovich, Rachmaninoff. So really very intense music let's say, and loud" (Int 18, Music: Licinio Refice, Ombra Di Nube, performer: Claudia Muzio).

"(...) my mum brought this into the house. She did a fashion show for her students every year at (name of a place) and she used to run up and down our living room pretending to be on the catwalk to check the timing for the show" (Int 10, Music: Grace Jones, Walking in the Rain).

"My dad was in a country and western band and that's where this sort of country that tries to expose this kind of music. And yeah, it's a song that brings back a lot of a lot of memories" (Int 17, Music: John Denver, Take Me Home, Country Roads).

Some of the songs or music they selected were connected with the special relationship they had with their family members. This music was part of their bond and the moments they shared during their upbringing. They had discovered something of their Self and their life with these significant others through the music:

"Well, I love Stevie Wonder because it was part of my upbringing with me my three sisters. We used to listen to Stevie Wonder incessantly and I think he was sort of a role model and also his music was just so beautiful and it's something we shared together and talk about what some of the nastiness in the world and wanting to be distant from the world, but Stevie Wonder also pulls me back in because he speaks about love in such a beautiful way all-consuming love, love that has no boundaries. And I think that's wonderful" (Int 2, Music: Stevie Wonder, As).

"Genesis, and Genesis was my first big musical love introduced to me by my brother (name). This was in my sort of mid-teens. (...) And I adored him, and he introduced me to Genesis, and it was like opening a window on the world for me" (Int 5, Music: Genesis, Undertow).

This connection between music and family members appears to be very important to the interviewees; even in cases where they did not themselves have any association between the music and their family, they wanted to take it to the island simply because it represented their

family in some way. In one case, an interviewee had explicitly asked his children which song they thought represented them and had a special meaning for them so that he could take this with him to the island and reminisce about his children when listening to it:

"Well, I have to admit I probably cheated a little bit; I asked my wife and my children. They said: You know what? Probably if you are thinking about us, you should play a Wannabe from the Spice Girls. So, this is about what they were" (Int 16, Music: Spice Girls, Wannabe).

The analysis also found that sometimes choice of music was a tribute to a significant other and the important relationships they had during their lives. Interviewees described how some of the music they selected was "music for (…)", "music about (…)" the people they wanted to remember, or the relationships they wanted to take with them because they were a significant part of their life:

"I actually arranged tickets for my mother to see Pavarotti at the MET in New York and she had a picture taken with them signed. He was her hero, so I think this is a tribute to my mom" (Int 3, Music: Giacomo Puccini, Nessun dorma).

"*It was a wonderful couple of weeks with him and he always remembers this one tape that was played over and over again as we travelled around. So, this is for Australia and my father"* (Int 5, Music: Al Stewart, Lord Grenville).

"I love it so much, but it takes me to all those friends and my sisters who you know have been such a big part of my life" (Int 5, Music: Joan Armatrading, Love and Affection).

This theme can be seen as an example of how the 'reminiscence bump' is present in music linked to autobiographical memories. Almost all the participants when selecting music associated with autobiographical memories, did it with music from their childhood years and early adulthood.

5.5.3 Healing and coping with loss and illness

"Healing and coping with loss and illness" was another overarching theme. Interviewees selected music from periods in their lives in which they had experienced difficulties relating to their own or significant others' mental and physical health.

i. Coping with illness - recovering from an illness

Interviewees talked about specific situations in which they used music to establish communication with a loved one when they were not able to communicate with language due to their physical condition. This finding pertains to Chapter 3 regarding personalised music interventions with people with a dementia diagnosis. In this chapter it illustrates how music could help people without a clinical background to find the lost qualities of communication within music or even use it as a simple, unsophisticated approach when other forms of communication had failed due to the specific symptoms of neurocognitive-related disease. Furthermore, it illustrates the importance of a personally meaningful context; in the case below, music was personalised to the caregiver, helping her to engage with her partner in a different form of communication. In the following excerpt, personalised music is combined with another art form, namely dance, in facilitating communication between the interviewee and her partner who has Parkinson's:

"(…) he was diagnosed with Parkinson's disease for a while we manage really very well indeed but the last ten years of his life it took a grip first of his body and then of his mind. And when this happened he wrote beautiful little cards and letters to me which he would leave on my pillow or leave on the hall table when I came home and when he couldn't write what we did was I would dance with him and we would dance a foxtrot. Then when that could not happen, I started singing my favourite musicals and I would come and say «Good morning! Good morning, the sun soon breakthrough», and he would join in and he never sung in his life before. And from then on, we duet it together until the time of his death. And I think those moments are so precious. They are like jewels, they remain in your mind, so I've chosen this «Hello young lovers» from the King and I, because will bring (name of her husband) back to me and remind me of the way that we used to have these two acts together" (Int 6, Music: Valerie Masterson, Hello Young Lovers).

Music is described by this interviewee as having provided a way to overcome a challenging and difficult experience. The selected piece therefore connects with a challenging period of her life when she was having to re-negotiate her relationship and adapt communication with her partner. At the same time, music brings her loved one back to her, whilst acknowledging the process of recovery.

In this next excerpt, music figuratively signifies both the experience of the difficulty and the relief of recovery:

"(…) I had a period, I was very depressed and anxious and unhappy when I was at [name] University, and I spent a short time in a psychiatric hospital and had psychotherapy for quite a long time afterwards which I found enormously helpful. I think everybody is better of a bit of psychotherapy. When I came out of the hospital I played in a rather self-consciously emotional way this one, of the late Beethoven string quartets which I think Beethoven wrote over Thanksgiving on recovery from a long illness and it's a slow movement of the Opus 132, does a very, very slow fugue conjures up an enormous sense of recovery of life starting again" (Int 15, Music: Ludwig van Beethoven, String Quartet No. 15 in A Minor, Op. 132: III. Molto adagio).

One interviewee referred to a song that was not only linked to her experience of being diagnosed with cancer but had been written specifically for her by her son. However, she then chose a different song as she did not want to bring that particular memory with her to the island:

"[my kids] are songwriters and [my son] wrote the most moving song when I had cancer called Pink Ribbons, which is a very beautiful message of hope. But somehow, I thought on that island I didn't really want to remember that time of having cancer and a bad prognosis. So, in fact I chose a song that both of them had done together called Sunrise (…)" (Int6).

This illustrates very vividly how individualised different people's needs and focus may be in relation to musical choice, and how something that has an effect on one person does not have the same on another.

ii. Loss

Music associated with loss was a challenging finding to analyse. I wondered why people wanted to take music with them to the island that brought back very painful experiences and memories. In these examples, music evokes the memory of a loved who is no longer with them. In this sense, the piece of music is a kind of farewell to that person. At the same time, it is seen as encapsulating all that these people meant to them, as well as keeping the memory of that person alive and present in their lives:

"Yes, this is my dad's lament when my father died. I didn't know what I could do. Also, he was such a wonderful man. I didn't want him forgotten and I was looking for some music we could play at the funeral and I bumped into this track and it was so poignant and so sad. And the first notes come in and they just take me down to a level so when I ever I hear it my heart slows down and I get into a certain place. And the main phrase is «Remember me» and I decided that's the only thing I can really do. Remember my father because he's living on through me" (Int 2, Music: Henry Purcell, When I am laid in earth (Dido's Lament) (from Dido and Aeneas)).

"(…) magical absolutely magical piece of music and I lost my, my lovely dad in March last year. And when we were selecting music for his funeral, I went through his music collection and found the Vespro which I had remembered must have been deep inside me and I love the fact that you've got these two voices calling to each other and responding" (Int 10, Music: Claudio Monteverdi, Vespro Della Beata Verine Gloria Patri).

Castaways selected music that they associated consciously with very strong emotions of loss and grief that they had experienced. They also selected this music because they felt that experience to be a core element of who they were in the present; as evidenced in Section 6.3 above, music can play a central part in such experiences and become intertwined with our sense of self and who we perceive ourselves to be. Thus, even painful experiences of loss and grief become firmly connected to the Self; music becomes a vehicle for preserving this sense of self and taking the music to the desert island signifies a desire to take as much of what their Self used to be before becoming a castaway. In the next excerpt, music becomes a vehicle not just for the preservation of self but of the loved ones that have been lost:

"This song is difficult actually to talk about it. Sometimes I find that you know listening to certain songs can be really helpful to take you back to a certain place and you know I lost a child 3 years ago now, and I just remember leaving the hospital you know empty handed so to speak and driving from my hometown (...) all the way down to (...). And that's the song being on a cd that (name of her husband) was playing and it's in a weird way just a nice song to kind of connect to something in me" (Int 8, Music: Etta James, I'd Rather Go Blind).

This interviewee's account gives a sense of the 'found' nature of some musical memories – the music was not originally selected by her at that moment but somehow fitted and now has that meaningful association.

5.5.4 Inspiration

"Inspiration" was another theme: interviewees spoke about finding inspiration when they listened to a specific piece of music and it being a motivational force. Under this theme, interviewees described how particular pieces of music had given them the strength to either continue to or fulfil their dreams and aims.

i. Motivation- reinforcing

Interviewees talked about how particular pieces of music had encouraged them in key moments in their lives:

"I wanted to be an [athlete], and kind of be an outcast for that, this kind of music gave me confidence to fulfil that really" (Int 11, Music: Ian Dury & the Blockheads, Reasons to be Cheerful Part 3).

They described how they found in music the motivation that they needed but also how they used music as an inspiration and reinforcement for themselves, or to induce inspiration and influence other people during catalytic moments in their life:

"It's unusual. It's a bit of gospel music, and I'm not religious at all. It's called Oh happy day, and this was a real kind of a break glass in case of emergency song, I had my [professional activity] age 26 and if I was feeling down in the dumps, but sort of myself a bit lonely, this was a song that always put a smile on my face and spring in my step" (Int 17, Music: Edwin Hawkins Singers, Oh Happy Day).

"I play it on the first day of the course I have it at top blasters all the students come in and I think they don't know what's hit them because I can tell you I'm not like a normal nursing tutor. I'm really trying to motivate them to be self-sufficient just like I was taught to be because once they're in a resource poor area as nurses they're probably going to be the only medical person for hundreds of miles around" (Int 9, Music: Paul Simon, Call Me Al).

5.5.5 Motion

Another theme that emerged was around the idea of "motion". Under this theme, interviewees described their experience of the embodiment of musical experience through both movement and dance.

i. Movement- dance

Interviewees talked about dancing to music and the importance of expression through physical motion. In some cases, they imagined themselves on the island dancing along to their musical selections. These mental imaginary projections were very vivid and the bodily sense that music evoked was described in rich detail. Dance and movement were present as a function of social engagement, and the experience or imagery projection was reported in a social context, something to share with other people, rather than as a solo activity:

"But Ian Dury was a wonderful singer and I saw him when I was at medical school and I saw him not long before he died, and everybody of a certain age in their jeans and t-shirts just dancing away was fantastic" (Int 1, Music: Ian Dury & The Blockheads, Hit Me With Your Rhythm Stick).

"(…) it's always a trap whenever it comes on, that makes me want to dance and I love to dance! And I am imagining that I might have just eaten, I've got sand between my toes on the island, and what's beautiful about this piece is it is it is got a built-in audience. So, I have got all these people who are in flickering lights of the bonfire helping me enjoy this piece to" (Int 10, Music: Marvin Gaye, Got to Give it Up).

ii. Embodiment

The embodied representation of music was also discussed in DID interviews where people talked about music experienced in a bodily way. They reported how specific music engaged with certain parts of their body, as well as how the music tapped into their physical vitality, and the importance of this in relation to their imagined emotional state on the desert island:

"It gives me butterflies listening to this song because it's takes me back to like a fun happy positive time" (Int 8, Music: The Streets, Blinded by the Lights).

"There's a tremendous energy in this music that always sweeps me along so be really very happy to have this wonderful long twelve-minute track with me on the island" (Int 10, Music: Fela Kuti, Water No Get Enemy).

5.5.6 Social connection

"Social connection" was the next theme generated by the thematic analysis. Music as was described earlier in this chapter, is a means by which people establish and create a connection with others but also with their self, their emotions, autobiographical memories or their goals. There was a strong association between music and different aspects of peoples' life: people connected with specific aspects of their self or their environment through certain pieces of music.

i. Professional self

I chose to include the professional self under this theme because all the interviewees referred to this role either in correlation with others such as their colleagues, or as a function of how their profession placed them in the social world, or how they perceived their profession within the social environment and their interaction with others. I need to note here that the

interviewees on DIDs are a particular sample, and it would be uncommon for these people to not identify as having a career, profession or public persona. Interviewees often selected music that brought actual memories from their work environment but also music that in some way represented their discipline. They associated musical elements and the qualitative characteristics of their choices to corresponding characteristics of their profession, as they perceived them:

"but alongside me were people like [names of colleagues], we used to sort of have great fun but also we used to have the Ferret Song, which was like all morning assembly anthem and it was so ridiculous that I would like that on my island because he would always make me laugh and remember those very exciting as [name of a colleague] would say superb days" (Int 6, Music: John Cleese & the Loving Pruneful, The Ferret Song).

"Is a modern composer who I love, and I think it captures this pure beauty which I see in [my discipline] but in particular this piece Für Alina it's a short enchanted piece of purity which for me is like a representation of the kind of cleanness and the, essential is the characteristic of being essential and simple which is in [my discipline]" (Int 13, Music: Arvo Pärt, Für Alina).

Some people offered metaphors to represent their discipline and in describing their everyday difficulties and challenges, music became part of that metaphor:

"But it's the analogy. Being a [my profession] *is rather like being on a tightrope. Yes, you need frightfully good sense of balance to walk a tightrope. Yes, to be a* [my profession] *you need to be good with your hands. But the really difficult is not looking down is the context. Yes, we could all walk on a narrow strip on the ground but if there's a 100 foot drop below it is a different experience and what really what makes* [my profession] *difficult is not the technicalities of* [my profession] *in which actually after a few years of training is quite easy. It is the seriousness of things if they go wrong. It's a human context"* (Int 15, Music: B.B. King, Better Not Look Down).

ii. Music as a gift

Under this theme, I have included music that interviewees referred to as having been gifted to others or gifted to them. Sometimes the piece of music is referred to as one that they would offer as a gift to significant people in their lives, as well as music that had been gifted at a particular point in time, as in the following excerpt:

"It's just one of the most perfect pieces of music, I give this music to people that I care for, I don't know who it was who said that the cello is the voice of the heart. But I think there's no doubt that it is" (Int 1, Music: Johann Sebastian Bach, Suite for solo Cello No. 1 in G major-Prelude).

As I have illustrated in other themes in this chapter, people use music to express their emotions literally, bodily and in abstract ways; within this theme, music is described as a material object that people exchange as a gift to express their emotions and their connection to others:

"This music was given to me by my mother when I came back from my first mission with the [my profession], and she gave it to me and said, «Here my friends and I, decided this is you»´ and her friends were from her "keep fit" group she did" keep fit" all, all her life right up until the year she died which was when she was 94, and so giggling, they sang this song to me" (Int 9, Music William Thomas Orchestra, The Rose of No Man's Land).

iii. Music to send a message

Under the theme "social connection", music was also discussed in terms of its ability to send a message. Interviewees spoke about the power of music to communicate ideas and to be a global voice for all people. Some pieces were chosen because of that quality: music as carrying and communicating ideas, social meaning and values:

"I love this song because it says you know what you have a voice and don't let anyone ever take that away from you (…) and I love that message" (Int 4, Music: My Chemical Romance, Sing).

iv. Connecting with the world

Interviewees selected music which they described as giving them the feeling of connection with their personal environment and of belonging. As was described earlier in this chapter, people chose music that they had listened to during their adolescence. As well as signalling the importance of music during this specific period of life, reference is made to the process of

finding one's place in the world, creating their social self through connection with certain groups and the qualities they represent.

"(…) first summer I started travelling was about 71', 72' when I started going out West as a junior [profession] and my, my friends and teammates around that time, one of us had Abba cd not cd, tape back then of course, so you felt very international and very made me feel grown up, like we belong because we were cool with the music that was going on out West (…)" (Int 3, ABBA, Dancing Queen).

In addition, the music chosen sometimes includes a human quality; in the following excerpt, it is in the form of the sounds made by the audience:

"(…) it is one that I listened to over and over again because you can hear the crowd and I was on my own [professional activity]. And you can hear people clapping and whistling and there was something magical about that about being transported back to civilization and back to the sort of warm happy human life performance of a great music" (Int 17, Music: Seal, Crazy [Acoustic]).

The interviewee chose the live version of the music because the reaction of the audience is part of what makes this piece meaningful and it is as a co- creation of a new cover of the song, from the performer and the people experiencing the music.

5.5.8 Spirituality

Music choices that fell under the theme of "spirituality" could be divided into three sub-themes: faith and belief; redemption; hope. The association between particular pieces of music and spirituality could be made regardless of whether they chose a religious piece of music or not.

i. Faith- belief

For some interviewees, faith was represented by a specific religion and so they wanted to have music that related explicitly to this religion. Consequently, the piece of music encapsulated explicit meanings that were relevant to the beliefs of the faith group that the interviewee identified with. As with the previous theme, overtly religious music can be thought to represent

one's own connection with a particular group as well as its message to the world. This could be seen as belonging to the sub-theme "connecting with the world". However, the explicit and direct evocation of philosophical interpretations that each religion proposes to their congregants, seemed to require a category of its own. Certainly, it seemed to fulfil a need that was not simply about the need to belong.

In the following excerpt, the chosen quote illustrates both the sub-theme faith-belief and the sub-theme of redemption, which is further illustrated in the following section:

"This is Dare to Believe and actually it is the [religious group], they did a show called Alice based on Alice in Wonderland and it was sung with 300 people on the stage and it's saying that we all can stand up and make a difference just dare to believe you can do it, believe in your dreams and just go for it" (Int 9, Music: SGI choir & Peter Osborn, Dare to Believe).

ii. Redemption

In the following excerpt, the way in which music can evoke spirituality and connection with the higher values in life is described very vividly. People who do not belong to an organised religion nonetheless may express the need to find, establish and describe their moral principles, guided by non -religious rules and concepts. This next excerpt describes how individuals both connect with this need through music while simultaneously addressing this need through eliciting these higher meanings:

"(…) but I like it particularly because I don't have any religious faith. Never did. My parents are both very sincere but very relaxed Christians it was a very important part of their life, but it seems to me when I think about something like Erbarme Dich or Forgive us Oh Lord, you can reach very similar ethical conclusions to Christian ones without having to have God simply applying the Golden Rule of "do as you would be done by" and all of us as [my profession] can think of many occasions when we did not do that. (…) so we all have sort of skeletons in our cupboards and guilty secrets the wish for forgiveness, the need for forgiveness, I think is very deeply rooted in people and you don't have to invoke a sort of fierce Christian God as a source for that.(…) And for me that that music sums it up" (Int 15, Music: Johann Sebastian Bach, Matthäuspassion. Aria: "Erbame dich").

Interviewees also talked about how music could evoke the idea of redemption that they needed as individuals:

"And I heard this on the radio, and I knew then that this sublime was going to give that sense of an old-fashioned world redemption. It is full of the idea of forgiveness and release a true freedom" (Int 6, Music: Charles- François Gounod, Repertir).

iii. Hope

Certain pieces of music were described as eliciting the sense of hope irrespective of the original emotion that might have been "sad". This is another example of how people can find a special meaning in music that may evoke a very different emotion:

"(…) beautiful Puccini opera of Madame Butterfly. It's just it's sad but it's the same time just kind of give you a sense of spirit and hope" (Int3, Music: Giacomo Puccini, Un bel di vedremo).

5.5.9 Timelessness

In many cases, interviewees chose a musical piece because it was characterised by an almost abstract concept of time perception. One way they described this was by referring to how music is unaffected by the passing of time, in contrast with other experiences in their life, such as the experience of certain emotions. They described music as a constant in their life and how through repeated listening, they came to appreciate both the emotional and aesthetic qualities of a particular piece:

"Because it's a music that doesn't start doesn't end, it cannot be exhausted and it's soft and sweet, it would be wonderful to have it on the island" (Int 13, Music: Jerry Garcia, Love Scene).

"(…) it fades over time, but Schubert quintet does not fade with time" (Int 15, Music: Franz Schubert, String Quintet in C major, Adagio [2nd movement]).

In other interpretations, music was described as having the ability to flow and to continue eternally, irrespective of other events in life. Interviewees even drew an analogy between music and life itself, disaffiliated from human limitations:

"Well there is [name of the river] that I grew up on [name of the city], flows into [name of the river] which then flows into [name of the river] which then flows into the Atlantic. So, it's kind of a continuation of life" (Int 3, Music: Bedrich Smetana, Vltava from Ma Vlast-My Homeland).

5.6 Phenomenological discussion of the findings

As described in Chapter 5, having thematically analysed the DIDs broadcasts, I decided to look further into the findings through a phenomenological lens and was fortunate to be able to discuss the findings with a phenomenologist (Marc Applebaum 2019, personal communication, 16 August 2019; 28 October 2019; 20 December 2019). As described in Chapter 5, phenomenology is a philosophical discipline as well as a research approach in psychology that is interested in how individuals experience the specific phenomenon of interest.

In DIDs, interviewees are invited to choose music for a situation in which they will lose their normal everyday life context: *"Of course, being on a desert island means being away from the people you love"* (Int 13). In this further discussion of the findings, I explore whether common psychological meanings can be identified in these choices, and if so, what is the structure that is shared in these meaningful choices of music? When describing the phenomenon in my analysis, I was mindful to refrain from interpreting "why" the interviewees chose specific pieces of music, but to limit myself to observing "how". I focused on defining the phenomenon as something to do with music that is chosen by a person in an imagined situation in which one's life context disappears or changes radically, in the scenario of being a castaway on a desert island.

One of the first findings was that people find their connection with music; in other words, this does not happen passively but is a connection that occurs in the present moment, when actively searching for and describing a meaning, as they recollect and relate with the music in a memorable way. In the paradigm of DIDs there is the factor of choice: the castaways actively and consciously name their choice of music and are actively encouraged to bring to mind a memory, an emotion, a feeling, an image, an idea or a concept. The active aspect of this process

is that music speaks to them about their past lives, but in a way that relates to who they are in the present moment, which involves and includes who they were in the past. In other words, what they are bringing with them with their musical choices encapsulates facts and aspects of their life and self that are important for them now. The way they build this connection with music is not preconceived and is not something that necessarily occurred when they first listened to that piece of music; it happens and is actively found in the interview, through the process of being invited to talk about and explain this choice. In phenomenological terms, the experience of choosing music to take with them to the desert island includes both active and passive elements. Specifically, in terms of Husserl's phenomenology, the passive and active intentionality of finding and making meaning, happens at the same time.

Passive intentionality in the context of these findings is the given meanings that the music already had for them, before they were invited to reflect on it. When they listen to the chosen piece, there is already a felt emotion as was described in the first theme, "emotions evoked by music", where interviewees described evoked feelings such as freedom, being carefree or happiness. When listening to music there are meanings and sentiments that are held in the lived body; when interviewees talked about feeling the music, they actually talked about bodily sensations, as described within the "Embodiment" and "Movement" sub-themes in Chapter 6.

Intentionality becomes active as soon as the interviewee reflects on it, through naming the experience and the state that they were in at the time of the recalled memory or in the here and now. Active intentionality starts from asking the question "If you were to be cast away alone on a desert island, which eight gramophone records would you choose to have with you (..)?".

When the interviewer asks guests to make a choice, their responses are based on how they already feel about the music, which was already in their life, and now that they need to decide which piece of music to take with them, what they associate the piece of music with. In other words, meaning making begins with the naming of the music, through the process of relating

all the emotions and feelings that were already with them in a pre-conceived and a pre-reflective state, and all the meanings they notice in the here and now.

Another observation is that in selecting songs or pieces of music, prospective castaways linked them to many different emotional AMs, including painful and/or difficult ones. During the broadcast, interviewees might express very strong emotions, but interestingly, when they were talking about these emotional autobiographical memories, the emotion they had as they were describing the memory was not the as they had experienced during the autobiographical event itself. In other words, emotions might be transformed into something less challenging through the process of reminiscing. Furthermore, positive aspects can be added to that autobiographical event, without losing its initial emotional quality.

In this regard, I observed that in many interviews, the music chosen related to emotional autobiographical memories that were challenging (although I describe an exception to this in Section 5.5.3). At a superficial level, we might imagine that when people are preparing for an entirely new and different environment like a desert island, they would select music (or in general activities) that linked to positive or less challenging emotions and autobiographical memories of their life, because we might assume that the aim is to be in a positive state in this new environment. But if we go back to the question DID interviewees are asked, we can start to understand the reasons and see a pattern in the way that they frame their answers. How they choose to answer this question partly reveals what is important for them as they imagine facing an unknown environment and a way of life that will be entirely different to life as they have experienced it so far.

Along with the need to physically survive in that environment is the need to find a mental balance; in an isolated environment, this balance can be derived from the self and the sense of identity. I observed that their answers included what they felt was important for them to remember. The AMs they shared were important as a part of their self and their life history to

remember and reflect on. From this perspective, it becomes clear that what is important to recall about the self cannot only be the feel-good events and memories; the challenging memories that are associated with specific pieces of music are also significant elements of their sense of self and encapsulate what really matters to them and what they wish to remain connected to. Furthermore, there may be a strength or confidence in self that is associated with surviving difficulties and overcoming challenges.

Examples of the above can be seen in Section 5.5.1 in the sub-theme "Emotional Autobiographical Memories" as well as "Healing and Coping with Loss". With regards to music intervention in the field of dementia, this finding raises some questions and suggests new approaches to answering these questions, in relation to what the aims of music intervention might be for specific populations. As I discussed further in this chapter, contact with the self can be achieved and even regained through discussions in which the importance of the different evoked emotional memories are acknowledged; rather than focusing solely on positive emotional states, contact with self can be found through evoking challenging emotions. To be in touch with the self is a positively characterised experience, even if this contact is preserved or regained through remembering events that evoke difficult emotions. In other words, the choice of music and the meanings and emotions it evokes connecting to the sense of self is not on a scale of happiness to sadness.

As described earlier, the interviews analysed in this study are very particular in that interviewees are asked to envision a situation where they are castaways on a desert island, in other words, uprooted from their home environment. An important sub-theme that came out of the analysis is an experience that I identified as "Nostalgia", as one of the core meanings of the music chosen. The etymology of the world nostalgia is homesickness, the origin of the word being from the Greek word "nostos" (νόστος), which means return to home, and "algos" (άλγος), which means pain. Nostalgia as described within this sub-theme does not refer so

much to a physical home or environment but much more to past experiences and past qualities of the self. What interviewees seem to want to remember is not so much their present home but an imagined situation. In other words, the meaning of nostalgia in these interviews concerns not only the physical home or empirical environment of the castaways, but also their emotional home, the memorial home of all their lived memories that they want to carry with them to the desert island: *"It takes me back to an era that I very much enjoyed (…)"* (Int8). One interesting finding within this theme of nostalgia is that interviewees explicitly refer to the idealized constitution of past memory, acknowledging that what they actually do when they are being nostalgic is to revive a memory that they want to carry with them to the desert island, taking them back, for example, to an era which they very much enjoyed.

5.7 Chapter Summary

This chapter has focused on the qualitative study, starting with providing a brief history of DIDs broadcast. I discussed some of the ethical considerations regarding the use of online data and described what decisions I took in this regard. I introduced the methodological approaches I used to analyse the data, describing the theoretical framework and defining its characteristics. I then described the sampling method used and the procedure I followed in transcribing and analysing the audio files.

I then presented the of my thematic analysis, organised into eight overarching themes. The findings show how music is present in many if not all aspects of peoples' lives. I illustrated these themes with excerpts from the interviews, providing evidence of how people use music to summon up autobiographical material in the emotional work of coping with the unknown and the unfamiliar.

Chapter 6: Exploratory Focus Group Discussion Study; Practitioners' experiences and perspectives on music interventions for people living with dementia.

Introduction

In this chapter, I present the findings from an exploratory focus group discussion I conducted with practitioners. In the first section, I explain the rationale for the focus group discussion. I then discuss the methodological approach I adopted, the analysis and the focus group data. The thematic analytic framework I used to analyse the data is described before a discussion of the data findings.

6.1 Background and Rationale for the Study

The previous chapter explored how people use personalised music to talk about significant autobiographical memories. The need to further understand practitioners' views came out of the initial findings of my research.

Music interventions in dementia care vary widely in terms of the theoretical framework they draw on, the aim of the intervention and the people who carry out the intervention. As discussed in previous chapters, both music therapy and other music-based interventions can have a broad range of objectives in dementia care, either to improve cognition, memory retrieval or to affect specific symptoms such as depression, anxiety and agitation (Ho *et al.*, 2011; Cuddy *et al.*, 2012; Meilan Garcia *et al.*, 2012; Ing-Randolph, Phillips and Williams, 2015; Jacobsen *et al.*, 2015). Besides behavioural, psychological and psychiatric symptoms, music is used in dementia care to enhance the general quality of life for both the person living with dementia and their caregivers; it can create lines of communication, increase socialization and a sense of belonging within a social environment, and "being part of the world" (Irish *et al.*, 2006; Hara, 2011; McDermott, Orrell and Ridder, 2014).

The use of music in dementia care is not uncommon in clinical settings and there is growing research on the various ways and conditions in which music is beneficial. More specifically, there is ongoing research on the different ways that music interventions are developed, on the aims of different interventions and on who is delivering these interventions. Yet few studies, to our knowledge, explore the views of practitioners from a range of clinical backgrounds on music interventions in dementia care. Only one study (Ekra and Dale, 2020), focused solely on the experience of healthcare practitioners conducting a song and music programme in dementia care in nursing homes. Others, such as McDermott *et al*. (2014), Garrido *et al*. (2021) and Orrell and Ridder (2014), use various research designs, including focus group discussions, to understand the perspectives of people living with dementia, their carers and members of the staff involved in personalised music interventions.

To address this gap I therefore invited practitioners to share their views and experiences of music interventions in a focus group discussion. Practitioners were invited to talk about: the procedure of music interventions; assess the difficulties, if any; and to further discuss their role, how they enact interventions and the use of music in dementia care. In analysing the data, I aimed to explore their insights, to understand music interventions in dementia care from the perspective of the practitioners and what they perceive as being the benefits or barriers of music activities. As such, this part of my study also aimed to contribute to the relatively limited literature and set the grounds for future research on the role of practitioners and professionals in the development and implementation of personalised music based interventions. I use the outcomes from the exploratory focus group discussion to develop a framework to inform the implementation of personalised music interventions. I also provide useful information for future developments and for the evaluation of evidence-based personalised music interventions in dementia care.

6.2 Methodology

6.2.1 Focus Group Discussion

Focus group discussion is a method in qualitative research which encourages a selected group of participants with experience of a specific topic to discuss with each other, to share their experience and perceptions. It is a method that facilitates and encourages discussion between participants (Denzin, 2005). Focus group discussions do not only generate individuals' views but also the shared opinions derived and developed though the "spontaneous dialogue with each other" (McLeod 2001, p. 138).

A focus group discussion can be constituted by a small number of participants in order to allow an in-depth dialogue on the topic. The discussion is facilitated by a moderator (in this instance, the researcher) who uses a topic guide for the discussion to ensure that all topics of interest are covered. One of the benefits of this method are that in-depth insights can be generated in a relatively short time due to the free discussion among the participants (Kamberelis, 2013; O.Nyumba *et al.*, 2018; Wong, 2008).

For this final study of my thesis, I chose the focus group discussion method because of its potential to generate an in-depth response to the topics, through enabling participants to listen to each other's responses and to respond to each other's contributions. In this instance, the topics emerged from the DIDs analysis and from the research reviews presented in the previous chapters. The small size of the focus group was purposely selected, because (i) it was an exploratory focus group aiming to test and discuss the outcomes of the three previous studies included in this thesis, (ii) it would allow the participants to feel more comfortable to discuss their experiences and perspectives (Kamberelis and Dimitriadis, 2005), (iii) it would be easier to recruit professionals and find a common date under the current circumstances (COVID-19).

My hope would be that the discussion would illuminate how experts talk about the mechanisms and processes of therapeutic use of music activities with people who live with dementia. The procedure allowed everyone to share their personal views and the different ways in which they implement music interventions. The group discussion also focused on how they perceive the results in their daily contact and routine with people living with dementia, and on sharing their thoughts regarding what needs to be added or changed in the use of music as an intervention in dementia care.

6.2.2 Focus Group Topic Guide

A topic guide was prepared to ensure that the important topics were covered and this was shared with the participants prior to the focus group date to allow them time to think about the topics. The topic guide derived from the analysis of the Desert Island Discs interviews along with the results of the systematic review "The effects of personalised music on behavioural and psychological symptoms in patients with dementia" (Chapter 3 of this thesis). The main topics introduced to the focus group discussion included: the overall experience of using music as an intervention; the experience of using music to communicate with people living with dementia; possible benefits and difficulties; and their views on the impact of the music intervention on people living with dementia, specifically on sharing memories and expressing feelings (Appendix 11).

6.3 Data collection and considerations of ethics

6.3.1 Ethical considerations

This study received full ethical approval from the Faculty of Medicine and Health Sciences (FMH) Committee of the University of East Anglia (Reference: 2020/21-060) on 5 March 2021

(Appendix 7). A copy of the participant information sheets (PIS), consent forms and the relevant documents for the study submitted to the FMH and Ethics Committee can be found in (Appendices 8 – 12).

i. Confidentiality and anonymity

All identifying information about participants was removed from the data at the point of transcription. Names were replaced with pseudonyms and workplaces were not named but described in broad categories. To ensure the confidentiality of personal data for all the participants, all data from all participants, including third parties and names of places referred to in the focus group notes, and all data forms, were anonymised by replacing real names with pseudonyms.

I maintained participants' confidentiality through secure data management. All participants were also asked to maintain confidentiality of what was discussed in the focus group. In addition, the participants had agreed to the confidentiality of the procedure in the consent form. However, I could not guarantee that participants would maintain confidentiality of what was discussed in the group. This issue was addressed by making it clear to participants in the information sheet and consent form, and again at the beginning of the focus group meeting.
To ensure online safety/ confidentiality, I used Microsoft Teams as a platform for our meetings. The platform is provided by the university through contract with Microsoft which follows all the relevant regulations regarding confidentiality and online safety.

ii. Secure Storage and Management of data

All project data were stored on UEA's secure Research Storage Infrastructure, based on IBM enterprise grade Storage Area Network (SAN) hardware housed in secure, environmentally controlled and monitored data centres. Data were backed up to tape with copies in both data

centres at UEA. Only myself and my two supervisors had access to the data. Any data were transferred through uea.net e-mail and were encrypted.

Regarding the duration of data storage for the various type of the data:

- Personal identified data: consent forms were encrypted and kept until the examination of the PhD and were then erased using commercial software applications designed to remove all data from the storage device.
- Video recording was securely deleted directly after the examination of the PhD.
- The anonymised transcription documents will be stored for the longer applicable period of time (10 years, as advised in Updated_Research_Data_Management_Policy_v1-8), after the end of the study. After the end of this period, all data will be destroyed, paper records will be shredded and recycled, records on a computer hard drive will be erased using commercial software applications designed to remove all data from the storage device.

iii. Right to withdrawal

Any participant had the right to withdraw from the study at any given point, without having to give any reasons for her / his decision. In the case where a participant decided to withdraw from the study, all data collected up to this point were retained in anonymised form to be used in analysis and reporting, and the individuals were informed about this beforehand.

6.3.2 Sampling

i. Participants and sample

A qualitative study was conducted with one focus group consisting of four practitioners with experience of music interventions, who work with people living with dementia in diverse settings such as day-care and the third sector.

Three of the participants were women; one participant was from the UK and the other three were from Greece. The discussion was in English, all the participants were fluent English speakers. They all had university education, and their working experience with music intervention in dementia care ranged from 1 to 15 years. Their professional education was the following: social worker, music therapist, psychologist and actor (Table 10).

The participants in the study were selected using purposive (criterion) sampling (Palinkas *et al*., 2013), with the following criterion: all individuals who were approached would have experience in working with people living with dementia using music interventions. With this sampling strategy, I aimed to draw clear and credible inferences and information from the data. In addition, I aimed to capture both the similarities as well as the differences of participants' characteristics and practices in dementia care, in order to be able to generate new knowledge of the phenomenon. Thus while I aimed for a commonality between the participants, who would all have worked with people with dementia and used music-based interventions, I also aimed for some diversity in terms of settings and professional backgrounds.

ii. Recruitment

Potential participants were recruited through sites I had identified such as organisations and care- homes where they use music with people living with dementia. I had also identified the https://musicalmap.co.uk/, the outcome of a UK campaign (2019), to identify nationwide dementia-friendly musical activities and services. I contacted them either through social media or email. Recruitment methods also included the snowball sampling technique, i.e. participants were asked if they knew someone meeting the criteria and who would be potentially interested in participating in the study.

Each participant was sent the "invitation to the study letter" by email with documents which included the aim and description of the study, the consent form and the topic guide for the focus group meeting. Data were collected by recording the meeting on an online platform

(Microsoft Teams). I sent the invitation letter to the official email addresses and the social media of the sites to distribute to their professional practitioners. I asked the manager to give my contact details to any interested participant; I did not contact them directly via personal email or social media.

The practitioners were contacted directly by email only if they replied to the first invitation email. The gatekeeper's consent was implied if they passed on the information. When the practitioners replied to the first invitation email, I responded through email, attaching research information Participant Information Sheet. I provided full details of the study and the design, including how long they would need to be in the study, the number of sessions, how long each session would last approximately and what the session would include. Once consent was obtained, I collected the demographic details, I sent them an email with focus group topic guide (Appendix 11) and continued the procedure with the arrangements for the focus group meeting.

iii. Method

Data collection included the recording of the online meeting, the automatic generated transcription and note taking. After the introduction, I initiated the discussion within the focus group by using the topic guide to help the discussion and keep it on topic, and to elicit participants' experience and viewpoint. The focus group was facilitated online through the platform Microsoft Teams which allowed people from different countries to be able to participate and therefore brought another dimension of diversity to the discussion. The focus group took place on the 8th of April 2021 and lasted 94 minutes.

iv. Focus group Meeting Video Recording

Best practice for focus groups is to audio record the meeting; usually, a facilitator will take additional notes of who is speaking when. Since the focus group was online because of the Covid -19 pandemic, the only reason for a video recording was to enable correct attribution of individual statements to participants when transcribing the discussion. I did not use the visual

information of the video as additional data. The platform is such that there was no option to audio record only.

6.4 Data Transcription

The initial transcription was automatically generated by Microsoft Teams. I then checked the manuscript while listening to the video recording, to ensure accuracy and made corrections where needed; this step also gave me the opportunity to further familiarize myself with the data. The final transcriptions had a specific format that included the timestamps, speakers' names and comments.

6.5 Data Analysis Process

6.5.1 Thematic Analysis

The analysis involved examining how participants interacted with the topics used to structure the discussion and thus was a priori, thematic. Thematic analysis can be used both deductively and inductively (Braun and Clarke, 2006); in a deductive approach, the starting point of coding and developing the themes is the theory whereas in the inductive approach the analysis is driven by the data (Boyatzis, 1998; Braun and Clarke, 2006). I used a "hybrid" process of inductive and deductive thematic analysis, drawing on Fereday and Muir-Cohrane (2006) who describe it as consisting of five steps: i) researchers consider sampling and design issues; ii) they then develop a template of themes by defining and describing them when identified; iii) the reliability of the template of themes is then tested and validated; iv) the data is summarised and initial themes described; v) the analysis is finalized by confirming and justifying coded themes.

I used a template approach in the form of template of themes (Fereday and Muir-Cochrane, 2006), with the codes and themes identified and reported in the thematic analysis of the "Desert Island Discs" broadcasts, along with the main outcomes of the two systematic reviews (see Chapter 4). The data coding from the focus group meeting led to the development of themes

(Braun *et al.*, 2019). The process of the analysis moved from a detailed description of the data to an interpretation, where patterns from the meanings and descriptions from the semantic level start to materialise into a developing theory. The process of analysis was discussed with the supervisory team and both supervisors reviewed the themes and the codes. In Table 10, I present the template of themes as developed in the previous chapters and begin to develop the analysis of the focus group.

Table 10. Template of themes codebook developed by the analysis of the two systematic reviews and the "DIDs" interviews

	Overarching themes & Sub themes
1.	**Theme**: Reminiscence Bump
2.	**Theme:** Social sharing and the self
3.	**Theme:** Effect on depression, agitation, and anxiety scales
4.	**Theme:** Music evoked autobiographical memories, social sharing, and the self
5.	**Theme:** Nostalgia and emotional AMs
6.	**Theme:** Active connection with the music
7.	**Theme:** Music linked to challenging emotions and AMs

8.	**Theme: Diagnosis** **Sub-Theme:** Differentiate according to the diagnosis

6.6 Results

The findings from the focus group discussion address the following two research objectives:

1. To investigate the views of practitioners on the use of music interventions in the field of dementia.

2. To explore how practitioners perceive the effects of music on people living with dementia.

A total of four professionals participated in one exploratory focus group discussion which was conducted online due to the Covid-19 pandemic. This allowed people from different countries to be able to participate, and therefore brought more diversity to the study. Three of the participants were women; one participant was from the UK and the other three were from Greece. The discussion was in English and all the participants were fluent English speakers. They all had university education, and their working experience with music intervention in dementia care ranged from 1 to 15 years. Their professional education was the following: social worker, music therapist, psychologist and actor (Table 11).

Table 11. Focus Group Practitioners Demographic Characteristics

	Gender	**Profession**	**Site / Organisation**	**Years of Experience**	**First Language**
1.	Female	Music therapist	Charity Trust & Self-employed	45 (10 years with PLwD)	English
2.	Female	Social Worker	Nursing Home	15	Greek
3.	Female	Psychologist	Seniors Care	1	Greek
4.	Male	Actor	Theatre Company	10	Greek

As described, the themes were identified using thematic analysis by a combination of an inductive and deductive approach. The template of themes for the deductive approach was based on the findings from the systematic reviews and the analysis of DIDs interviews. In Table 12, I summarise the identified relationships between the themes that arose in the focus group analysis and the findings and themes identified in the three previous studies.

Table 12. Template showing relationship of themes and codes developed by the analysis of the two systematic reviews and the "DIDs" interviews

Themes developed by initial thematic analysis	**Definition of Themes & sub-themes from Practitioners Focus Group**	
	Top-Down **Themes identified from deductive thematic analysis**	**Bottom- Up** **Themes from inductive analysis**
Theme: Reminiscence Bump	Understand each person's history	Music related to meaningful and great historical events
Theme: Social sharing and the self.	Music as a mode of communication	
Theme: Effect on depression, agitation and anxiety scales.		
Theme: Music evoked autobiographical memories, social sharing, and the self		
Theme: Nostalgia and emotional AMs		
Theme: Active connection with the music		
Theme: Music linked to challenging emotions and AMs	Grief Ceremonial Process emotion	

Theme: Explore more sensitive outcomes for music interventions	Need to find different ways to evaluate the outcomes of music interventions	
Overarching Theme: Diagnosis **Sub-Theme:** Differentiate according to the diagnosis	Diagnosis of a specific type of dementia	Early diagnosis
		Music activities are not suitable for all the people living with dementia
		Music engages language and speech
		Musical skills are preserved
		The importance of practitioners' engagement with (music) interventions

The deductive and inductive analysis of the focus group yielded a total of 10 themes (1) understand each's person history; (2) music as a mode of communication; (3) enable emotions; (4) critically evaluate the methods in which the outcomes of music interventions are measured; (5) importance of differentiation in dementia types diagnosis, (6) musical skills are preserved; (7) music is not suitable for everyone; (8) early diagnosis is important; (9) music engages language; (10) the importance of professionals' engagement with the (music) interventions. These themes, sub-themes and related comments are set out in Table 13.

In the following sections of this chapter, I present each overarching theme and sub-theme in relation to the objectives of the study and illustrate the findings with selected participants quotations.

Table 13. Themes & sub-themes with Illustrative Quotes from exploratory Focus Group discussion

Top-Down **Themes identified from deductive thematic analysis**	**Bottom- Up** **Themes from inductive analysis**	**Illustrative Quotes**
Autobiographical memories/ Professional self Understand each person's history	Music related to meaningful and great historical events	*We were playing recorders together. I was playing the recorder and she was playing the recorder and she was very happy because she was remembering when she was a teacher in primary schools, and she talked about the children. Then she talked about the children she worked with and the music that she did with them and how she was teaching the recorder and how much she enjoyed it"* (Pract. 1) *Through music you can lead the way to you know enrich their lives and their and their unique identity 's and make them choose what they want, like."* (Part. 4) *They have different cultural backgrounds and different historical backgrounds here in Greece. We have been through many, many wars and you know dictatorship and all that,* so when you play music that comes from these periods that there were peaceful their reactions are less than when you are play music from the dictatorship period and the war because they are engraved in their memories. These are important memories (..) and (the music) bringing, evoking these memories back up. (Pract. 4) *They go in a care home, and they play songs from the old Athens and all that you know old times and all that, but they don't really know what these people really liked (…) So this is a very you know very important when working with music in the background is very, very, very important because we can easily go and say they really like this, but they actually don't.* (Pract. 4)
Music as a mode of Communication		*"She's very young, too, and she was she was a professor, she was (…) now she cannot communicate at all, except with music"* (Pract. 3) *(music) is what gives them their emotional and social well-being really and helps them to develop, so that just as important for babies and carers as it is for the elderly and their relationships. So you can see the importance of music as a as a mode of communication. (Pract. 2)* *So, I believe a music is as strong link towards communication and I really like that.* (Pract. 4)
Enable Emotions Grief Ceremonial		*the music therapist came, mum's cat had died. That morning, she discovered that her cat that she had for 15 years had died. So, the music therapist was very skilled. She got playing a piano duet with mum and they sang a song together about how mom loved the cat about how the cat was her*

Process emotion		*companion, and her friend and her partner, she always used to talk about her cat being her partner. because my dad died 30 years ago you know before, and I think that really helped her to express her feelings about the cat and it was very lucky that the the musician was there, she was there on the day that the cat had to be buried. They played Chopin 's funeral March while they took the cat buried in the garden.* (Pract. 1)
Diagnosis of a specific type of dementia		*(…) if you specifically know also the type of dementia like frontal, temporal and the type and there are many (types of dementia), and then you can, you can see which parts of the brain are affected so specific types of memories are affected (…)* (Pract.4)
Need to find different ways to evaluate the outcomes of music interventions		*(…) maybe only with a small facial expression or a finger that moves so this is a reaction and then it's our work to try to find and keep working with them and try to categorize if this reaction was a laugh or something else or something different, so we are looking towards their faces facial expressions are totally different language itself and we have to pay attention to this.* (Pract. 4)
	Early diagnosis	*I'd like to add that it is very important from what we all said, that we have an early diagnosis because with an early diagnosis, especially individually you can help more (…) because an early diagnosis is directly linked to the advanced care planning so everything goes as smoothly as possible and not wait like 10 years for the symptoms to be unbearable, have a diagnosis is very, very important, and then the social worker and the relative have all the clues there, so they can combine music as an intervention more effectively."* (Pract. 4)
	Music activities are not suitable for all the people living with dementia	I wanted to share that it was a lady that came here 3 days ago. She was new at the room with two other ladies, and I had the small musical instrument, and we always play with the other two and they were sing, and they really like it. This vibe was very confusing for her. It's the first time that I saw that, and even if she knew the songs we were singing. She didn't like it and she complained, and I think she was very upset (Pract. 3)
	Music engages language and speech	*As I said he doesn't speak, he almost doesn't speak. I don't know if he uses more than five words, during daytime, but when he listens to certain songs that I find he sings, I try to find what triggers him* (Pract. 3)
	Musical skills are preserved	*You know, she couldn't read a book, but she could read the music and play the piano, so she played for about two hours.* (Part. 1)
	The importance of practitioners' engagement with (music) interventions	*(..) among the many different programs that I tried to organize here, painting, cinema, stories. I mean, yeah, among this range, I think that the music program is their favourite. And I think that this says something about me as well, because this(music) is my favourite.* (Pract. 2)

Figure 3 illustrates the two different categories of the themes according to the deductive and inductive process of the analysis. The deductive procedure led to the themes that are represented in the outer circle; these themes verified the findings presented in Chapters 2, 3 and 5. The inner circle presents themes derived from the inductive thematic analysis of the exploratory focus group discussion.

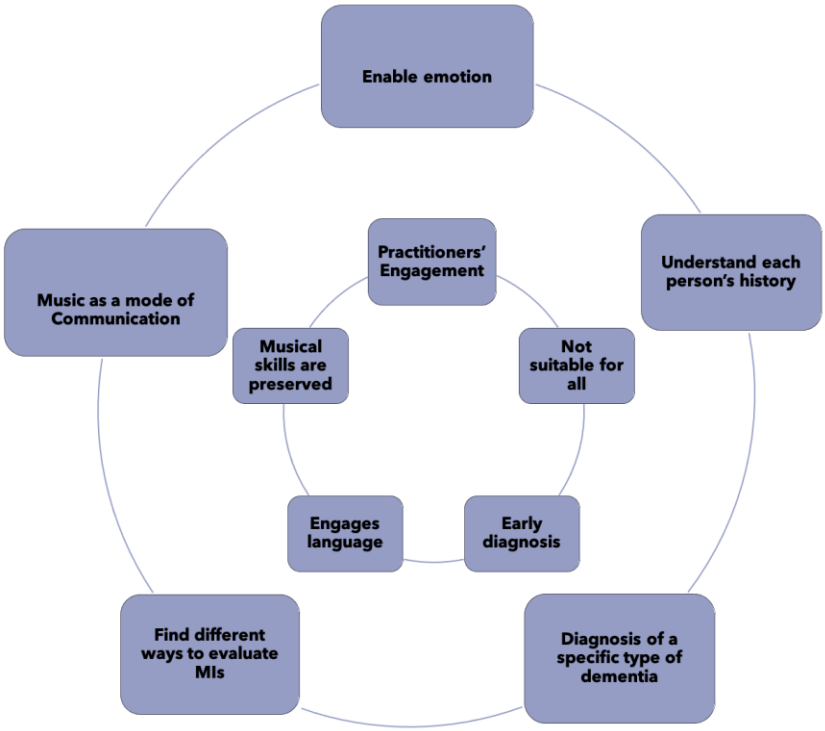

Figure 3. Themes from the Exploratory Focus Group Discussion. The Outer Circle represent the themes derived from the deductive thematic analysis; the Inner Circle present the themes following the inductive thematic analysis.

6.6.1 Understand each person's history/ music related to meaningful and great historical events

Participants described the importance of understanding each person's history; they recalled paradigms of how music is used in care settings. Participants shared their views on how generic music can be sometimes just based on a specific time period, without taking into consideration peoples' personal choices. In addition, they discussed how music in care settings can be a

reflection of the carers' opinions and tastes, which might limit the results of music interventions or even have the opposite results that clinicians are aiming for.

They go in a care home, and they play songs from the old Athens and all that you know old times and all that, but they don't really know what these people really liked (…) So this is a very you know very important when working with music in the background is very, very, very important because we can easily go and say they really like this, but they actually don't (Pract. 4).

The importance of personal selected music is linked to the connection of the self and the different roles people have during their life, such as their professional identity. The focus group discussion identified the importance of this connection. Participants described how this was used in their work with people living with dementia. In the following excerpt, one of the participants shares their experience, describing how it was the playing of an instrument that initiated the interaction and the sharing of memory.

We were playing recorders together. I was playing the recorder and she was playing the recorder and she was very happy because she was remembering when she was a teacher in primary schools, and she talked about the children. Then she talked about the children she worked with and the music that she did with them and how she was teaching the recorder and how much she enjoyed it (Pract. 1).

Their emphasis on personally selected music from people living with dementia was further explained when they talked about how music can also link to cultural backgrounds and important historical events. They described a correlation between evoked memories with music which is related to conflict events and periods, and how this music seems to enhance the connection with the person's history because of the significance of the memories. They discussed the importance of connecting life history with great historical events and described occasions where they found this connection to be very relevant during their work, as illustrated in the next excerpt.

They have different cultural backgrounds and different historical backgrounds here in Greece. We have been through many, many wars and you know dictatorship and all that, so when you play music that comes from these periods that there were peaceful their reactions are less than

when you are play music from the dictatorship period and the war because they are engraved in their memories. These are important memories (..) and (the music) bringing, evoking these memories back up (Pract. 4).

6.6.2 Music as a mode of communication

One theme to emerge strongly from the focus group discussion is how music engages communication. All the participants explained how music facilitates communication and this factor was identified as crucial in their work with people living with dementia. The word 'communication' was repeatedly and explicitly used in the discussion in the context of patients being more responsive to music stimulus during their interaction, or just as a word to describe their opinion of what music means to them. Developing relationships and communication with people living with dementia was indicated by peoples' bodily responsiveness, with gestures or facial expressions or even by humming a song.

She's very young, too, and she was she was a professor, she was (…) now she cannot communicate at all, except with music (Pract. 3).

Participants used example of infants to explain how music can replace the lack of language skills: they described how carers communicate and establish connection with infants through music and a baby's' reaction to singing.

(music) is what gives them their emotional and social well-being really and helps them to develop, so that just as important for babies and carers as it is for the elderly and their relationships. So you can see the importance of music as a as a mode of communication (Pract. 2).

6.6.3 Enables emotions

Participants frequently commented on how music enables people living with dementia to express their emotions. In the following quote, one of the practitioners shared with the group a personal experience with her mother who had dementia.

The music therapist came, mum's cat had died. That morning, she discovered that her cat that she had for 15 years had died. So, the music therapist was very skilled. She got playing a piano duet with mum and they sang a song together about how mom loved the cat about how the cat was her companion, and her friend and her partner, she always used to talk about her cat being her partner. Because my dad died 30 years ago you know before, and I think that really helped her to express her feelings about the cat and it was very lucky that the the musician was there, she was there on the day that the cat had to be buried. They played Chopin 's funeral March while they took the cat to be buried in the garden. (Pract. 1).

In the above quote, music is described as creating a safe space for people living with dementia to connect with and express their emotions in a constructive and creative way. It also highlights how music can facilitate the sharing of emotions, especially difficult emotions that in other circumstances might evoke stress.

Their examples signify how music can be a powerful medium to safely connect people with their emotions, not necessarily only emotions that they might be experiencing in the present moment but also those related to significant events and memories from their past. This can be seen in the above quote from Practitioner 4 when referring to how people would connect with songs linked to periods of conflict. The discussion with practitioners affirmed the value of music even if it evokes difficult emotional memories, because it enables connection with the self.

6.6.4 Reconsider how we evaluate the outcomes of music interventions

Practitioners discussed how music intervention outcomes are evaluated by measurements and scales. While they did not underestimate the value of current assessment approaches, they were keen to discuss their limitations. Their concern was that such assessments might not capture valuable information about the results of the intervention, due to the focus on more negative symptoms and the generality of the questions. They agreed that attention needed to be paid to body language, physical responses and facial expressions and voiced the need to evaluate participant reactions individually in addition to standardised outcome measurements. From

their experience, these reactions can be more informative in terms of the effects of the music interventions. To successfully evaluate the behavioural responses of participants, the person evaluating needs to know the patient well; furthermore, attention needs to be paid to the interactions during the interventions. This can also apply when participants cannot express their responses through other modes of communication:

(…) maybe only with a small facial expression or a finger that moves so this is a reaction and then it's our work to try to find and keep working with them and try to categorize if this reaction was a laugh or something else or something different, so we are looking towards their faces facial expressions are totally different language itself and we have to pay attention to this (Pract. 4).

6.6.5 The impact of early diagnosis and the different types of dementia in personalised music interventions

One practitioner shared her opinion on the importance of differentiating between diagnoses of dementia:

(…) if you specifically know also the type of dementia like frontal, temporal and the type and there are many (types of dementia), and then you can, you can see which parts of the brain are affected so specific types of memories are affected (…) (Pract.4).

Another practitioner talked about the positive impact of early diagnosis when designing and implementing a personalised music intervention:

I'd like to add that it is very important from what we all said, that we have an early diagnosis because an early diagnosis, especially individually you can help more (…) because an early diagnosis is directly linked to the advanced care planning so everything goes as smoothly as possible and not wait like 10 years for the symptoms to be unbearable, have a diagnosis is very, very important, and then the social worker with the relative have all all the clues there, so they can combine music as an intervention more effectively (Pract. 3).

6.6.6 Musical skills are preserved

Participants concurred that in most cases music interventions have a positive general effect and there was discussion as to why this might be. They talked about working with people living

with dementia who had musical skills and noticing that these skills are preserved even when other cognitive functions have been heavily affected:

You know, she couldn't read a book, but she could read the music and play the piano, so she played for about two hours (Pract. 1).

6.7.7 Music engages language

In the same vein, practitioners identified that music is a stimulus which can engage cognitive functions such as language. They described cases where people exhibited difficulties with speech language and yet were able to sing the lyrics of certain songs:

As I said he doesn't speak, he almost doesn't speak. I don't know if he uses more than five words, during daytime, but when he listens to certain songs that I find he sings, I try to find what triggers him (Pract. 3).

This theme not only illustrates how music can engage language but how meaningful personalised music can facilitate the retrieval of lyrics.

6.6.8 Music is not suitable for everyone

One practitioner highlighted the importance of evaluating if music is suitable for the individual living with dementia. She shared an experience with one resident in a care home who was very upset by the music activity. Though the other practitioners had no similar experience, they discussed the importance of getting to know peoples' individual needs. They agreed that the focus needs to be not on the tools and interventions the practitioner is comfortable with but on exploring with the individual what will work for them and adjust the plan of care accordingly.

I wanted to share that it was a lady that came here three days ago. She was new in the room with two other ladies, and I had the small musical instrument, and we always play with the other two and they would sin, and they really like it. This vibe was very confusing for her. It's the first time that I saw that, and even if she knew the songs we were singing. She didn't like it and she complained, and I think she was very upset (Pract. 3).

We have to note in this quote, that the music was selected by the practitioner, and the confusion could have been a result of this; nevertheless, it is important to evaluate each reaction individually.

6.6.9 The importance of professionals' engagement with the (music) interventions

The last theme to emerge from the focus group discussion was the professionals' engagement with the interventions they use. Each practitioner had a special connection with music; almost all of them were musicians themselves and either sang or played an instrument. Apart from one practitioner who solely used music in her work with people living with dementia, the rest used other kinds of interventions as well or worked with people living with dementia and their carers in other aspects of their care. However, they all expressed a preference for interventions with music. Acknowledging their preference for music, they also concluded that the engagement of the practitioner who implemented the intervention was crucial for the "success" of a care plan.

(..) among the many different programs that I tried to organize here, painting, cinema, stories. I mean, yeah, among this range, I think that the music program is their favourite. And I think that this says something about me as well, because this(music) is my favourite (Pract. 2).

6.7 Discussion of key findings

The exploratory focus group discussion aimed to further understand the theoretical framework of music interventions in dementia care. The discussion had a topic guide formed by the three previous studies presented in this thesis: the two systematic reviews and the thematic analysis of DIDs interviews.

One of the main themes was "music related to meaningful events and great events". The importance of using personalised, meaningful music that is personal and meaningful to the person with dementia rather than general music based on time periods or the preferences and

choices of the clinicians or carers, is a key finding. Practitioners concurred that personalised, meaningful music has a distinctive effect on people living with dementia. They talked about how background music might not have any effect or even how music selected by others could cause confusion. Even though music might generally have a positive impact, it is important to understand an individual's needs and to provide person-centred interventions.

"Music as a mode of communication" was the second theme in the analysis. Music might facilitate communication, enable discussion and allow people to share their life narratives. Music helps people to narrate important events of their life which connect with their self and the different roles they have had in their life, such as their profession or being parents or partners. Practitioners mainly referred to active music listening or playing. Practitioners talked about how they used music to initiate conversations and establish relationships. They described how during music activities, people responded with gestures or by humming.

The social interaction in these activities was a dynamic one: people shared in the moment, enabling the expression of emotions as well as the sharing of self-defining autobiographical memories. Music was the cue to the spontaneous recall of autobiographical events, and it facilitated their narration. This procedure connected with their self, and the meaning was given at the moment of this interaction. The active process of sharing meaningful music seems to be the key component for people with dementia to recall meaningful autobiographical events. It is a process that appears to result in the re-establishment of the self and the experience of belonging in their environment. This might have a direct effect on quality of life as well as on the symptoms of depression and anxiety, as presented in Chapter 3.

The findings of the focus group illustrate the impact of music on the expression of emotions, especially emotions connected to difficult experiences such as loss. Participating in music activities might offer a safe space in which to express such emotions in a structured way, and to acknowledge their emotions in a creative and structured expression with music. This

procedure might be very helpful for people living with dementia, especially in cases of wandering or periods of agitation.

Within the theme, "Early diagnosis and differentiation of dementia type", practitioners talked about the importance of an early diagnosis to be able to develop a care plan with the person living with dementia, including designing a personalised music intervention by selecting their own music. They also referred to the diagnosis of dementia types and how this can inform person-centred music interventions.

Assessments and the evaluation of music activities and interventions with people living with dementia was also an important professional concern. Practitioners talked about the limitations of the current assessments. Individual reactions might not be able to be evaluated in a scale system and crucially, current assessments were not designed to evaluate non-verbal communication or individual differences.

6.8 Chapter summary

In this chapter, I have presented the findings from the qualitative focus group I conducted with practitioners of music interventions with people with dementia. I explained why I chose to conduct a focus group and explained my approach to analysing this data, describing the theoretical framework and defining its characteristics.

I then presented the findings of the thematic analysis, organised into ten overarching themes following a deductive (five themes) and an inductive (five themes) approach. The findings describe the effects and limitations of music interventions as discussed by practitioners, their views and concerns regarding how to improve their practices and the evaluated methods. In summary, their perspectives provided more evidence of how music is linked with personal history and meaningful historical events, how it enables communication and the high positive impact of personalised music in emotional expression.

Chapter 7: Discussion

Introduction

The purpose of this study was to develop a deeper understanding of how personalised music can engage autobiographical memory functioning. In addition, I aimed to conceptualize the mechanisms of autobiographical memory in sharing personal events with music in the context of approaches to dementia care. Consequently, my PhD thesis has explored what core processes in the autobiographical memory system are involved in sharing personally meaningful choices of music. In light of the understanding of the autobiographical memory system in people with dementia, it has discussed how music can be used to represent and support a sense of self, and how this knowledge might be applied in the design and applications of interventions with music for people with a dementia diagnosis.

The methods I used to achieve these aims were two systematic reviews, a qualitative analysis of DIDs broadcasts and an exploratory focus group discussion study with practitioners who use music interventions in dementia care. In this chapter, I review and discuss the key findings in relation to the current literature and reflect on the study's limitations. I conclude by presenting this thesis's contribution and future implementations of the findings to personalised music interventions and research in the field of dementia.

7.1 Summary of key findings in the systematic reviews

As reported in Chapter 4, the two systematic reviews explored the function of autobiographical memory in different types of dementia and the effects of personalised music intervention in psychological and behavioural symptoms in dementia, respectively. 28 studies were included in the first review: the findings identified the main differences among sub-types of dementia in relation to memory, namely, the temporal gradient effect and the over-generality of recalled memories. People with AD and vascular dementia diagnosis recall better AMs from their

childhood and early adulthood (time periods included in the reminiscence bump) compared to AMs from the recent past (last five years), and when compared to people with a diagnosis of FTD and SD. People with SD recall non-specific memories across the entire life span, with no distinction between remote memories and memories from their recent past, compared to other dementia types. Reminiscence bump of AM is present in AD participants and in participants with a diagnosis of mild SD. Lastly, people with FTD show significant impairment in the semantic details of remote memories.

The findings from the 30 studies of the second review showed that personalised music has a positive effect on depression, agitation and anxiety scales, although the effect did not last beyond the end of the interventions in the majority of the studies. The second review also indicated an absence of correlation between the different dementia diagnoses and the effect of the interventions. Finally, the effect on these scales and on QOL scales is more significant for active personalised music interventions, either active listening or group personalised interventions, compared to the passive listening of personalised music with no interaction. This indicates the importance of the process of sharing. This finding led me to identify this area as in need of further investigation to explore and better understand the process and the psychological elements of sharing personally meaningful music in supporting and presenting a sense of self.

To further understand this process, I carried out a qualitative analysis of DIDs broadcasts, comprising 18 interviewees of the popular show presented by Kirsty Young. Thematic analysis of the transcribed broadcasts generated and synthesised eight over-arching themes: (1) Emotional effect, (2) Autobiographical memories, (3) Healing, (4) Inspiration, (5) Motion, (6) Social connection, (7) Spirituality, (8) Timelessness.

To explore the findings of the two reviews and DIDs analysis in relation to dementia care and inform the theoretical framework for the design of personalised music interventions, I invited

practitioners to participate in an exploratory focus group discussion to talk about their experience when using music interventions in dementia care. For the analysis, I followed a thematic methodology. I implemented both an inductive and deductive approach, utilising a template of themes, based on the findings of the DIDs analysis and the systematic reviews. The analysis synthesised 10 themes: (1) understand each's person history; (2) music as a mode of communication; (3) enable emotions; (4) critically evaluate the methods in which the outcomes of music interventions are measured; (5) importance of differentiation in dementia types diagnosis, (6) musical skills are preserved; (7) music is not suitable for everyone; (8) early diagnosis is important; (9) music engages language; (10) the importance of professionals' engagement with the (music) interventions.

7.2 Discussion of the key findings

7.2.1 Music and emotion

Emotions and their association with music make up a considerable body of literature and research in the field. Scholars have explored emotions through music from many different points of view, such as the emotions experienced during performing music as a musician (Lamont, 2012) or when listening to music (Scherer and Coutinho, 2013). In addition, research has focused on the perceived emotions expressed in music and the correlation with emotional theories and other factors such as cultural differences (Juslin, 2013; van der Schyff and Schiavio, 2017; Cowen *et al.*, 2020). With regards to listening to music, researchers have explored the emotions induced by trying to understand the effect of music on specific emotional components such as subjective feeling, valence, physiological response or arousal, expression and regulation (Sloboda and O'Neill, 2001; Coutinho and Cangelosi, 2011; Juslin *et al.*, 2008; Zentner, Grandjean and Scherer, 2008).

In the analysis of DIDs, interviewees referred to all these components; they described how intensely they experienced the evoked emotions linked to their personalised music choices and whether these co-existed with physical arousal, as to be subjectively perceived by them. Pereira *et al*. (2011) investigated the effect of familiarity of music on the activation of emotion-related regions of the brain, comparing this both to unfamiliar music and aesthetic preferences in music. The results showed that music preference had no significant effect on the activation of related brain areas. On the other hand, familiar music did generate activation of emotions associated with brain areas, irrespective of whether the participants liked or disliked the music (Pereira *et al.*, 2011). The authors of this study explained this finding in terms of the influence of popularity as a proxy for familiarity with a particular piece of music and how this can affect the listener's emotional response, regardless of personal preference.

A further interpretation, supported by the analysis of DIDs interviews, would highlight the autobiographical influence on emotional experiences of music. For example, one of the DIDs interviewees made a selection based on an associated AM and not based on a personal aesthetic musical preference. When I highlighted this finding in Chapter 5, I referred to what that memory represented and how it related to personal meaningfulness and the sense of self in terms of what piece of music the DID guest chose. Even though there is no direct association with emotions in this particular example, there is a very rich and vivid recall of the event. This finding provides support for the idea that music does not only evoke AMs but also elicits lucid and realistic ones, with many details and great specificity. Research on emotions in music brings together evidence from many different disciplines, such as psychology, medicine, sociology and education, where researchers explore how music effects or regulates emotions, as well as how and what types of emotions are evoked by music (Blais-Rochette and Miranda, 2016).

In terms of behavioural, psychological symptoms and QOL outcomes, findings from the two reviews (see Chapter 4) were that active personalised music interventions had a greater effect compared to passive ones which do not include interaction with others. One argument is that it is the process of sharing personalised music that seems to be the key component in terms of recalling AMs for people with dementia. In turn, this results in the re-establishment of self and the experience of belonging in their environment; the interaction that occurs in the process of sharing may also have positive effect on psychological and behavioural symptoms and QOL.

Alea and Bluck (2003) proposed a model of the social functions of AM where they also described the characteristics of sharing AMs, according to recalled details and the vividness and emotional intensity of the memories. In their model they explored sharing in relation to the personal characteristics of the people sharing their AMs as well as factors in the process of sharing AMs related to the listeners. These factors, described in Chapter 4 in relation to the narration of life history and the effect of sharing music-evoked AMs, can be summarised in the form of two questions: how familiar is the listener with the speaker?; how responsive are they during the interaction and sharing (Alea and Bluck, 2003).

Understanding the correlation between emotions and music has also been a focus of interest in research on promoting well- being, disease prevention and interventions for vulnerable groups or groups of people with a diagnosis of mental or physical health disorder. For example, Blais-Rochette and Miranda (2016) investigated the variables of emotional regulation in music-evoked AMs in young adults as a prediction of mental health; their findings suggest that music-evoked AMs arbitrate between emotion regulation and mental health. More specifically, they found that the social sharing of music-evoked autobiographical memories among participants who tended “to refrain from suppressing their emotions”, had an effect on their emotional regulation, which in turn could have a positive effect on their mental health.

The findings from the focus group discussion with practitioners (Chapter 6) showed that music interventions enable the expression of emotions and might provide a safe environment in which to express difficult emotions such as grief. Practitioners shared paradigms from their clinical and personal experiences where music was used to support the expression of feelings. They also talked about how they identified non-verbal changes in the mood of their participants during music activities, such as laughter or positive changes in their facial expressions. Similar findings were also reported by a focus group study by Garrido and colleagues where therapists reported how music positively affected participants' emotional state (Garrido *et al.*, 2021). Emotional expression and emotional engagement with music was also described in another focus group study (McDermott, Orrel and Ridder, 2014) which reported that participation in music activities was an emotional experience for people living with dementia. The expression of emotions during music activities can also facilitate the engagement of people living with dementia with their environment and practitioners. In many cases, therapists expressed their surprise when they witnessed emotional reactions during music interventions (McDermott, Orrell and Ridder, 2014; Ekra and Dale, 2020).

7.2.2 Nostalgia and emotional autobiographical memories

As demonstrated in Chapter 5, nostalgia frequently featured as a sub-theme in the DID interviews. Nostalgia is a complex emotion involving a longing for a past event or experience (Sedikides, Wildschut and Gaertner, 2008). Studies have presented nostalgia as an emotional process in which people find a sense of meaning, one which has a positive effect on mood, as well as on self-esteem, and which promotes a sense of belonging to a social environment (Routledge *et al.*, 2012; Routledge *et al.*, 2011). The complex emotion of nostalgia was also very commonly described by DID interviewees either explicitly using the word nostalgia or by referring to their listening experience of a specific piece of music as transporting them to a place or an era in their life.

An exploratory questionnaire focusing on emotions induced in non-experts music listeners, participants identified nostalgia as among the most experienced emotions (Juslin and Laukka, 2004). Studies investigating emotional experience as elicited by music report nostalgia as among the most common emotion (Jakubowski and Ghosh, 2019; Zentner, Grandjean and Scherer, 2008). Furthermore, a study on emotions in music-evoked AMs, found nostalgia to be the third most commonly cited emotion (Janata, Tomic and Rakowski, 2007). In a study by Juslin *et al.* (2008) comparing most frequently experienced emotions in a situation where there was music compared to a situation where there was no music, participants self- reported nostalgia as among the most common emotions. In an evaluation of how nostalgic participants felt when they were listening to popular music, Barrett *et al.*, (2010) found a greater association with the emotion of nostalgia when the music had autobiographical associations or/and was familiar to the listener. Similarly, the interviewees in DIDs described the recalled event in great detail, including detailed description of the place or the time period to which they were brought back. They also described in depth how they were feeling during that period and the desire to relive that emotional experience.

In order to understand what the function of nostalgia is, what triggers it and what is its content, Wildschut *et al.* (2006) carried out a qualitative analysis on autobiographical narratives. A trigger for nostalgia was found to be to refine their mood and also social connection. Regarding the function of nostalgia, the findings point towards social connection and the establishing of social bonding, along with increasing one's sense of self; an additional function of nostalgia is to create a positive emotional state (Wildschut *et al.*, 2006). In terms of content, the study found that the narratives did not only include happy or positive events and experiences; indeed, most of the narratives contained challenging events. Interestingly, even when what people focused on in the narratives was not positive, their emotions were less negative and had a mainly positive complexion at the moment of nostalgic narration (Wildschut *et al.*, 2006). Similarly,

DID interviewees often chose music because of its nostalgic quality and because it was meaningful to them due to the recollection, not because of the positive emotions of these events. The interviewees during this recollection made a strong association with elements of their past self which they wanted to incorporate, and to take with them into the future.

In their study of the effect of nostalgia in people with a dementia diagnosis, Ismail and colleagues(2018) not only investigated the psychological and mnemonic effects of nostalgia but whether people in the nostalgia group experienced higher psychological distress because they recalled more "self-referent" and "dementia-related statements drawing on a study by Cheston and colleagues (2018) that explored "Mnemic neglect for dementia information in people with mild dementia*"* (p.1065). The study generated statements related to the dementia diagnosis and categorised them from high and to low negativity and then divided these statements according to whether they referred to the self or to another person (using a neutral name) (Cheston *et al.*, 2018). Ismail and colleagues used these statements to explore if nostalgia had a negative effect in triggering distress in the participants. The results showed that this was not the case: people who recalled and recognised more dementia-related statements because of the nostalgia did not experience higher psychological distress; indeed, recall and recognition regardless of the memory involved, correlated with higher positive affect (Ismail *et al.*, 2018).

Nostalgia, along with the challenging emotional AMs, might represent important resources for sustaining the sense of self and enabling self-construction and continuity over time. As seen in the study by Wildschut *et al.* (2006), peoples' life histories are not only populated by happy autobiographical memories and events but what is important is the preservation of meaningful autobiographical memories that might represent important aspects of the self. In their study interviewees often selected music that was associated with memories of illness or loss and therefore with challenging emotions (Wildschut *et al.*, 2006).

In the DIDs paradigm, interviewees presented their music selections as meaningful to them in various ways: in terms of their association with important people in their lives; events and parts of their selves to take with them to the unknown environment of a desert island. We might imagine that if someone was going to be on a desert island all by themselves with no social interaction, that they would prefer to take music that would evoke only happy emotions and AMs. The research into nostalgia suggests otherwise. It suggests that what is important is the association with self-defining memories, irrespective of the emotional valence. This could also be correlated with the effects of personalised music interventions in dementia care: the behavioural and psychological symptoms could be a projection of the AM decline and the difficulties people experience to feel connected with their self, due to that decline.

In clinical interventions with vulnerable populations, many programmes aiming to improve the quality of life, well-being or psychological and behavioural symptoms of the participants, do so by designing and aiming to create an overall positive environment, excluding anything that might have a challenging effect on participants' emotions. I would argue that my findings related to nostalgia (based on the DIDs study) and on emotional expression (based on the focus group discussion) suggest otherwise. One implication for interventions that are not simply aimed at relaxation or at assisting the daily activities of participants, is that music needs to be personalised and meaningful for each individual if it is to facilitate the re-construction of the self. Only the participants themselves can answer the question "for who might this be challenging'? Perhaps people who deliver such interventions in their clinical practice need to be further educated in order to accommodate the appropriate circumstances for everyone to express and be connected with their self, rather than just focusing on creating a temporary happy environment. Within this framework, music can be used to evoke emotional AMs and the complex emotion of nostalgia to create this connection with the self.

7.2.3 Music evoked autobiographical memories and the self-defining-period/ reminiscence bump

The reminiscence bump has been defined as the phenomenon where people recall AMs from the time period of adolescence to early adulthood (approximately 10-30 years) (Munawar, Kuhn and Haque, 2018). This self-defining period includes many self-defining memories; the phenomenological characteristics of these memories are significant to development of the self (Rathbone, Moulin and Conway, 2009). The recalled memories within the reminiscence bump have been charaterised as being of high importance in peoples' lives (Williams, Conway and Cohen, 2008). As discussed in both Chapter 1 and Chapter 4, scholars have developed different theories about the reminiscence bump. One theory is that the majority of novel events occur during these decades, (Munawar, Kuhn and Haque, 2018; Pillemer, 2001). Another theory underlines the cognitive aspects of the events of this period, and suggests that people process and acknowledge these events as part of their personal development (Janssen and Murre, 2008).

A key finding of the DIDs analysis that music was selected from the self -defining period of their lives. All the interviewees, with no exception, selected musical pieces that were linked to or evoked, an autobiographical memory from the self-defining period. Interviewees' music-linked AMs included either specific autobiographical events from their adolescence and early adulthood, or events related to significant people in their lives, such as family members from these periods, or a meaningful music link to a member of their family, within this period. Similarly, in another study analysing music choices in DID interviews (Loveday, Woy and Conway, 2020), music was found to be from the self -defining period (10-30 years) and was associated with significant memories which connected the interviewees with places, people and important events.

A study by Rathbone, O' Connor and Moulin (2017) also identified the reminiscence bump for personalised and very significance songs but not for films. Study participants were asked to

consider the personal significance of each item and rate significant and non-significant songs. The study showed that personally significant songs were more likely to be associated with episodic memories whereas personal but not significant songs were not. The findings indicate that songs within this time are associated with the formation of self and identity. The authors describe how this is associated with the element of reliving the memory (Rathbone, O'Connor and Moulin, 2017). The findings from the DIDs analysis show that interviewees not only selected music that corresponded to their own self-defining period but also music that was significant and meaningful to family members within their equivalent period. This finding contributes to the body of evidence about how the self- defining period is present in music and how this links to autobiographical memories.

In this regard, findings from a study by Krumhansl and Zupnick (2013) show that the association between music and the reminiscence bump may transcend generations. In their study, participants (college students) heard 11 music excerpts from the years 1955- 2009 and reported whether they recognised each piece or not, how much they liked it, their emotional response to the music and if they had a memory linked to that song. The authors found evidence of a music reminiscence bump from years before the participants were born. This period was between 1980-1984 and they found that this music bump was from the participants' parents' adolescence and early adulthood. Regarding the emotional experience associated with this period, participants reported nostalgia (Krumhansl and Zupnick, 2013). In the same study, songs from an even earlier period, corresponding to participants' grandparents' music were found to be significant. In line with this finding, another study showed how the music preferences of parents influenced children's music preference (ter Bogt *et al.*, 2011). Thus, significant personalised music seems to be inherited into AMs.

7.2.4 Music evoked autobiographical memories, social sharing, and the self

People's music-evoked autobiographical narratives are recounted within their social relationships and their social environment and are created and formed in the process of sharing with others. This process seems to be a key component in the formation of self. Sharing meaningful autobiographical events helps to place the self in the different periods and events of one's life history, establishing self-continuity and creating a sense of belonging in their environment (McAdams, 2001; Bruner, 2003; Singer, 2004; McLean, Pasupathi and Pals, 2007). As discussed in Chapter 4, for people with a dementia diagnosis, sharing personalised music seems to be the key component in recalling AMs, facilitating the re-establishment of the self and the sense of belonging in their environment. Thus, music seems be a tool that enables cognition, communication and access to the self but the social component of the music seems also to be very important for enabling these processes. The importance of social interaction in music has been discussed in Chapter 4; the findings from the DIDs analysis provides further insight into how people think of music in relation to their social environment, the ways that music links them to the world and the ways that they use music to establish a connection with the world during a specific period of their life.

The analysis of the focus group discussion showed also linked music activities with AMs: participants noted how music enables people living with dementia to recall AMs from their professional life and how music facilitated detailed recollection of these memories. Participants in the focus group also emphasized the importance of understanding each person's history as was reflected by AMs evoked by music. These practitioners shared examples from their clinical experience where people living with dementia responded to and engaged more with music that they associated with important historical events (such as periods of conflict or war) compared to music from other periods; this could be due to the importance of those events and the connections they had with their social environment. This may also be to do with the process of

finding and forming their sense of self as well as their social self by relating with certain groups and the values or status that these groups symbolise.

Music evokes AMs and the process of their narration can be used to provide self-continuity, where people share personally meaningful music to reflect on their sense of self. In a case study of severe dementia (Matthews, 2015), a favourite piece of music was chosen by the participant with the help of his caregivers; his responses were then observed and he was asked about his experience while listening to the music. The author describes the positive effects of the music and the behavioural differences observed in a change from an "apathetic condition" to a responsive one: "Henry's agency, to be sure, is scaffolded by his external circumstances, the music and the carers who make it available" (Matthews, 2015).

Heraclitus of Ephesus (530-470 BC) stated that "B49a. *potamois tois autois …* Into the same rivers we step and do not step, we are and are not. (Heraclitus Homericus)" (Graham, 2019). The 'self' can be considered with these words: it is not changeless nor constant across an individual's lifetime; one's self is the gathering of the selves in different states of life. Music-associated AMs reflect these different situations and aspects of peoples' selves to create continuity and a reference point for what the self consists of.

The phenomenologist Alfred Schutz (1899-1995) explored the meaning of music in relation to the physical characteristics of music, the association of music and the social relationships between the music and the listener or between co-performers. Schutz proposed that listeners respond to music not only to the perceived sounds, waves or other physical properties but just listening to music (Skarda, 1979; Barber, 2018). In one of his writings about experiencing music he says:

> "(…) we find that the decision to listen to pure music involves a peculiar attitude on the part of the listener. He stops living in his acts of daily life, stops

> being directed towards their objects. His attention toward life has been diverted from its original realm; in Bergson's terminology, his tension of consciousness has changed. He lives now on another plane of consciousness" (Schutz (1976) cited in Skarda (1979) p.82).

Experiencing and sharing music-linked AMs can be characterised by this shift of attention from the present to the past and consequently to a transition from the past selves into the present self.

7.2.5 Early Diagnosis & differentiation of different types of dementia.

Early diagnosis and differentiation of different types of dementia is of high importance in clinical care for the design and implementation of interventions. The results of the second review (see Chapter 3) showed a common limitation in studies is that they do not differentiate between the different types. As a result, most interventional studies did not evaluate their outcomes in relation to the different types of dementia. The focus group participants highlighted the need for an early diagnosis to involve people with dementia in their care plan and of the differentiation between the types of dementia. In a study that did focus on a specific dementia type, Baird and colleagues demonstrated the different effects of music in music-evoked autobiographical memories, in people with Alzheimer's disease diagnosis and with a diagnosis of Behavioural variant of frontotemporal dementia (Bv-FTD) (Baird *et al.*, 2020). Comparing music-evoked autobiographical memories with photo-evoked autobiographical memories, they found that people with a Bv-FTD diagnosis recalled more photo-evoked autobiographical memories compared to music-evoked while no significant differences were found between the two types of dementias in the frequency of the recalled music-evoked autobiographical memories (Baird *et al.*, 2020).

This study supports the findings from the focus group study where participants raised their concerns for a specific diagnosis, also demonstrates the importance to explore in future studies the effects of music in different types of dementia.

7.2.6 Evaluating the effect of music interventions in dementia care

The second systematic review concluded that there was a need to reconsider the evaluation of music intervention. The studies included in the review reported an overall positive effect of personalised music interventions on depression symptoms and agitated behaviour yet there was uncertainty regarding the significance of this effect particularly as it was unclear how long term the changes were. This finding might reflect the way that we evaluate the results of the interventions. A theme of the focus group discussion study was also to "Reconsider the way we evaluate music interventions". Neuropsychological assessments have their place but we might also need to think about additional and complementary ways to measure the effects of personalised interventions. These might involve assessing non-verbal responses during the intervention, such as aspects of engagements, interactions, expression of emotions, along with physical responses and facial gestures. We could also work in the development of questionnaires or assessments specifically designed for people living with dementia along the lines of the work of Vanstone et al. (2016) who developed a Music Experience Questionnaire. Qualitative methods could also be included to enable outcomes to be evaluated individually.

7.3 Personalised music interventions and dementia care

As already reported in this thesis, music has been used in dementia care in different ways to facilitate cognition, psychological and behavioural symptoms and the social needs of people with a diagnosis of dementia for a better quality of life. Autobiographical, self-defining meaningful musical choices seem to be important in the field of music interventions in dementia, where interventions are designed to enhance the sense of self and focus on the needs

of the individuals. Considering these findings in terms of the role of music in dementia care, one can argue that dementia carers and clinicians aim to work with these reflections and to evoke the whole emotional history of that person that is already there for them. It is as if their entire life story is embodied in a pre-given way, the way in which we carry our history with us and ourselves (Merleau-Ponty, 1962). However, this is not fixed and in the paradigm of musical interventions, the meaning of a piece of music may change and transform but can still remain constantly with the person.

The goal is to establish the connection an individual may have with a piece of music. While the music may always be present, specific conditions are needed in which it is foregrounded so that the individual can connect with its specific given meaning in the moment. The meaning may derive from an AM or a collection of AMs that people want to have with them; the aspect of choice is an important part. The music selected by the participants for the personalised music intervention could be from different periods of their life, from memories and events with mixed emotional valance; these selections could be more effective at an individual level since the connection found in the music with the AM is important for the construction of the sense of self.

In this chapter. I have presented findings that describe the link between meaningful music and AMs through emotions, nostalgia and social connection, in a population with no diagnosis of dementia. This body of evidence, along with the findings of the systematic reviews, contribute to a better understanding of how the AM system connects to music and how these mechanisms could be implemented in personalised music interventions in dementia care. To examine the qualities of the connection between people living with dementia and the clinical implementation of music interventions, I employed a third study, an exploratory focus group discussion with practitioners who use music in dementia care. The aim of this study was to further explore the outcomes of the systematic reviews and the analysis of DIDs interviews in

the light of the practitioners' views and discuss their implications for how music activities could be used in clinical settings.

7.4 Strengths, limitations, and reflexion of the thesis

I concluded Chapter 4 by discussing the limitations of the systematic reviews. In this sub-section I reflect on the strengths and limitations of the qualitative analysis of DIDs broadcasts and the exploratory focus group discussion. One limitation is the dataset I used for the study. DID broadcasts are interviews conducted for entertainment purposes and not for research. As stated in Chapter 5, the current qualitative study is to my knowledge the fourth to use DID interviews for research and academic purposes. This dataset is not straightforward to work with and as I described in Section 5.1, different sets of elements need to be considered to secure a study's quality in order to make further contribution to the findings in the field. Since DID broadcasts have a specific time frame, another limitation could be that interviewees were constrained in their descriptions and what they were saying because of the time constraints of the show.

In terms of the sample, all interviewees were in the public eye and this is a significant difference compared to people who might otherwise participate in studies. Another difference is that as public figures they might be more comfortable and responsive in interview and might be more experienced in being interviewed. Since the interviews were in a very public place, another potential limitation is that interviewees may have self-censored what they shared. Moreover, as I did not carry out the interview. I therefore had no have control over the data collection, over the questions asked or how deeply topics were explored. Furthermore, though the DID interviews followed a similar format similar to a semi-structured interview and were conducted by the same presenter, the interviews were not designed intentionally for qualitative research purposes.

In the same vein, I had no direct interaction with the interviewees and I could not further interact with them or inform the collected data with their perspective, as would have been the case if the interviews had been part of a qualitative study. At the same time, this could also be seen as a strength since the interviewees could not be influenced by the research aim, or the research questions. Another strength of this data set is that interviewees had time to consider the question and prepare for the interview and were therefore able to articulate well their ideas and thoughts.

In terms of strengths, the findings of this thesis have contributed to the research of music linked AM in the field of dementia field; the systematic reviews presented the differences in AM characteristics among the sub-types of dementia and also the effects and limitations of personalised music interventions in managing the psychological and behavioural symptoms of dementia. The findings from the DIDs analysis have contributed to the understanding about music-evoked AMs, and how they correlate with the complex emotion of nostalgia. The importance of music as a social sharing and the importance of preserving personally meaningful music, regardless of the emotional autobiographical context, has useful implications when using music interventions in the care of people with a dementia diagnosis.

One might consider the small number of participants in the exploratory focus group discussion as a limitation. Since the study was exploratory, I set out to recruit experienced participants from different professional backgrounds and settings. My aim was diversity of perspective rather than quantity of participants. In fact, the small number meant that it was easier for to participate equally in the discussion: there was space for everyone to interact and respond to each other's comments and views. Such a small number also turned out to be ideal for online discussion.

The online environment of the exploratory focus group discussion is certainly different to a physical environment and might have limited the participants to those who have access to an

online platform but under the current circumstances (COVID-19), it was the only way to conduct the study. Online focus group discussion required additional considerations for good research practices and for the practicalities during the meeting. But it meant that people could be included not only from different clinical settings but also from different countries, which also enriched the data and the outcome of the analysis.

7.5 Implication of the findings

The present thesis has described the processes involved in sharing meaningful autobiographical events with music. It has shown how music can be used to represent and support a sense of self in terms of approaches to dementia care. The first systematic review highlighted the differences in self-defining memories and the temporal gradient effect of AM among the different types of dementia; the second systematic review provided evidence of how personalised music interventions have a positive although not lasting, effect on psychological and behavioural symptoms in people living with dementia, and a greater significant effect on the symptoms and quality of life when the music intervention (listening, singing, music play) was active rather than passive music listening.

Through an analysis of DIDs interviews, this thesis has shown how music enables people to share emotional meaningful AMs, including painful and/or difficult ones. Furthermore, it has shown how people choose music partly because of its nostalgic quality and how this is associated with elements of the self that they wish to incorporate, recall or bring with them into the present moment and into the future.

The focus group discussion has shown how practitioners working in dementia care are aware of the positive effect of music on the expression of emotions, especially emotions during difficult experiences such as loss. Practitioners emphasized the importance of understanding

each person's history and the need to find alternative and complementary ways to evaluate the effects of music interventions in dementia care.

The findings of this thesis have the following implications:

The temporal gradient effect is present when participants with AD and vascular dementia diagnosis are assessed for AM function; people with FTD and SD can better recall recent AMs compared to remote AMs. This finding has implications for tailoring interventions for the specific type of dementia and the participants' preserved functions.

Self-defining memories are impaired in people with AD, irrespective of the recalled time period. One implication of this is that interventions and a personal plan need to be designed as soon as possible after diagnosis, to access self-defining memories while they are still intact. Assessing participants specific for self-defining memories prior to the personalised music intervention could enhance its effects on behavioural and psychological symptoms.

Participants with AD and mild SD diagnosis present a reminiscence bump in AMs. This phenomenon could be further explored in the different types of dementia and the findings applied to the development of more effective personalised interventions.

The majority of studies that have evaluated the effect of personalised music interventions on psychological and behavioural symptoms in dementia patients did not differentiate between participants according to their diagnosis; as a result, the effect or not of the intervention cannot be associated with the type of dementia. This was also a theme described in the exploratory focus group discussion: participants talked about the need for diagnosis differentiation to achieve person-centred interventions; certain music interventions might not be beneficial for all people living with dementia. Additionally, the importance of early diagnosis has implications for future research which could prioritise more fine-tuned diagnosis of the participants rather than sample size. Having a specific diagnosis is also important since music

interventions might exert different effects on distinct dementia types. Detailed specific evidence-based research could inform interventions at an early stage, particularly since the effects of the intervention might differ depending on the different diagnoses**.**

The second review showed that in the majority of studies, the positive effect of personalised music interventions did not last beyond the end of the intervention. I have argued that this might because of the outcome measurements used rather than the intervention itself. The practitioners in the focus group discussion also raised this issue. Specifically, they discussed the need to pay attention to the details and to individual responses. These considerations could inform future research, involving more sensitive outcomes or devising outcomes that assess the sense of self or the emotional process of nostalgia. The benefit of such outcomes is that they focus on the person as a whole rather on the symptoms. One hypothesis in this approach is that if the sense of self is preserved or can be re-constructed, this could have an indirect and positive effect on the behavioural and psychological symptoms. Another clinical implication of this finding regards the duration and frequency of personalised music intervention, which might need to be incorporated into the daily programme of care homes and dementia sites.

Nostalgia emerged as a core process when people talk about and share personally meaningful music-linked memories. Personalised and meaningful music interventions might facilitate the re-construction of the self but might also elicit the expression of difficult emotions. This Findings from this study show that rather than excluding such music interventions so as to create a "happy environment", caregivers and clinicians could be further educated in order to develop a safe environment for everyone to express and be connected with themselves, including with sad or painful aspects of their life story. Within this framework, music can be used to evoke AMs and nostalgia to create a connection with the self; on turn, this could have a positive effect on the individual's psychological resources.

I have argued that the social sharing of music-linked autobiographical memories is a key component in the formation of self and provides a sense of belonging in one's environment. An implication of this argument is that the autobiographical narration and sharing process could be incorporated into music-based interventions for people with a dementia diagnosis.

7.6 Directions for future research

The current thesis contributes to further understanding the process of sharing meaningful autobiographical music in the field of dementia care. The findings have implications for future research approaches and indicate some avenues for further research. Future research on personalised music interventions could focus on exploring the effect of personalised music interventions on the different types of dementia. Methodologically, the effect of the interventions could be investigated using approaches that include qualitative methods: in-depth interviews with participants with mild-moderate dementia, to understand how they experience using music to share personally significant AMs; qualitative assessments for the characteristics of self-defining memories. The aim of the study would be to explore the differences, if any, among people with a different diagnosis, and to identify if the diagnosis affects the experience of sharing personally meaningful music, as well as the characteristics of the music-linked, self-defining memories. When planning interviews with persons with dementia diagnosis, researchers might need to consider different strategies to optimize the interview process such as: elimination of environmental distractors; use of cues and reminiscence; allow more time for the process; offer frequent breaks when needed; and monitor for nonverbal behaviour indicating fatigue or anxiety.

Additionally, I would like to further investigate what the effects are of personalised music interventions on nostalgia and whether nostalgia enables the sense and formation of self and self-continuity in a population with a dementia diagnosis. This could be explored in a study with groups of people based in community sites or care facilities and by using outcomes that

evaluate nostalgia and the sense of self. Answering these questions may facilitate the development of more effective personalised music interventions, with longer lasting effects.

Another area for future research could be to further explore the procedure of personalised music interventions from the perspective of carers and clinicians, to understand their role and how they enact the procedures. This could build on the exploratory focus group used in this study and investigated through combining an observational study of the intervention processes with the views and considerations of the carers and the clinicians who deliver the intervention.

7.7 Conclusion

I set out to explore the core processes in the AM system involved in sharing personally meaningful choices of music. I have shown how music is used to represent and support a sense of self. The thesis identified a difference in the temporal gradient of AM among the subtypes of dementia, as well as differences in the recall of self-defining memories in AM assessments in people with different types of dementia. Nostalgia has been identified as a core process when people talk about and share personally meaningful music linked memories. I have shown that personalised music interventions have a positive effect on psychological, behavioural symptoms and quality of life for people living with dementia but found that this effect does not last beyond the period of the intervention. I have highlighted the significance of the social sharing and the narration of music-linked AMs in terms of enhancing the formation of self and the sense of belonging in one's environment. Music can be a powerful medium to safely enable the expression of emotions but it is important to differentiate between dementia types and to re-consider how we evaluate (personal) music interventions.

The thesis has contributed to the expansion of knowledge about the AM system in people with dementia and how this knowledge might inform the design and applications of music-based interventions for people with a dementia diagnosis. To conclude, the findings of this thesis

support the importance of personalised meaningful music in recalling and sharing self-defining AMs, and its potential in the dementia care field, both in terms of benefitting people with a dementia diagnosis and in future clinical intervention research.

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APPENDICES

Appendix 1. Protocol PROSPERO Systematic Review "How is Autobiographical Memory affected in different types of dementia?"

UNIVERSITY of York
Centre for Reviews and Dissemination

NHS
National Institute for Health Research

PROSPERO International prospective register of systematic reviews

Autobiographical memory in dementia: systematic review

Danai Theodosopoulou, Simon Horton, Anne Killett, Guy Peryer, Toby Smith

Citation

Danai Theodosopoulou, Simon Horton, Anne Killett, Guy Peryer, Toby Smith. Autobiographical memory in dementia: systematic review. PROSPERO 2016:CRD42016032307 Available from http://www.crd.york.ac.uk/PROSPERO_REBRANDING/display_record.asp?ID=CRD42016032307

Review question(s)

What are the specific autobiographical memory deficits in different types of dementia?

Searches

A) The following electronic published literature databases will be searched: MEDLINE, CINAHL, PsycINFO, the Cochrane Library (Cochrane Database of Systematic Reviews; Cochrane Central Register of Controlled Trials (CENTRAL), the ALOIS (www.medicine.ox.ac.uk/alois), the Cochrane Dementia and Cognitive Improvement Group Specialized Register). A preliminary search started in October 2015.

B) Secondary strategy search will include OpenGrey database as well as a hand searching of conference- proceeding and relevant journals and special issues.

Keywords include autobiographical memory; episodic memory; dementia; Alzheimer's disease; frontotemporal dementia; vascular dementia; Lewy Bodies dementia (LBD). Reference lists of related systematic reviews will be reviewed.

Studies only in English language and published between January 2000 and December 2015 will be reviewed. The searches will be re-run just before the final analyses and further studies retrieved for inclusion.

Types of study to be included

Non randomised trials, randomised controlled trials, case control studies, case series, case reports and qualitative studies will be included.

Condition or domain being studied

The autobiographical memory system consists of significant events related to an individual, includes memories of specific episodes and personal experience and facts of one's life.

Autobiographical memory is informed by both semantic and episodic memory. The systematic review will focus on autobiographical memory deficits in dementia syndrome.

Participants/ population

Inclusion criteria:

Patients with dementia; Alzheimer's disease; frontotemporal dementia; dementia with Lewy bodies; vascular dementia, as have been diagnosed using recognised diagnostic manual such as ICD-10, DSM-IV, DSM-V and present with significant impairments in cognitive domains such as: memory; language; execution of purposeful movement; recognition/familiarity; visuospatial function; self-control/ management.

Exclusion criteria:

No valid diagnosis of dementia and the subtypes according the recognised diagnostic manuals.

Intervention(s), exposure(s)

Appendix 2. Systematic Review "How is Autobiographical Memory affected in different types of dementia?"

Systematic review documentation: search strings

1	dementia. mp.
2	alzheimers disease.mp.
3	vascular dementia. mp.
4	frontotemporal dementia. mp.
5	Lewy Body dementia. mp.
6	semantic dementia. mp.
7	1 or 2 or 3 or 4 or 5 or 6
8	autobiographical memory. mp.
9	episodic memory. mp
10	7 and 8
11	7 and 9
12	8 or 9
13	7 and 12

Appendix 3. Protocol PROSPERO Systematic Review "The effects of personalised music on behavioural and psychological symptoms in patients with dementia"

UNIVERSITY of York
Centre for Reviews and Dissemination

NHS
National Institute for
Health Research

PROSPERO International prospective register of systematic reviews

The effects of music on behavioural and psychological symptoms in patients with dementia

Danai Theodosopoulou, Simon Horton, Anne Killett, Guy Peryer, Toby Smith

Citation
Danai Theodosopoulou, Simon Horton, Anne Killett, Guy Peryer, Toby Smith. The effects of music on behavioural and psychological symptoms in patients with dementia. PROSPERO 2015:CRD42015032446 Available from http://www.crd.york.ac.uk/PROSPERO_REBRANDING/display_record.asp?ID=CRD42015032446

Review question(s)
How do music listening and music interventions affect behavioural and psychological symptoms in dementia?

How do music listening and music interventions affect behavioural and psychological symptoms in dementia?

Searches
A. The following electronic published literature databases will be searched: MEDLINE, CINAHL,PsycINFO, the Cochrane Library, the ALOIS.

B. Secondary strategy search will include OpenGrey database as well as hand searching of conference-proceeding and relevant journals such as Journal of Music Therapy, British Journal of Music Therapy, and Music Therapy Perspectives.

Studies only in English language will be reviewed. The search will be re-run just before the final analysis.

Keywords include: music; music listening; music interventions; music therapy; dementia; Alzheimer's disease; ageing; behavioural symptoms; mood; emotion; agitation; depression. Reference lists of related systematic reviews will be reviewed.

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Types of study to be included
Non randomised studies, randomised controlled trials, case control studies, case series and case reports will be included.

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Non randomised studies, randomised controlled trials, case control studies, case series and case reports will be included.

Condition or domain being studied

Appendix 4. Systematic Review "The effects of personalised music on behavioural and psychological symptoms in patients with dementia". Systematic review documentation: search strings

1	dementia/ or Alzheimer disease/ or dementia, vascular/ or frontotemporal lobar degeneration/ or Lewy body disease/
2	behaviour/ or anxiety/ or neurobehavioral manifestations/
3	agitation.mp.
4	depression.mp.
5	behavioural symptoms.mp.
6	psychological symptoms.mp.
7	quality of life.mp.
8	music therapy.mp.
9	music.mp.
10	personalised
11	individualised
12	Person-centred
13	1 and 2
14	9 and 10
15	1 and 3
16	9 and 11
17	1 and 4
18	9 and 12
19	1 and 5
20	9 and 13
21	1 and 6
22	9 and 15
23	1 and 7
24	9 and 17
25	8 and 10
26	8 and 11
25	8 and 12
26	8 and 13
27	8 and 15
28	8 and 21
29	8 and 23

Appendix 5. Email to BBC “Desert Island Discs “team

Dear “Desert Island Discs” Team,

My name is Danai Theodosopoulou Bourlogianni, I am a PhD Candidate at School of Health Sciences, Faculty of Medicine & Health Sciences, University of East Anglia. My supervisors are Dr. Anne Killett and Dr. Simon Horton.

With this email I would like to inform you, that for the purpose of my PhD research project I am analyzing the content of the “Desert Island Discs” broadcasts.

Me and my supervisors we are at your disposal if you have any inquiry, and we will be very happy to keep you updated on the progress and the outcome of the research project.

With kind regards

Danai Theodosopoulou Bourlogianni

Appendix 6. Development of Codes

Participants	Initial Codes	Secondary Codes
I1	happy	very happy memories
	give	give this music to people that I care for
		the cello is the voice of the heart
	dance	dancing away
	happiness	speaking of the happiness and the joy
	dance	dancing has been a very important part of my enjoyment
	father	my fathers' favourites
		a piece of me that means an enormous amount to me.
		we played at juniors' common room
		my children like him
	relationships	really exemplifies that I think is important about relationships
		very important to me which I sing in the choir
		get together to sing even song in cathedral around the country
		at candle mass we sing this
	faith	Oh is very important (Christian faith)
		is a piece that I sung
		it has a memory of me being in NY in 2002 the first anniversary of 9/11
		the most powerful piece of music I've participated in
I2		(music) comes in different categories
	emotions	(music) that evokes strong emotions
		(music) I like to bop to
		I was very isolated, and I really missed my husband
		when I hear it, I think of us dancing in the moonlight
		like a voyage of discovery
		could conjure up that much emotion and it made me cry
		invoke emotion like that to me is just amazing
		is quite quirky
		I love it because is quintessentially British
	physics teacher	was introduced to me by my physics teacher
		amazingly strong
	sister	introduced to me by my sister
		dad's lament
		I didn't want him forgotten
	certain place	the first notes come in and they just take me down to a level so when I ever I hear it my heart slows down, and I get into a certain place
	remember	the main phrase is remember me
		remember my father
		it was part of my upbringing
		(artist) he was a short of role model
	beautiful	his music is so beautiful
		something we shared together and talk about (sisters)
		pulls me back in (the world)
	love	he speaks about love in such a beautiful way, all-consuming love, love that has no boundaries
	dance	I can just dance to
		And this is one of those tracks I think my husband and I make a really good combination
	emotions	conjures up real emotions
		one of the things that I think I realized is as I was growing up was that people can do nasty things to other people but it's not just those people out there that can do that.
	emotions	very important because it invokes that emotion and it's always reminds me of the safeguards that we all need to have
I3	happy	it's a happy music

		the song came out when I was in and beginning of my relationship and it was pretty rocky at the beginning
		fabulous music week with my girlfriend
		and so I could related to her (singer) on an emotional level
		(her voice) is the most colourful and the one that you feel the most
		so, you felt very international and very made me feel grown up like we belong because we were cool with the music
		and it's happy music it just puts you in a good mood every time
	mom	I actually arranged tickets for my mother to see Pavarotti at the MET in NY and she had a picture taken with them signed. He was her hero, so I think this is a tribute to my mom.
		and, the song is love is here to stay I mean when all this fails love will be around.
		I love both of their voices
	emotional	the two of them coming together with a very emotional song is about as good as it gets
	a continuation of life.	Which is the river that I grew up on [name of the river] flows into the [name of the river] which then flows into the [name of the river] which then flows into the Atlantic. So it's kind of a continuation of life.
	spirit and hope	beautiful Puccini opera of Madame Butterfly. It's just it's sad but it's the same time just kind of give you a sense of spirit and hope
I4	sentiment (of the song)	I just love the sentiment of this.
	message in the song	And I love the message in this song as well.
	(song/ words) are so moving	I love the way it's arranged as is just him and his guitar, and the words I feel are so moving
	a smile on my face	this is the first song I remember listening to on radio that made me laugh howl with laughter
	calm and peace	one of those songs that I hear, and it just brings a sense of calm and peace over me
	I love what it says	I love what it says and it's about you need to walk in someone else's shoes to really know them
		the reason I picked this, is because of my hubby.
	and I love this message	I love this song because it says you know what you have a voice and don't let anyone ever take that away from you
		and I've told my hubby that if I die before him, I want this played at my funeral. So, I love this song
I5		it was the start of my musical life
	amazing dance	along the way we spent some time in and business areas and we went to tango clubs late at night and the tango is such an amazing dance
	opening a window on the world	and I adored him, and he introduced me to Genesis and it was like opening a window on the world for me.
	this is for Australia and my father	During the year my father came out to Australia and we spent a couple of weeks looking at farmland and we stopped up in the evenings and cooked steak and we had a wonderful time. It was a wonderful couple of weeks with him and he always remembers this one tape that was played over and over again as we travelled around
	love and affection	I love it so much, but it takes me to all those friends and my sisters who you know have been such a bug part of my life
	playful piece	such a playful piece and I think we're all at our best when we are in slightly more playful and relaxed mode
	playful and relaxed mode.	when they're sort of coming in on the little biplane and zipping in and zipping out and it just feels light and I want some lightness in my life.
	lightness in my life	
	my passion	and it does express something about my passion for this green and pleasant land.
I6	her favourite composer (mother's)	my mother was a gifted pianist but she didn't become a concert pianist because she followed my father

		when I was a student, I met this charming Polish emigre psychiatrist very attractive and I fell in love with him. (…) Well you can imagine with all I felt about Chopin that probably sealed my fate but I had to wait many years before I actually married him
	bittersweet reconciliation to loss	and it brings back to me all that kind of heartbreak of when one's in one's 20s now waiting for someone to return waiting for the telephone call that doesn't come, waiting for the letter that never arrives and then gradually that bittersweet reconciliation to loss.
	make me laugh and remember these exciting superb days	we used to sort of have great fun but also we used to have The Ferret Song, which was like all morning assembly anthem and it was so ridiculous that I would like that on my island because he would always make me laugh and remember those very exciting [name] would say superb days.
		very very personal meaning for me
		(kids) are songwriters and (son wrote the most moving song when I had cancer (…) But somehow, I though on that island I didn't really want to remember that time (…)
	precious moments, they are like jewels.	(…) he was diagnosed with Parkinson's disease for a while we manage really very well indeed but the last ten years of his life it took a grip first of his body and then off his mind (…) the when that couldn't happen I started singing from my favourite musical and I would come and say good morning " good morning , the sun breakthrough" and he would joining and he never sung in his life before. And from then on, we duet it together until the time of his death.
	bring back [husband] to me	remind me of the way that we used to have these acts together.
	redemption	this sublime was going to give that sense of an old-fashioned world redemption
	forgiveness	it's full of the idea of forgiveness and release a true freedom
	true freedom	
	really beautiful	
	life was worth living	
I7	his lyrics accompanied me	I think at different stages in my life in my journeys his voice, and his lyrics accompanied me.
	connection	when I hear this song I think it takes me back to this other connection that I have and maybe I was never able to build,
	emotional	There's something in this song that makes me very emotional.
	multi-culture	in my mind it's so multicultural Misirlou
	transcend	It is the whole Mediterranean the Middle East in my mind and it shows so beautiful music tranced those national boundaries that we mistakenly take for granted
	timeless	Timeless in my eyes
		Political aspect to their work
	high energy	Loud harsh music
I8	takes me back	Takes me back to an era that I very much enjoyed (…)
	songs that paint pictures	and my dad being his most sort of anarchic, and although that was painful at the time in retrospect it looked like quite a lot of fun and I was very attracted to songs that paint pictures.
	teenage years	It's just a song that I heard in lights or teenage years and it's been something that stayed with me and in my discman, Walkman, iPod ever since
	funny. Jump pop	I have no idea what it's about but it's just a funny sort of jump pop anarchic ridiculous song.
	it gives me butterflies	takes me back to like a fun happy positive time
	fun happy positive time	
	identify with it	There is a short of weepy guitar in it that I really identify with and just watch out for how he says woman.

	take you back to a certain place	listening to certain songs can be really helpful to take you back to a certain place
	song to kind of connect	And that's the song being on a cd that [husband] was playing and it's in a weird way just a nice song to kind of connect to something in me.
	be dancing in my tracks	and I don't want talk to anyone I just want to have a drink in my hand and have my hood up and be dancing in my tracks.
		This song was the first dance of mine and my husband's
I9	my childhood	brings back to me all of what my life was about as a child
	calmness and happiness	
	back home and calm	So, I was Hiawatha (song of Hiawatha) and I was standing there and I was immediately back home and calm.
	given by my mother	This music was given to me by my mother (…) she gave it to me and said Here my friends and I decided this is you
		giggling they sang this song to me.
	it just means something very special	
		we all can stand up and make a difference just dare to believe you can do it believe in your dreams and just go for it.
I10	dance	that makes me want to dance and I love to dance
	energy.	There's a tremendous energy in this music that always sweeps me along so be really very happy to have this wonderful long twelve-minute track with me on the island.
	is very timely	reminds me of the cottage this wonderful place that we were brought up in the place that was my place of discovery
	perfectly beautiful piece	on the edge of tears every time I hear it and I'll be very very happy to be sitting there enjoying that as part of my experience of being alone.
		this wonderful string sequence that sweeps you away and allows you to be lost and it's beautiful song.
	magical absolutely magical piece of music	I lost my my lovely dad in March last year. And when we were selecting music for his funeral, I went through his music collection and found the Vespro which I'd remembered must have been deep inside me and I love the fact that you've got these two voices calling to each other and responding
	my mum brought this into the house	And I remember her doing this to this fantastic album and I went to see [musician] a few years ago and she's just such a larger than life enormous charismatic person. I couldn't be on the island without.
I11	the first piece of music I remember thinking	
	it reminds me of my childhood this song	some Christmas with all the family around and after to watch the Queen on the telly going down the British Legion and playing darts and things like that and playing cards for entertainment as a family it seems that times have changed and it's not like that anymore and Chas & Dave kind of sum up for me a little bit and they're rock royalty and I love them.
	rebellious band	they're quite a rebellious band and I've always loved that kind of rebellion in people and as a party why I'm such a huge fan of the Jam and Oasis
	confidence	this kind of music gave me confidence to fulfil
		I spoke a lot about my teenage years and I was 14 years of age so right that kind of critical kind of influential stage of my life and you know one track in particular that gave me confidence to go out there
		I used to sit in the back of a car going to [activity] with my walkman listen to this just feeling 10 feet tall and then felt like I could take on the world.
	reminds me of a very happy time	It reminds me of a very happy time where I met someone that was the first proper girlfriend and that was to spend the rest of my life with her and that was it

	encapsulates	So yeah you know the next song obviously you know it's something encapsulates all that for me because I remember I was off racing and I missed my son's birth because I couldn't get back in time and I missed it by a few hours. Got to the hospital saw him for the first time and I went home and I put T. Rex on.
I12	dance	I must have been you know possibly about 10 or 11 and I had this for the first time on Soul Train and I just could not stop dancing her tracks are just so funky.
	funky	
	childhood	this very much reminds me of my childhood in [country] and I'm bilingual, so he sings in Europe.
	is just pure nostalgia for me	
	Mother	reminds me of my mother, because this is from my mother's record collection
		And there was no way my parents would have approved of anything like that but because my parents didn't approve of him, I really loved him.
	just too funky	
	compelling	
	uplifting in that kind of pathos of the opera	because I always felt the melancholy of opera which I was later to find cathartic as an older person as a younger person I just wanted to dance, and I didn't want anything sad in my life
	It's political	
	It's about conflict	
	It’s about trying to resolve	
I13	liberty	it's a song that has a represent I think more than anything else the music of my life
	freedom	
	breaking out	
	taking a risk	
	taking the things all the way through	
	rebellion	song that reminds me of those years in which I was going into my younger rebellion in Italy I was living at the time in a sort of a funny place in the countryside
	living together	
	absolute magic	And I had the incredible fortune that at the time of high school of I could go once a week in an empty church where there was a group that was playing Vivaldi that was unknown at the time. (…) And we boys from the school would go there and listen to them, And it was absolute magic. It was my entry into music.
	my entry to music	
	pure beauty	
	purity	enchanted piece of purity which for me is like a representation of the kind of cleanness and the, essential is the characteristic of being essential and simple which is in theoretical physics
	lightness of love was marvellous	
	pure joy	And I remember distinctively I was in high school, I was at a party with some friends and a friend of mine came to me and said You're gonna like this one and put some headset around my ear and the these two voices, pure joy started singing and since ever I keep hearing this piece of music.
	simple sweet anthem	It's a simple sweet the anthem of a generation and the world. So many of us dreamed. Quite different from the present world. A a world where there are no boundaries there are no superstitions. There is no war. And when

		somebody kills us we don't react by saying okay let's kill all of them but we react by saying well let's talk and stop killing one another.
	it's about sleep, about maybe death about being elsewhere.	It's a marvelous piece of music to which I often go back. I have had a rather stormy life, I've changed a countess many times have changing a lot in my life. This is so dreamy and it's about sleep, about maybe death, about being elsewhere. It's soft is sweet. And Jim Morrison voice is so wonderful. It's about elsewhere
	soft and sweet	
I14	first marriage was probably staring to fall apart	(…) and I used to sing this song my tractor quite a lot. And it was at a time when my first marriage was probably starting to fall apart, so it seems very poignant to me. I did have four children they weren't hungry and there were the crops in the fields. I loved country music. I love its simple directness and I can be a bit soppy as well. I love
	wild parties	
	mother loves calypso	mother loves Calypso. Actually she grew up in Trinidad and Calypso was the music. And she particularly loved Harry Belafonte is devastatingly handsome which I suspect might have been one of the reason my mum liked him so much. And this is Chickens
	pretty extraordinary and pretty dreadful music really	Comment by KY: I just looked at you during the playing of that guy and I said you're not loving this are you. You said no I'm not really. I brought you back to that maybe.
	this track really brings back that kitchen.	
	it takes me back to my heady days of discovery in NY	
I15	always make me laugh	
	buts it is the analogy (with work)	Being a [profession] is rather like being on a tightrope. Yes you need frightfully good sense of balance to walk a tightrope. Yes to be a [profession] you need to be good with your hands. But the really difficult is not looking down is the context. Yes we could all walk on a narrow strip on the ground but if there's a 100 foot drop below it hesitated different experience and what really what makes [profession] difficult is not the technicalities of the operation which actually after a few years of trading is quite easy. It is the seriousness of things if they go wrong. It's a human context.
	unhappy	I was depressed and anxious and unhappy (…)When I came out of the hospital I played in a rather self-consciously emotional way this one of the late Beethoven string quartets which I think Beethoven wrote on the score over Thanksgiving on recovery from a long illness and it's a slow movement of the Opus 132 does a very very slow fugue conjures up an enormous sense of recovery of life starting again.
	recovery	Conjures up an enormous sense of recovery of life starting again
	mother	(…) problems which I suppose gained from my mother. The problem of the individual what you do and your individual conscience when you are living in a deeply unsympathetic society
	happy time	I was listening to a lot when I was a (…)l student on (…) working for my (…)finals. It was a happy time fairly carefree. I was happily married to my first wife. We lived in a very small flat to the top of my parent's house in London
	fairly carefree	
	unhappy in love	
	embarrassing	
	love	It brings back how being madly in love is wonderful
	unified	It fades over time but (music) does not fade with time
	friendship	
	forgive	The wish of forgiveness, the need of forgiveness

		You can reach very similar ethical conclusions to Christian ones without having to have God simply applying the Golden Rule of "do as you would be done by"
I16	little boy	
	just starting high school	
	conflict and resolution	next one actually at first, it's a theme song from a movie that I that I enjoy and always felt was very underrated. Legends of the fall but I also thought was just a great story about conflict and resolution.
	being a teacher	working with young people and getting them excited about [profession] has always been something I love. One movie that I always love was the TO SIR, WITH LOVE. So I love that song.
	our wedding	
	for your three kids	Well I have to admit I probably cheated a little bit I asked my wife and my children by sudden said you know what probably if you're thinking about us you should play a Wannabe from the Spice Girls. So, this is about what they were a little because they wanted a lot of things were.
	wife	
I17	break glass in case of emergency song	if I was feeling it down in the dumps but sort of myself bit lonely, this was a song that always put a smile on my face and spring my step.
	spring my step	
	my brother and I	
	dad	Brings back a lot of a lot of memories
	her mother passed away (his grandmother)	
	on my [professional] (activity)	It is one that I listened over and over again, because you can hear the crowd and I was on my own for 72 days
	being transported back	and back to the sort of warm happy human life performance of a great music.
	Motivation	this is a song that was guaranteed to sort of keep my feet moving in [professional activity]when things were tough
	think my life	
	daydreaming	
I18	mood setter	And this is my well my happy music, I mean I think is an extremely good mood setter. It has the key to our soul for some reason.
	key to the soul	
	farewell	
	family	I mean I was constantly surrounded by music because my, my parents and grandparents. They all love classical music they had a huge collection of LPs and tapes, so the first thing in the morning was to put on some music that was quite heavy stuff.
	divine	
	heart-breaking	
	distracted	why this song and many others written in these in the 20s and 30s are so persuasive and really pull you into this other world are because people were in misery and needed something to get distracted from.
	forget about their sorrows	

Appendix 7. Faculty of Medicine and Health Sciences Research Ethics Committee Ethical approval

Faculty of Medicine and Health Sciences Research Ethics Committee

University of East Anglia

NORWICH MEDICAL SCHOOL
Bob Champion Research & Educational Building
Rosalind Franklin Road
University of East Anglia
Norwich Research Park
Norwich NR4 7UQ

Email: fmh.ethics@uea.ac.uk
www.med.uea.ac.uk

Danai Bourlogianni
School of Health Sciences
University of East Anglia
Norwich Research Park
Norwich
NR4 7TJ

5th March 2021

Dear Danai

Project Title: Practitioners' experiences and perspectives on music interventions for people living with dementia: a focus group study

Reference: 2020/21-060

Thank you for your email of 21st February 2021 notifying us of the amendments you would like to make to your above proposal. These have been considered and I can confirm that your amendments have been approved.

Please can you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance, and that any adverse events which occur during your project are reported to the Committee.

Approval by the FMH Research Ethics Committee should not be taken as evidence that your study is compliant with GDPR and the Data Protection Act 2018. If you need guidance on how to make your study GDPR compliant, please contact your institution's Data Protection Officer.

Please can you arrange to send us a report once your project is completed.

Yours sincerely

Dr Jackie Buck
Chair
FMH Research Ethics Committee

COVID-19: The FMH Research Ethics Committee procedures remain as normal. Please note that our decisions as to the ethics of your application take no account of changes in Government measures and UEA guidelines relating to the coronavirus pandemic and all approvals granted are, of course, subject to these.

Appendix 8. Invitation email / social media (sites)

Invitation email/ social media (Sites) Version 1 (18/02/2020)

Subject heading: Focus Group invitation, music and dementia.

Dear Sir/ madam

I would like to invite the practitioners of your site to take part in an approximately 90 minutes focus group study through Microsoft Teams software.
My PhD has investigated how people use personalised music to talk about significant autobiographical memories. Now I would like to talk to people who use music with people living with dementia to get your views.
I am contacting you because you are working with music with people with dementia, and I found your contact details …… (individualised for each site).
It is a focus group study to Investigate Practitioners Activities and Experience with Personalised Music Interventions for People living with Dementia.
The aim of the study is to discuss your views towards the music interventions and music activities with people living with dementia.
I would be very grateful if you could forward this invitation email to your practitioners.
If you do not consent to the people take part in the study, please do not take any further action.

Thank you

With kind regards

Danai Theodosopoulou Bourlogianni
Email: d.theodosopoulou@uea.ac.uk

Appendix 9. Invitation email/ social media (practitioners)

Invitation email/ social media (practitioners) Version 2 (18/02/2020)

Subject heading: Focus Group invitation, music and dementia.

Dear Practitioner

Thank you for your email respond.
With this email I would like to invite you to take part in an approximately 90 minutes focus group study through Microsoft Teams software.
My PhD has investigated how people use personalised music to talk about significant autobiographical memories. Now I would like to talk to people who use music with people living with dementia to get your views.
I am contacting you because you are working with music with people with dementia.
It is a focus group study to Investigate Practitioners Activities and Experience with Personalised Music Interventions for People living with Dementia.
The aim of the study is to discuss your views towards the music interventions and music activities with people living with dementia.
In this email you will find attached the information sheet about the study and a consent form. After reading the participants information form you will have time to think and discuss your participation with friends and family, and if you would be willing to participate, please reply to this email to arrange an online meeting with the principal investigator to give your consent and to ask any question regarding the study.

Thank you

With kind regards

Danai Theodosopoulou Bourlogianni
Email: d.theodosopoulou@uea.ac.uk

Appendix 10. Practitioners Information Sheet

Participation Information Sheet Version 3 (18/02/2021)

Focus Group Study to Investigate Practitioners Activities and Experience with Personalised Music Interventions for People living with Dementia

(Practitioners)

Chief Investigator: Mrs. Danai Theodosopoulou Bourlogianni

Introduction

I would like to invite you to participate in this project. The project is about understanding the experience of practitioners in using music interventions and music activities with people living with dementia. We also want to know if using personalised music in interventions can help people with dementia. This knowledge would be useful for people who have been diagnosed with dementia, as well as their family and care givers, health professionals and others involved in the health management and treatment.

Purpose of this Information Sheet

This information sheet is to inform you about what you will be asked to discuss in the focus group. It also will explain what the possible risks and benefits of participating are.

What will happen?

In this study you will participate in a focus group, and you will share your views about music intervention and/ or activities with people living with dementia. This will consist of 4-6 people who are all practitioners using music with people living with dementia, and me facilitating the group. You will be sent a list of topics that will be discussed, before the focus group so that

you will know what will be talked about. There will be no right or wrong answers. Members in the focus group may have similar or different ideas and views about the topics.
The process will be online and will last approximately 90 minutes and will be video- recorded. The video recordings will be typed into a written document. The document will be identified with a number and your name will not appear on the typewritten text. The text will be used only by me and my two supervisors in order to understand your experience.

Why have I been invited?

You have been invited to participate in this study because of your experience in music interventions and / or activities with people living with dementia. It is important that you can speak and understand English, and this is primarily because I speak English and want to learn and understand your experience.

How much of my time will participation involve?

The total time will be approximately 90 minutes in one meeting.

Possible Risks

While there are no anticipated risks of participating in this study, sometimes people talk about certain subjects which might make them feel sad or anxious. If this happens, please feel free to express this anytime during the procedure.
Furthermore, you have the right to refuse to answer any question or discuss any topic that you do not wish to talk about.
To ensure online safety/ confidentiality, we will use Microsoft Teams platform for our meetings, this platform is provided by the university and follows all the relevant regulations regarding confidentiality and online safety.

Confidentiality and exceptions

Anything that you say during the meeting of the focus group will be strictly confidential.
Your name and any other identifying information will not be used in any reports from the research. Short quotations from the video transcripts and interviews may be used in the written report and scientific publications. Any quotations from your interview will not identify you in any way. To ensure the confidentiality of personal data, all data, including third parties and names of places, referred to the focus group, notes, and all the data forms, will be anonymised by replacing real names with pseudonyms.

Since the focus group will be online because of the current Covid -19 pandemic situation, the only reason of a video recording will be to enable correct attribution of individual statements to participants in making a transcription. I will not use the visual information of the video as additional data.

All identifying information about participants will be removed from the data at the point of transcription. Names will be replaced with pseudonym, and workplaces not named, but described in broad categories.

What participants say in the discussion group cannot remain confidential within the group, but all participants have accepted confidentiality of the procedure in the consent form.

What will happen if I start but then don't want to carry on with the study?

You can withdraw at any point of the study and you don't have to say why you choose to do so. If you decide to stop taking part in the study, you will just need to inform Danai Theodosopoulou. In the case where you decide to withdraw from the study, all data collected up to this point will be retained in anonymised form to be used in analysis and reporting

Who do I contact if I have a complaint?

In case you have any complaints you can address them to Dr Anne Killett Senior Lecturer, School of Health Sciences Telephone: +44 (0)1603 59 3319 and the Head of School of Health Sciences (HSC) Professor Sally Hardy , Secretary: Joy Taylor +44 (0)1603 597062.

Compensation

There will be no compensation for participating in this study.

Who is organizing this study?

The study has been organized by Danai Theodosopoulou, Postgraduate Researcher in the School of Health Sciences, Faculty of Medicine and Health Sciences, University of East Anglia, Norwich, UK.

Who has reviewed and approved this study?

The study has been reviewed by the academic supervisors. This study has been considered and approved by the …. Research Ethics Committee ( ). The Ethics Committee checks that the risks associated with the study have been reduced to a minimum and balanced against potential

benefits. They also check you have been given enough information to make an informed choice about whether or not to take part.

What happens next?

If you are interested in taking part in the study, you are asked to send an email to me at d.theodosopoulou@uea.ac.uk. Once I have received the email, I will send you an email with the consent form to read, sign and return to me. If you wish to ask further questions you can do that either by sending an email to me or we can arrange to meet online at a time that is convenient for you. I can then answer any questions you may have about the research and about taking part.

If you decide you would rather not participate in this study, you need not to email to me. Simply ignore this email and no further contact will be made.

Dr Anne Killett Senior Lecturer School of Health Sciences Faculty of Medicine and Health Sciences University of East Anglia Norwich Research Park NR4 7TJ 01603 593319 a.killett@uea.ac.uk	Dr Simon Horton Honorary Fellow, School of Health Sciences Faculty of Medicine and Health Sciences University of East Anglia Norwich Research Park NR4 7TJ s.horton@uea.ac.uk

You can reach me by email at d.theodosopoulou@uea.ac.uk .

Thank you very much for taking time to read this information and considering taking part in my research study.

For more information about the study, you can contact the study team:

With kind regards
Danai Theodosopoulou Bourlogianni

Appendix 11. Focus Group Topic Guide

Focus Group Topic Guide Version 2 (01/01/2021)

Focus Group Study to Investigate Practitioners Activities and Experience with Music Interventions for People living with Dementia.

The purpose of this focus group is to gain a deeper understanding on music interventions with people living with dementia. The process in the focus group will be to discuss about your experience of music interventions and music activities with people living with dementia. In the focus group meeting we will discuss your views also on the following topics.

My PhD has investigated how people use personalised music to talk about significant autobiographical memories and the following topics have been derived from the findings of my research.

Please keep in mind that there no right or wrong answers.

1) The overall experience of using music as an intervention.

2) The experience of using music to communicate.

i. In what ways using music affect the way you communicate with people living with dementia?

ii. From your experience, do you think music made a difference in your communication with people living with dementia?

3) The Impact of sharing memories and linking them to music on people living with dementia feelings.

Indicative Questions

i. In what ways using music affect the way personal memories are evoked?

ii. What is the emotional impact of sharing memories and linking them to music?

Appendix 12. Consent Form

Consent Form Version 3 (18/02/21)

Practitioners' Experience using Music Interventions/ Activities with People living with Dementia

Principal Investigator: Danai Theodosopoulou Bourlogianni
Email: d.theodosopoulou@uea.ac.uk

Purpose

This study investigates practitioners' experiences of music interventions and music activities with people living with dementia. For this study, you will be asked to participate in a focus group and discuss your views and experience in relation to the topic guide you have been provided with. This study will take approximately 90 minutes.

Participants Pseudonym:

	Yes/No	Initials
I have read and understand the Participant Information Sheet (Version 1 20 November 2020) and have the opportunity to ask questions.		
I understand that I am free to take part or not – it is my choice.		
I understand that I may choose not to participate or withdraw at any time during the study.		
If I withdraw from the study, I understand that any data collected from me up to this point will be retained in anonymised form to be used in analysis and reporting.		
I understand parts of my responses will be written as part of PhD thesis and published, but I will not be identifiable in it.		
I understand that what participants say in the discussion group cannot remain confidential within the group.		
I understand that I am accepting confidentiality of the procedure during the meeting of the focus group.		
I understand that no one will be able to identify me when the results are reported, and my name or any other identifying information will not appear anywhere in the written report or publications.		
I understand that I cannot share other people's identities or responses from the focus group with others in order to maintain the anonymity of the participants outside of the focus group.		

I understand that that my responses will not be linked to me in any way.		
I understand that I have the right to refuse to answer any question or discuss any topic that I do not want to talk about.		
I give my permission for the discussion to be video- recorded. I also understand that the video- recording will be destroyed at the end of the project and the transcript will be archived.		
I understand that what I talk about in the discussion will be kept strictly confidential outside the group discussion.		
I agree to take part in a focus group discussion.		
I understand that upon completion, I will be given full explanation and feedback for the study.		

If you wish to get feedback upon completion of the study, please write your email address.

Email: _____

If I am uncomfortable with any part of this study, I may contact Dr Anne Killett supervisor of the study a.killett@uea.ac.uk.

Consent to Participate
I acknowledge that I have read the Participants Information Sheet. I acknowledge that my participation is fully voluntary.

Print Name: _____

Signature: _____ Date: _____