# AN EXPLORATION OF INDIVIDUALISED MUSIC ON LEVELS OF AGITATION IN PEOPLE WITH DEMENTIA IN A SPECIALIST MENTAL HEALTH SETTING: A MIXED METHOD APPROACH


**A thesis submitted for the degree of Masters by Research (MRes)**

**by**

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**March 2018**

**Declaration**

Candidate's declarations:

I, Helen Ruth Skinner, hereby certify that this thesis submitted in partial fulfilment of the requirement for the award of Masters by Research (MRes), Abertay University, is wholly my own work unless otherwise referenced or acknowledged. This work has not been submitted for any other qualification at any other academic institution.

Signed
Date

Supervisor's declaration:
I, Geoff Dickens, hereby certify that the candidate has fulfilled the conditions of the Resolution and Regulations appropriate for the degree of Masters by Research (MRes) in Abertay University and that the candidate is qualified to submit this thesis in application for that degree.

Signed
Date

**Certificate of Approval**

I certify that this is a true and accurate version of the thesis approved by the examiners, and that all relevant ordinance regulations have been fulfilled.

Supervisor
Date

**Acknowledgements**

I would like to express my special appreciation and thanks to my research supervisors Professor Geoff Dickens and Mrs Suzanne Croy. They have guided and supported me throughout the process of undertaking this research study, and at times gave me the motivation and belief to keep going when it felt impossible. It has been a bumpy ride over the last two and a half years – experiencing redeployment at work, a new job resulting in a change from part time to full time working, and dealing with serious illness within the family. But despite these challenges their encouragement has reignited my passion for research, for which I am hugely appreciative, and I intend to nurture.

I would also especially like to thank all the participants involved in my study. The people living with dementia, their family carers, and the nursing staff - without their involvement my study would not have been possible. I am eternally grateful for this.

And a final thank you has to be made to my family - to my husband Athole, and my children Finlay and Isobel. Although it was stressful at times, I hope I have been a role model demonstrating the importance of education and how hard work is worth it in the end!

**Abstract**

Aim: The aim of this study was to explore the effect of individualised music on levels of agitation for people with moderate to severe dementia being cared for in a specialist mental health hospital setting; additionally the experiences of family carers and healthcare professionals were explored.

Background: The therapeutic use of music in healthcare has significantly grown in popularity. Recently there has been an increase in the use of individualised music in the care of people with dementia to reduce levels of agitation. No studies have explored the use of individualised music in specialist mental health hospital settings for people with moderate to severe dementia.

Design: The design of the research study utilised a mixed methods approach. A single case experimental reversal design was employed to explore the effect of individualised music on levels of agitation in people with dementia. The other elements of the study used a qualitative approach to explore the experience of using individualised music from the perspective of healthcare professionals and family carers.

Methods: Five participants with moderate to severe dementia were recruited. During intervention weeks the individualised music was administered daily. Agitation levels were measured daily using the Agitated Behaviour Scale and weekly using the Cohen-Mansfield Agitation Inventory. Five healthcare professionals and four family carers were interviewed.

Results: There was a mixed response in the therapeutic value of the individualised music. Some participants displayed a positive behavioural reaction to the music in terms of agitation levels, engagement and enjoyment of the music. However this was not consistent across the

repeated administrations of the intervention and across all participants. Healthcare professional and family carer interviews provided positive feedback on the use of individualised music.

Conclusions: Individualised music was found to have a mixed response in relation to reducing levels of agitation in people with dementia. The intervention was found to be feasible and practical to administer. Individualised music was highly regarded by both healthcare professionals and family carers as a valuable intervention to use in the specialist mental health hospital setting. It provided a therapeutic approach to care that helped to reduce agitation and ultimately improved the quality of life for people with dementia in hospital.

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## Abbreviations

| | |
|---|---|
| **ABS** | Agitated Behaviour Scale |
| **AHP** | Allied health professional |
| **ASSIA** | Applied Social Sciences Index and Abstracts |
| **AWI** | Adults with Incapacity |
| **CINAHL** | Cumulative Index to Nursing and Allied Health Literature |
| **CMAI** | Cohen Mansfield Agitation Inventory |
| **EMBASE** | Biomedical and Pharmacological Database of published literature |
| **HCP** | Healthcare professional |
| **MEDLINE** | Medical Literature Analysis and Retrieval System Online |
| **MoCA** | Montreal Cognitive Assessment |
| **MWC** | Mental Welfare Commission |
| **NHS** | National Health Service |
| **PICO** | Population, Intervention, Comparator, Outcome |
| **PLST** | Progressively Lowered Stress Threshold |
| **PRN** | Pro re nata (as needed) |
| **PsychINFO®** | Database of abstracts and citations of behavioural and social science research |
| **SCN** | Senior Charge Nurse |
| **UK** | United Kingdom |
| **WHO** | World Health Organisation |

## Chapter 1: Introduction

In 2015, it was estimated 46.8 million people worldwide were living with dementia, and that this number will almost double every 20 years, reaching 74.7 million in 2030 and 131.5 million in 2050 (Alzheimer's Disease International 2015). Within the United Kingdom (UK), figures from the 2014 Dementia UK: Update Report claim the total cost of dementia to society is £26.3 billion, working out at an average annual cost of £32,250 per person with dementia (Alzheimer Society 2014). The socio-economic impact of dementia on society is significant and will continue to increase as the number of people living with dementia rises.

The World Health Organization (2017) defines dementia as a syndrome, usually of a chronic or progressive nature, in which there is deterioration in cognitive function beyond that which might be expected from normal ageing. Dementia can adversely affect an individual in many ways – including memory, cognition, orientation, comprehension, calculation, learning capacity, language and judgement. Emotional control, social behaviour, and motivation can also deteriorate.

Dementia is an umbrella term that refers to several types of dementia. Alzheimer's disease is the most common. It is estimated that 66% of people living with dementia in Scotland have Alzheimer's disease (Alzheimer Scotland 2016), and worldwide that estimate is between 60-80% of dementia cases (Alzheimer's Association 2017). Other types include vascular dementia, dementia with Lewy Bodies, Fronto-temporal dementia, Creutzfeldt-Jakob disease and Posterior Cortical Atrophy to name but a few.

Dementia progresses differently in every person. The disease tends to develop slowly and gradually worsens over several years. Hughes et al. (1982) developed a clinical scale for the staging of dementia which offers five stages to help understand the severity of the disease: none, mild

cognitive impairment, mild dementia, moderate dementia and severe dementia. Assigning diagnostic labelling in this way can be viewed negatively as it creates stigma and stereotyping, but it allows researchers to assume that all members of a group are generally homogeneous in the underlying nature of the illness, and provides a convenient way of describing patients (Garand et al. 2009). To ascertain what stage a patient is at using the Clinical Dementia Rating Scale, their cognitive and functional performance is assessed in relation to six areas: memory; orientation; judgement and problem solving; community affairs; home and hobbies, and personal care. Table 1 presents the stages as defined by Hughes et al (1982) and the level of deficit for each stage.

<table>
<tr><th></th><th>None</th><th>Mild Cognitive Impairment</th><th>Mild Dementia</th><th>Moderate Dementia</th><th>Severe Dementia</th></tr>
<tr><td>Memory</td><td>No memory loss or slight inconsistent forgetfulness</td><td>Consistent slight forgetfulness; partial; recollection of events; benign forgetfulness</td><td>Moderate memory loss; more marked for recent events; defect interferes with everyday activities</td><td>Severe memory loss; only highly learned material retained; new material rapidly lost</td><td>Severe memory loss; only fragments remain</td></tr>
<tr><td>Orientation</td><td>Fully orientated</td><td>Fully orientated except for slight difficulty with time relationships</td><td>Moderate difficulty with time relationships; orientated for place at examination; may have geographic disorientation</td><td>Severe difficulty with time relationships; usually disorientated to time, often to place</td><td>Orientated to person only</td></tr>
<tr><td>Judgement and problem solving</td><td>Solves everyday problems and handles business and financial affairs well; judgement good in relation to past performance</td><td>Slight impairment in solving problems, similarities, and differences</td><td>Moderate difficulty in handling problems, similarities, and differences; social judgment usually maintained</td><td>Severely impaired in handling problems, similarities, and differences; social judgment usually impaired</td><td>Unable to make judgments or solve problems</td></tr>
<tr><td rowspan="2">Community affairs</td><td rowspan="2">Independent function at usual level in job, shopping, volunteer and social groups</td><td rowspan="2">Slight impairment in these activities</td><td rowspan="2">Unable to function independently at these activities although may still be engaged in some; appears normal to casual inspection</td><td colspan="2">No pretence of independent function outside home</td></tr>
<tr><td>Appears well enough to be taken to functions outside a family home</td><td>Appears too ill to be taken to functions outside a family home</td></tr>
<tr><td>Home and hobbies</td><td>Life at home, hobbies, and intellectual interests well maintained</td><td>Life at home, hobbies, and intellectual interests slightly impaired</td><td>Mild but definite impairment of function at home; more difficult chores abandoned; more complicated hobbies and interested abandoned</td><td>Only simple chores preserved; very restricted interests, poorly maintained</td><td>No significant function in home</td></tr>
<tr><td>Personal care</td><td colspan="2">Fully capable of self-care</td><td>Needs prompting</td><td>Requires assistance in dressing, hygiene, keeping of personal effects</td><td>Requires much help with personal care; frequent incontinence</td></tr>
</table>

Table 1: Clinical Dementia Rating Scale (Hughes et al. 1982)

One of the main symptoms of dementia is cognitive impairment, which is a key antecedent to agitation (Gerdner 2013). Agitation in people living with dementia is a common, persistent and distressing problem (Livingston et al. 2014), which also causes difficulties for relatives caring for people with dementia at home (Hulme et al. 2010, Ozel-Kizil et al. 2014, Victoroff, Mack and Neilson 1998), and for healthcare professionals in hospital and care home settings. Agitation is frequently not well understood or managed by healthcare professionals (Dewing 2010, Poole and Mott 2003).

Seminal work to comprehend the concept of agitation was undertaken over 30 years ago, and is still recognised as the principal theory on the understanding of the emotional state (James 2011). Agitation was defined by Cohen-Mansfield and Billig (1986 p712) as “inappropriate verbal, vocal or motor activity that is not explained by needs or confusion per se”. Behaviours associated with agitation can include aimless wandering, pacing, cursing, screaming, biting and fighting (Cohen-Mansfield 1986). Mansfield and Billig (1986) offer four categories of agitated behaviour:

- Aggressive – physical
- Aggressive – verbal
- Non aggressive – physical
- Non aggressive – verbal

The physically aggressive agitated behaviour is the most disruptive to the functioning of a ward or unit, whereas the non aggressive behaviours are the least disruptive yet most frequently occurring in care settings (Cohen-Mansfield 1986). Agitation is known to adversely affect quality of life for people with dementia (Samus et al. 2005), places individuals at risk of harm to themselves as well as others, and frequently becoming a reason for admission into long-term care (Dewing 2010).

Traditional management of agitation in people with dementia has commonly involved restraint, either physically or chemically (McCloskey 2004), which was often used to minimise or prevent unwanted

behaviours. The good practice guide *Rights, Risks and Limits to Freedom* states that “restraint should be seen as a ‘last resort’, where there is absolutely no alternative” (Mental Welfare Commission 2013 p6). Chemical or pharmacological management of agitation in people with dementia, a form of restraint, is often used as a therapeutic intervention to manage symptoms of agitation when specific symptoms cannot be ameliorated by any other means. Any form of restraint to manage agitation is not without problems and risks. The psychological and physical side-effects of restraint can be considerable. The use of anti-psychotic medication as a form of restraint has been a priority to reduce because of the risk of side-effects such as falls or stroke (Banerjee 2009, Mintzer and Burns 2000). This has resulted in a focus on alternative strategies to manage agitation in people with dementia, namely non-pharmacological approaches, such as the use of massage, music, and Snoezelen multi-sensory environments.

There are several models of understanding agitation. Many are based on the premise that the individual with dementia has unmet need which is unrecognised (Cohen-Mansfield 2000, James 2011), or that an individual’s personhood is not supported (Kitwood 1997) .The need-driven dementia compromised behaviour model indicates that agitation occurs because of an inability of the caregiver to understand the needs of a person with dementia, and that person’s inability to make their needs known (Algase et al.1996). A model of understanding agitation based on a decreased threshold for environmental stress in people with dementia has been developed by Hall and Buckwalter (1987). They outlined the Progressively Lowered Stress Threshold (PLST) model of care which provides an important framework for healthcare professionals and family carers to comprehend why people with dementia become agitated. Cognitive impairment, a symptom of the dementia, results in the individual having a decreased ability to receive and process sensory stimuli, resulting in a progressive decline in the person’s stress threshold (Hall and Buckwalter 1987). Therefore people with dementia are less able to manage stress as the disease progresses (Smith et al. 2006), and

when faced with intense levels of stress, the person with dementia initially experiences anxiety, which in turn becomes agitated behaviour when this lowered stress threshold is exceeded (Hall and Buckwalter 1987). Stressors which negatively affect individuals with dementia and can lead to agitation include fatigue, change in routine, environment or caregiver, multiple or competing stimuli, demands that exceed functional ability, feelings of loss or anger, pain and new medications (McCloskey 2004). All of these stressors can be experienced when an individual with dementia is admitted to hospital.

Using the theory of PLST to understand the manifestation of agitation in people with dementia has helped healthcare professionals and family carers understand, prevent, and manage agitation for people in their care. It has led to the use of non-pharmacological strategies, as mentioned previously, to reduce stress and in turn hopefully prevent agitation. One such strategy is the use of music. The therapeutic use of music in healthcare has significantly grown in popularity over time (Lin et al. 2011). One form of using music is music therapy, which is a recognised healthcare intervention delivered by a qualified music therapist registered with the Health and Care Professions Council. Music therapy is a psychological therapy that aims to facilitate positive changes in emotional wellbeing and communication through engagement in live music interaction between the client and therapist, often with the client playing musical instruments or singing. More recently there has been an increased interest in the use of individualised music in the care of people with dementia which can be delivered by anyone, in any setting. Individualised music also referred to as preferred music, or personally meaningful music, is different to music therapy. It is music that has been integrated into the person's life and is based on personal preference (Gerdner 1992, quoted in Gerdner 2013, p.8). Individualised music more frequently involves listening to pre-recorded or downloaded music, and the music has significant meaningful memories for the individual.

Gerdner was the first to systematically investigate the use of individualised music as an intervention for agitation in people with dementia, finding a statistically and clinically significant reduction in agitation during the 30 minute presentation of individualised music (Gerdner 1992, quoted in Gerdner 2013, p3). Gerdner (1997) put forward a mid-range theory of individualised music intervention based on the PLST model to explain the effects of individualised music in persons with dementia based on the following prepositions:

1. Persons with Alzheimer's disease and related disorders commonly exhibit agitation. The temporal patterning of these behaviours is often predictable based on application of the PLST model.
2. Music evokes an individualised emotional response within the listener. This response is based on association with personal memories.
3. Response to personal memory is enhanced when music selection is based on the patient's past personal preference.
4. The presentation of an individualised music intervention alleviates agitation in the person with Alzheimer's disease and related disorders.
5. There is a positive correlation between the degree of significance that music had in the person's life before the onset of cognitive impairment and the effectiveness of individualised music.
6. Individualised music is most effective when the intervention is implemented before the peak level of agitation is reached.

When individualised music is administered for the person with dementia, prior to peak times of agitation, it provides the opportunity to recall distant meaningful memories. This has the potential to change the focus of attention from the impending stressor to memories associated with positive feelings. This can have a calming effect on the person with dementia, which in turn will prevent or alleviate the agitated behaviour. See Figure 1.

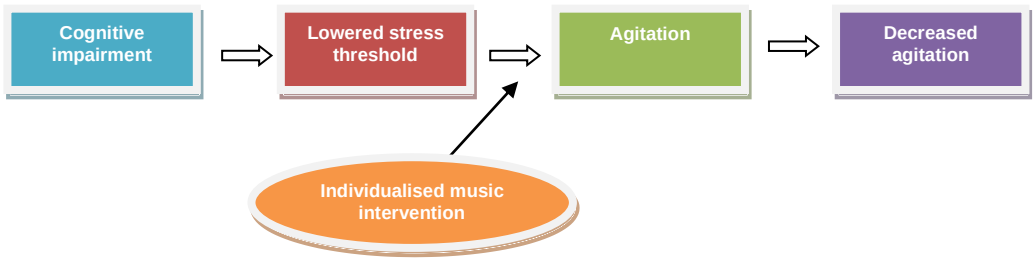


Figure 1: Gerdner's mid-range theory of individualised music for agitation (Gerdner 1997 p178)
*(Reproduced with permission of Linda Gerdner)*

Since the mid 1990's, the use of individualised music has become more widespread in the care of people with dementia. An increasing number of researchers have explored the trend, sometimes comparing with other non-pharmacological strategies.

This thesis presents a critical review of the current literature on the use of individualised music in dementia care. There is some good evidence in relation to its effectiveness in managing levels of agitation in people with dementia, but it is lacking in relation to people with more advanced stage dementia, and also people with dementia being cared for in a hospital setting. To address this, a pilot study was undertaken in a specialist mental health hospital to explore the use of individualised music for people with moderate to severe dementia in this particular setting. People with moderate to severe dementia are often less likely to be recruited in to research studies due to particular challenges around capacity to consent to research, but the researcher felt it was an important area to investigate and so ensured the necessary legal and ethical considerations were addressed to allow the study to take place.

The aim of the pilot study was to better understand the potential of individualised music in dementia care and treatment, developing theoretical and practical knowledge to support the use of individualised music in hospital care.

## Chapter 2: Use of individualised music to decrease agitation in people with dementia – an integrated review of the literature

### 2.1 Background

People living with moderate to severe dementia experience substantial cognitive impairment, a key antecedent to agitation (Gerdner 2012). Although a main symptom of dementia is cognitive decline, agitation is common, persistent and distressing. Agitation in people with dementia can result from unmet need (Algase et al 1996, Cohen Mansfield 2000, James 2011) or from a decreased ability to receive and process sensory stimuli. This results in a progressive decline in the person's stress threshold, and a heightened potential for anxiety (Hall and Buckwalter 1987). As the disease progresses, it can become more difficult for people with dementia to elicit their unmet need, or fewer stressors are necessary to meet and surpass the stress threshold, resulting in anxious and agitated behaviours. Cohen-Mansfield and Billig (1986 p712) define agitation as an "inappropriate verbal, vocal or motor activity that is not explained by need and confusion per se". Agitation in people with dementia results in poorer quality of life for the individual as well as negative impact on the carer. Agitation is reported as the most important cause of caregiver burden (Ozel-Kizil et al. 2014, Victoroff, Mack and Neilson 1998). Importantly, burden decreases if agitation is successfully treated (Kong, Evans and Guevara 2009).

Assessment of agitation in people with dementia admitted to hospital is an essential part of the healthcare professional's role. Agitation may have many different causes so a full and careful assessment of possible physical, psychological and environmental factors is essential. It is important to determine if the agitation is causing significant distress to the person with dementia, their carer or others, as not all agitation requires treatment (Howard et al. 2001). In some situations, agitation may be an appropriate response to a difficult circumstance or environment. When no reversible physical cause can be identified for the agitation it is necessary to explore

strategies to manage it. A sequential approach to managing agitation should be employed, attempted in the following order:

- an assessment of the quality of the care situation and identification of any unmet need or environmental stressors, and addressed as appropriate
- non pharmacological strategies to manage agitation which should be the mainstay of treatment options
- pharmacological strategies when all other approaches have failed

However, at present many people with dementia are inappropriately treated with medication as a first line. Pharmacological treatment is at times routinely used to manage agitation, but it is now discouraged as the side-effects of such treatment can cause greater challenges, namely drowsiness, high risk of falls, cardiac problems, stroke and accelerated cognitive decline (Livingston et al. 2014). A systematic review (Sink, Holden and Yaffe, 2005) to evaluate the efficacy of pharmacological agents used in the treatment of neuropsychiatric symptoms in dementia such as agitation, aggression, delusions and hallucinations, found that pharmacological therapies such as the atypical antipsychotics risperidone and olanzapine currently have the best evidence for efficacy, but the effects are modest and further complicated by the risk of stroke. Antipsychotic medication works by blocking molecules in the dopamine pathways of the brain. Typical antipsychotics, such as haloperidol and chlorpromazine, are known as first generation antipsychotics developed in the 1950s and have high risk of side effects. Atypical antipsychotics, such as those mentioned above, have been developed since the 1990s and the side-effects are less severe. But the taking of either type of medication has inherent risks, therefore alternatives, such as non-pharmacological strategies, need to be promoted, and their effectiveness evaluated through practice based research.

Non-pharmacological treatments of agitation, including music, are now more widely recommended and utilised. Music therapy, comprising listening to music, playing instruments, and singing, is often used, predominantly in group situations. Vink, Bruinsma and Scholten (2004) carried out a systematic review of music therapy for people with dementia and described

various positive effects including the improvement of articulation of speech through singing, reduction of anxiety and fear through reminiscence, and improvement of fine and gross motor coordination through playing instruments with others. The use of personally meaningful music administered on an individual basis is a newer concept, and is gaining popularity and awareness through the creation and work of the UK wide charity Playlist for Life©. Gerdner (2010, 2013) developed an evidence-based protocol for individualised music for people with dementia, based on the premise that familiar music from the past can assist in memory recall and elicit memories associated with positive feelings (Sung and Chang 2005). Based on the Progressively Lowered Stress Threshold of understanding agitated behaviour, Gerdner's mid-range theory of individualised music advocates using individualised music prior to peak times of agitation can help reduce or prevent that unwanted behaviour (Gerdner 1997). Many healthcare practitioners have started to use the approach of individualised music in caring for people with dementia, especially those experiencing stress and distress. Therefore there is a need to scope the current literature on its use in order to provide valuable practical information to contribute to the improvement of the quality of care for people with dementia.

## 2.2 Aim of the review

The aim of this review was to provide a summary of the current literature on the use of individualised music and its effect on agitated behaviours in people with dementia. It was important to do this to identify, appraise, and synthesise the existing national and international literature on the use of individualised music to help inform the current investigation. By undertaking this review it was possible to identify strengths, but also weaknesses in previous work, and thus eliminate them in the current study. It also provided an up-to-date understanding of the subject and its significance to current practice, and identified the gap in knowledge which this current study has addressed. There have been several studies that have explored the use of music therapy in dementia care (Chu et al. 2014, McDermott et al. 2013,

Ueda et al. 2013, Vink et al. 2013, Vink et al. 2014) but this review specifically explored the use of individualised music.

## 2.3 Method

### 2.3.1 Search strategy

The aim of the search was to identify all quantitative studies with an individualised music intervention that explored the effects on agitation levels in people with a diagnosis of dementia. The search was limited to quantitative studies as the researcher wanted to examine studies presenting data that can be used to look for cause and effect relationships, and therefore can be used to make predictions about the two variables in question - individualised music and levels of agitation. Search terms related to the study population and the interventions were combined. The following computerised data databases were searched: CINAHL, MEDLINE, PsychINFO, ASSIA, and EMBASE. Search terms used were music therapy, personal* music, preferred music, individual* music, dementia and Alzheimer*. The wild card approach (ending with *) was used to ensure inclusion of all permutations. Limits to the search process included: date (1995 to January 2017) as there was an increase of research in this topic around the mid nineties when Gerdner started to publish her work on the use of individualised music; design of study (randomised control trial, controlled trial, clinical trial, cross over trial); and to articles written in the English language. The initial search was carried out in August 2015 and this was extended in January 2017. The author reviewed titles and abstracts of the articles from the search and the full text version of any article that described a potentially relevant study was obtained. The reference lists of the articles identified for inclusion in the review were hand-searched to obtain further relevant articles. This resulted in one further study. The author's research supervisor shared a further article, which was also included.

### 2.3.2 Inclusion / exclusion criteria

The full text articles were assessed for eligibility using specific inclusion and exclusion criteria developed using the PICO model. PICO stands for population, intervention, comparator and outcome (Cherry and Dickson 2014). Using this model allowed clear definition of the key components of the research question. See Table 2 for the inclusion and exclusion criteria using the PICO model. The predominant reason for exclusion at this stage was that the intervention was not individualised music. Portions of papers were excluded that were qualitative evaluations.

| | Inclusion criteria | Exclusion criteria |
|---|---|---|
| Patient population | People with a diagnosis of any type of dementia: mild, moderate, severe | People without a diagnosis of dementia |
| Intervention | Preferred music, personalised music, individualised music | Non preferred music (music chosen by a researcher, musician, caregiver)<br>Music therapy<br>Singing<br>Playing instruments |
| Comparator | Treatment as usual<br>Any other non-pharmacological intervention | Pharmacological intervention for management of agitation e.g. antipsychotic medication |
| Outcome | Agitation<br>(assessed using some form of measurement tool / scale) | Falls, dietary intake, depression, anxiety, quality of life |
| Study design | Randomised control trial, controlled trial, quasi-experimental, cross over design | Qualitative review, qualitative case study, systematic review, thematic analysis |

Table 2: Inclusion and exclusion criteria for integrated review

### 2.3.3 Study appraisal

A general appraisal of the included studies was conducted in relation to their design, participants, study site, intervention, measures and findings. This

was carried out to allow the author to become more familiar and absorb the information in the article. To facilitate this process the Critical Appraisal Skills Programme (CASP) (CASP 2017) was used. CASP provide tools to enable the novice researcher to assess trustworthiness, relevance and results of published papers to decide if the findings are believable and useful. There are eight CASP tools for different research designs. The author used the tool for randomised control trials, which consists of eleven questions to help one make sense of a trial. The broad issues covered include methodological processes, presentation of the results, and potential to inform future practice.

### 2.3.4 Study design

The study design was identified for each of the included papers. Included research designs in the search process were:

- Randomised control trial – an experimental methodology that aims to reduce bias when testing an intervention. Participants are allocated at random to receive either the experimental intervention or the control intervention.
- Controlled trial – a methodology where the participants receive the experimental intervention (in a non randomised allocation) and a pre-test post-test comparison is made.
- Quasi-experimental study - shares similarities with the randomised controlled trial, but the assignment of the experimental condition to one group is controlled by the researcher.
- Cross over study - the participants serve as their own control and received a sequence of different treatments counterbalanced in terms of order of presentation.

### 2.3.5 Study quality

CASP allowed the researcher to gain a thorough understanding of the content of each study, but it was felt a more in depth analysis was required to

judge the quality of the study. Each study was assessed against six criteria contained in the Quality Assessment Tool for Quantitative Studies developed by the Effective Public Health Practice Project (Thomas et al. 2004). The criteria are selection bias, study design, confounders, blinding, data collection methods and study withdrawals/dropouts. Each study was then assigned an overall global rating based on individual quality ratings. The author also considered additional criteria, which are not included in the above tool. These were included as the author felt they added value to her understanding of the study and gave her greater confidence in the reliability and validity of the findings. The additional criteria considered by the author included explicit description of the hypotheses of the study, evidence of a power based sample size calculation, inter-rater reliability calculation performed for the assessors in that particular study, and inclusion of a washout period between interventions if a cross over design study.

### 2.3.6 Study analysis

Data from the above process, using the criteria described in Section 2.3.5, was extracted from the papers and tabulated to give an overview of the quality of each individual study. The global rating identified using the Quality Assessment Tool was documented in this table, along with the additional criteria added by the author. Following the consideration of both of these, a secondary overall quality rating was assigned to each study - see Table 5.

## 2.4 Results

The search strategy yielded 16 studies (see Figure 2) predominantly from United States of America (6 studies), but also from Australia (1 study), France (1 study), Italy (2 studies), Spain (1 study), Sweden (1 study), South Korea (1 study), Japan (1 study), and Taiwan (2 studies).

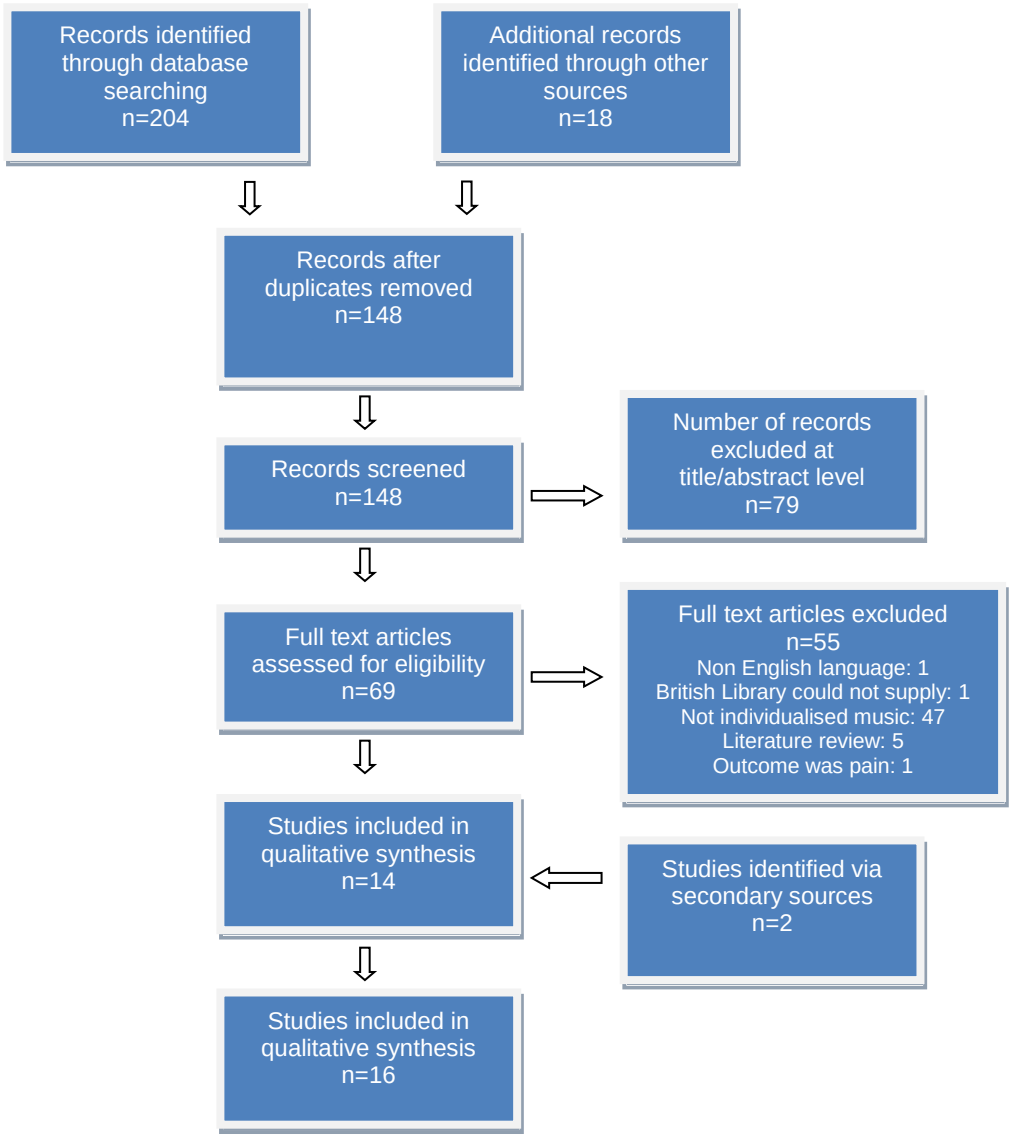


Figure 2: Flow diagram of literature search using the PRISMA Flow Diagram (Moher et al. 2009)

The studies were published between 1997 and 2016. All articles were published in peer-reviewed journals. Two articles were published in the letter section of the journal therefore not necessarily peer reviewed (Raglio et al. 2013, Sung, Chang and Abbey 2006). Healthcare professionals carried out the majority of studies, the exception being the study by Clark, Lipe and Bilbrey (1998), which was led by Assistant Professors of Music and a Co-ordinator of Social Services.

The characteristics of the included studies are summarised in Table 6.

Prior to discussing the main findings of the use of individualised music for people with dementia, information from the included studies is presented. They are described according to the main elements of a quantitative research study, namely sample, design, study interventions, measures and main findings.

### 2.4.1 Sample

The participants involved in all studies were people with a diagnosis of dementia, with the exception of one study where it was identified one participant did not have a formal dementia diagnosis (Cohen-Mansfield and Werner 1997). Participants were living in a nursing home or long-term care facility (10 studies), assisted living accommodation (1 study), care home and/or special dementia setting (1 study), nursing home and/or day care centre (1 study), their own home (2 studies), and the study site was unknown for 1 study. In total n=575 people with dementia were recruited into the studies but only n=517 fully completed their involvement giving a dropout rate of 10%. The sample size in the included studies varied from 4 to 120 participants. The median sample size was 30 participants. The sample size for the controlled trials was predominantly smaller, ranging from 4 to 26 participants. The cross over studies ranged from 17 to 60 participants, but the study (Cohen-Mansfield and Werner 1997) with a sample of 60 resulted in only 32 participants actually completing the study. The quasi-experimental design ranged from 52 to 57 participants. The randomised controlled trial studies had the largest sample size by far, ranging from 26 to 120 participants, but correspondingly had the greatest number of participants not completing their study involvement. This occurred in four out of the five studies (Guétin et al. 2009, Janata 2013, Raglio et al. 2015, Sanchez et al. 2016).

### 2.4.2 Assessment of stage of dementia

The most commonly used tool to assess or classify the cognitive function of the participants was the Mini Mental State Examination (Folstein, Folstein and McHugh 1975). However, a variety of assessment and classification tools were used and some studies utilised more than one. See Table 3 for detail. Only one study did not make reference to any instrument for assessing or defining the level of cognitive functioning or diagnosis (Sung, Chang and Abbey 2006).

One study included participants with mild to moderate dementia (Guétin et al. 2009), three studies reported their participants had mild to severe dementia (Gerdner 2000, Gerdner 2005, Park and Specht 2009), six studies included participants with moderate to severe dementia (Cohen-Mansfield and Werner 1997, Janata 2012, Park 2013, Raglio et al. 2013, Raglio et al. 2015, Sung, Chang and Lee 2010), four studies classified the participants as having severe dementia (Clark, Lipe and Bilbrey 1998, Garland et al. 2007, Ragneskog et al. 2001, Sakamoto, Ando and Tsutou 2013), and a final study included participants with a severe to very severe dementia (Sanchez et al. 2016). It is not possible to describe this characteristic in one study as no detail was provided (Sung, Chang and Abbey 2006).

| | MMSE* | Global Deterioration Scale | DSM IV Criteria** | GBS Rating Scale for Dementia Syndromes | NINCDS: ADRDA*** | Clinical Dementia Rating Scale | Brief Cognitive Rating Scale | Neuro-psychiatric Inventory**** |
|---|---|---|---|---|---|---|---|---|
| Clark , Lipe and Bilbrey (1998) | ✓ | | | | | | | |
| Cohen-Mansfield and Werner (1997) | | | | | ✓ | | ✓ | |
| Garland et al. (2007) | ✓ | | | | | | | |
| Gerdner (2000) | | ✓ | | | | | | |
| Gerdner (2005) | | ✓ | | | | | | |
| Guétin et al. (2009) | ✓ | | | | | | | |
| Janata (2012) | ✓ | | | | | | | ✓ |
| Park and Specht (2009) | ✓ | | | | | | | |
| Park (2013) | ✓ | | | | | | | |
| Raglio et al. (2013) | ✓ | | ✓ | | | | | |
| Raglio et al. (2015) | ✓ | | ✓ | | | | | |
| Ragneskog et al. (2001) | ✓ | | ✓ | ✓ | | | | |
| Sakamoto, Ando and Tsutou (2013) | ✓ | | ✓ | | | ✓ | | |
| Sanchez et al. (2016) | | ✓ | | | | | | |
| Sung, Chang and Abbey (2006) | | | | | | | | |
| Sung, Chang and Lee (2010) | | ✓ | | | | | | |

* Mini Mental State Examination

** Diagnostic and Statistical Manual on Mental Health Disorders 4th Edition

*** National Institute of Neurological and Communicative Disorders and Stroke: Alzheimer's Disease and Related Disorders Association.

**** Neuropsychiatric Inventory

Table 3: Classification and assessment tools used to identify type or level of cognitive impairment

### 2.4.3 Study design

Various research designs were used in the included studies. The earlier studies tended to use an experimental cross over design whereas later studies used the randomised control trial design. Six studies were carried out between 1997 and 2006. Of these, 33% were controlled trials, 17% quasi-experimental design, and 60% were experimental cross over studies. There were no randomised controlled trials during this decade. Of studies performed from 2007 to 2016, 20% were controlled trials, 10% quasi-experimental design, 20% were experimental cross over studies and 50% were randomised controlled trials. Randomised controlled trials are seen as the most rigorous way of determining whether a cause and effect relationship exists between treatment and outcome, and hence are the gold standard that researchers aim for, perhaps explaining the increase in more recent years.

One of the most common research designs (31%) was the experimental cross over study (Clark, Lipe and Bilbrey 1998, Cohen-Mansfield and Werner 1997, Garland et al. 2007, Gerdner 2000, Raglio et al. 2013). In one study (Clark, Lipe and Bilbrey 1998) the participants received only the treatment of individualised music compared to no music. In the other studies, the different treatments used as comparators included no music, family video and 1:1 social interaction (Cohen-Mansfield and Werner 1997), classical music (Gerdner 2000), family video and reading from a gardening book (Garland et al. 2007), and music therapy (Raglio et al. 2013). Four out of the five studies included a washout period to null any cumulative effects of the interventions, which ranged from two days (Garland et al. 2007), one week (Cohen-Mansfield and Werner 1997), two weeks (Gerdner 2000) and two months (Raglio et al. 2013). Clark, Lipe and Bilbrey (1998) did not include a washout period.

Four studies (25%) used the controlled trial methodology (Gerdner 2005, Park 2013, Park and Specht 2009, Ragneskog et al. 2001). The study by Gerdner (2005) also had a qualitative element to the research design as she

explored the experiences and views of relatives and of healthcare professionals in using individualised music.

Two studies (12.5%) used a ‘quasi-experimental’ design (Sung, Chang and Abbey 2006, Sung, Chang and Lee 2010). Each of these studies took place in a nursing home or residential home comprising two or more units. One unit was randomly assigned the experimental intervention of individualised music and another unit was assigned as the control group and received care as usual.

The remaining five studies used a ‘randomised control trial’ design (Guétin et al. 2009, Janata 2013, Raglio et al. 2015, Sakamoto, Ando and Tsutou 2013, Sanchez et al. 2016). Guétin et al. (2009) compared individualised music with rest and reading; Janata (2013) compared individualised music with no music; Sakamoto, Ando and Tsutou (2013) compared interactive individualised music, passive individualised music and no music; Raglio et al. (2015) compared individualised music, music therapy and standard care; and Sanchez et al. (2016) compared individualised music and a multisensory stimulation environment.

### 2.4.4 Study interventions

The included studies compared the use of individualised music with various different interventions. The comparators were:

- standard care (no music)
- classical music (non participant selected)
- music therapy
- family video or audio-tape
- relaxation music
- reading sessions
- multisensory stimulation environment

### 2.4.5 Implementation of intervention

Some researchers identified specific care events as an occasion to administer the experimental intervention. Clark, Lipe and Bilbrey (1998) explored the use of individualised music specifically during bath times as a method to decrease aggressive behaviours, whereas Cohen-Mansfield and Werner (1997) only administered the experimental intervention when the participant was most verbally disruptive, as reported by the nursing staff. Some researchers identified the peak time of agitation for the participant and administered the intervention in the preceding 30 minute time period (Gerdner 2000, Gerdner 2005, Park 2013, Park and Specht 2009).

The method of delivering the musical interventions varied between the included studies. The majority of studies delivered the music via a cassette tape player or compact disc player (Clark, Lipe and Bilbrey 1998, Cohen-Mansfield and Werner 1997, Gerdner 2000, Gerdner 2005, Park 2013, Park and Specht 2009, Ragneskog et al. 2001, Sakamoto, Ando and Tsutou 2013, Sung, Chang and Lee 2010), sometimes in the participant's room or in the day room of the study site. Others administered the music via headphones (Garland et al. 2007, Guétin et al. 2009), or via wireless streaming directly into the participants' room (Janata 2012) or via a personal computer (Sanchez et al. 2016). For one study (Raglio et al. 2013), it was not made clear how the music was delivered, only that it was administered to the participant alone. In another study led by the same author (Raglio et al. 2015), it is stated that the music was not administered by headphones, but it was not made explicit if this was therefore by cassette tape player, compact disc player, wireless streaming, personal computer or another method such as a docked MP3 player for example. In the study by Sung, Chang and Abbey (2006) there was no detail provided as to how the music was delivered.

In several studies the music intervention or comparator interventions were administered by research assistants (Clark, Lipe and Bilbrey 1998, Cohen-Mansfield and Werner 1997, Garland et al. 2007, Gerdner 2000, Ragneskog

et al. 2001, Sakamoto, Ando and Tsutou 2013, Sanchez et al. 2016). Three studies (Gerdner 2005, Sung, Chang and Abbey 2006, Sung, Chang and Lee 2010) used nursing staff to administer the intervention, and two studies were in the participant's own home so the family caregiver delivered the music (Park and Specht 2009, Park 2013). In the studies carried out by Guétin et al. (2009) and Janata (2012) the music was streamed into the participant's room and it was not explicit if a nurse, carer or research assistant was also present. In two studies the participant was alone when listening to the music (Raglio et al. 2013, Raglio et al. 2015).

The duration of the musical intervention also varied in the included studies. The shortest duration of music was 15 minutes (Garland et al. 2007). The next in length was 20 minutes, and this observed a specific pattern of presenting the individualised music by playing rhythmically stimulating music first (faster tempo, louder volume, with 10-20 instruments playing), followed by relaxing music with a slow rhythm, (slower tempo, quieter volume, 1-3 instruments playing), and finishing with music of a moderate rhythm (medium tempo, medium volume, 8-10 instruments playing) (Guétin et al. 2009). Janata (2012) delivered a very different format of music to any other study, presenting the music four times a day. The music was administered for 21-25 minutes in the morning and in the evening, and for 50-65 minutes twice in-between times. All the remaining studies delivered the intervention for a 30 minute period once per day (Cohen-Mansfield and Werner 1997, Gerdner 2000, Gerdner 2005, Park 2013, Park and Specht 2009, Raglio et al. 2013, Raglio et al. 2015, Ragneskog et al. 2001, Sakamoto, Ando and Tsutou 2013, Sanchez et al. 2016, Sung, Chang and Abbey 2006, Sung, Chang and Lee 2010).

The number of music sessions conducted in the studies also varied. There was as little as three sessions (of each type of music intervention) in one study (Garland et al. 2007), and as many as 336 sessions of individualised music in another study (Janata 2012).

### 2.4.6 Study outcome measures

The included studies explored the impact of individualised music on varying behavioural symptoms of dementia. Some studies were more explicit and identified specific outcome behaviours they measured. See Table 4 for a summary of the number of studies measuring specific behaviours.

| **Behaviour** | **Number of studies** |
|---|---|
| Agitation | 7 |
| Agitation and depression | 1 |
| Anxiety | 1 |
| Anxiety and depression | 1 |
| Verbally disruptive behaviour | 1 |
| Aggressive behaviour | 1 |
| Behavioural and psychological symptoms of dementia | 4 |

Table 4: Summary of the number of studies measuring specific behaviours

The most frequently used measurement tool was the Cohen-Mansfield Agitation Inventory (CMAI) or a modified version of this tool. Nine studies used either of these tools (Cohen-Mansfield and Werner 1997, Gerdner 2000, Gerdner 2005, Janata 2012, Park 2013, Park and Specht 2009, Raglio et al. 2013, Sung, Chang and Abbey 2006, Sanchez et al. 2016). Two studies developed their own observational behaviour checklists (Clark, Lipe and Bilbrey 1998, Garland et al. 2007), whereas Cohen-Mansfield and Werner (1997) developed a new tool specifically for this study, the Screaming Behavioural Mapping Instrument. The two tools used to measure anxiety were the Hamilton Scale for Anxiety (Guétin et al. 2009) or the Rating Anxiety in Dementia (Sung, Chang and Lee 2010, Sanchez et al. 2016). The Geriatric Depression Scale (Guétin et al. 2009) or the Cornell Scale for Depression (Janata 2012, Raglio et al. 2013, Raglio et al. 2015, Sanchez et al. 2016) were used to measure depression, and the Neuropsychiatric Inventory was used to measure neuropsychiatric symptoms (Janata 2012, Raglio et al. 2013, Raglio et al. 2015). Two studies videoed the participants and used measurement tools to assess emotions shown facially. Sakamoto, Ando and Tsutou (2013) used the Faces Scale and Ragneskog et al. (2001) used the Facial Action Coding System. Sakamoto, Ando and Tsutou (2013)

also used the Behavioural Pathology in Alzheimer's Disease Rating Scale to measure long term effects of changes in behavioural and psychological symptoms of dementia. Other than the tools developed by the researchers specifically for their individual studies, all other measurement tools are professionally recognised and utilised by healthcare professionals across the world. Their reliability and validity in measuring psychometric assessments are used in critically appraised academic literature. Seven of the included studies established inter-rater reliability (Clark, Lipe and Bilbrey 1998, Cohen-Mansfield and Werner 1997, Garland et al. 2007, Gerdner 2000, Gerdner 2005, Ragneskog et al. 2001, Sung, Chang and Lee 2010). Of the remaining studies, two used family members to undertake the assessments (Park 2009, Park and Specht 2009), and one study had only one rater (Guétin et al. 2009). The remaining studies did not provide evidence of inter-rater reliability (Janata 2012, Raglio et al. 2013, Raglio et al. 2015, Sakamoto, Ando and Tsutou 2013, Sanchez et al. 2016, Sung, Chang and Abbey 2006).

Only two studies made reference to training being given to the evaluators (individuals undertaking the measurements) in the use of the assessment tool (Gerdner 2000, Gerdner 2005).

Only six of the included studies made reference in the article to the evaluators being blinded to the experimental and comparator interventions (Garland et al. 2007, Guétin et al. 2009, Janata 2012, Raglio et al. 2013, Raglio et al. 2015, Sakamoto, Ando and Tsutou 2013). In five studies this was not applicable, as it was either music or no music (Clark, Lipe and Bilbrey 1998, Gerdner 2005, Park 2013, Park and Specht 2009, Sung, Chang and Lee 2010). One study compared individualised music with videotape of family and with social interaction, so it was not possible to blind to these very different comparators (Cohen-Mansfield and Werner 1997). But in a further two studies blinding did not take place where it was potentially possible (Gerdner 2000, Ragneskog et al. 2001). In these studies individualised music was compared with classical music. In the final two studies it was not clear from the article whether the evaluator was blinded to

the intervention or not (Sanchez et al. 2016, Sung, Chang and Abbey 2006). Participants were not blinded to the intervention.

### 2.4.7 Study quality

Using the Quality Assessment Tool for Quantitative Studies to score each study resulted in four studies rated as moderate and twelve studies rated as strong. See Table 5 for a summary of the study quality assessment. Following further assessment using additional criteria deemed important by the author, two studies were rated as weak, ten as moderate, and four as strong. The studies rated more highly provided evidence of a power based sample size calculation, inter-rater reliability, and utilised a valid and reliable measurement tool. The main limitations identified in the moderate or weak rated studies included lack washout period between interventions, no evidence of blinding of the raters, or use of measurement tools developed specifically for the study with no evidence of internal validity or reliability. No studies met all of the quality criteria applicable to their individual study design.

### 2.4.8 Study findings

Most studies reported positive outcomes for the use of individualised music in managing the occurrence of some types of agitated behaviours in older people with dementia. Only one study, which compared the addition of music therapy or individualised music to standard care, did not find individualised music to have a significant effect on behavioural and psychological symptoms of dementia (Raglio et al. 2015). In some studies, that compared individualised music with another intervention, individualised music did decrease the unwanted behaviour but the comparator intervention was found to be more effective. Cohen-Mansfield and Werner (1997) found social interaction reduced verbally disruptive behaviours by 56%, videos of family by 46%, and individualised music by 31%. But this was in comparison to a

reduction in behaviours of only 16% with no intervention. Similarly, simulated presence (audio recordings of family members talking) significantly reduced counts of verbally agitated behaviours whereas individualised music did not do this to a significant level (Garland et al. 2007). Multi-sensory stimulation environment was found to be more effective than individualised music on anxiety symptoms and dementia severity (Sanchez et al. 2016).

Gerdner (2000) compared individualised music with classical relaxation music and found a more significant reduction in agitation using individualised music than relaxation music. Ragneskog et al. (2001) in his small study of only four participants found that individualised music did reduce levels of agitation, but in the two participants most affected by dementia the effect of the music was minimal. In a study that compared passive individualised music with interactive individualised music, the latter resulted in participants exhibiting the strongest beneficial effects (Sakamoto, Ando and Tsutou 2013), although passive individualised music was better than no music at all.

| | **Quality Assessment Tool for Quantitative Studies** | | | | | | | ***Additional criteria determined and considered by author*** | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Selection bias | Study design | Confounders | Blinding | Data collection methods | Withdrawals and dropouts | **Global rating** | *Hypotheses stated* | *Power base sample size calculation* | *Washout period included in study design* | *Inter-rater reliability determined for study* | *Number of times intervention applied* | ***New rating*** |
| Clark, Lipe and Bilbrey 1998 | Moderate | Strong | n/a | Moderate | Weak | Strong | **Moderate** | ✗ | ✗ | ✗ | ✓ | *10* | ***Weak*** |
| Cohen-Mansfield and Werner 1997 | Strong | Strong | n/a | Moderate | Moderate | Weak | **Moderate** | ✗ | ✗ | ✓ | ✓ | *Not stated* | ***Moderate*** |
| Garland et al. 2007 | Moderate | Strong | n/a | Strong | Weak | Strong | **Moderate** | ✓ | ✗ | ✓ | ✓ | *3* | ***Moderate*** |
| Gerdner 2000 | Moderate | Strong | n/a | Moderate | Strong | Strong | **Strong** | ✓ | ✗ | ✓ | ✓ | *12* | ***Strong*** |
| Gerdner 2005 | Moderate | Strong | n/a | Moderate | Strong | Strong | **Strong** | ✓ | ✗ | *n/a* | ✓ | *56* | ***Strong*** |
| Guétin et al. 2009 | Moderate | Strong | Strong | Strong | Moderate | Strong | **Strong** | ✗ | ✓ | *n/a* | *n/a one rater* | *16* | ***Strong*** |
| Janata 2012 | Moderate | Strong | Strong | Strong | Moderate | Strong | **Strong** | ✗ | ✗ | *n/a* | ✗ | *336* | ***Moderate*** |
| Park and Specht 2009 | Moderate | Strong | n/a | Moderate | Moderate | Strong | **Strong** | ✓ | ✗ | *n/a* | *n/a family member* | *8* | ***Moderate*** |
| Park 2013 | Moderate | Strong | n/a | Moderate | Moderate | Strong | **Strong** | ✓ | ✓ | *n/a* | *n/a family member* | *4* | ***Moderate*** |
| Raglio et al. 2013 | Moderate | Strong | n/a | Strong | Moderate | Strong | **Strong** | ✗ | ✗ | ✓ | ✗ | *30* | ***Moderate*** |
| Raglio et al. 2015 | Moderate | Strong | Strong | Strong | Moderate | Strong | **Strong** | ✗ | ✗ | *n/a* | ✗ | *20* | ***Moderate*** |
| Ragneskog et al. 2001 | Moderate | Strong | n/a | Moderate | Strong | Strong | **Strong** | ✗ | ✗ | *n/a* | ✓ | *4 or 5* | ***Moderate*** |
| Sakamoto, Ando and Tsutou 2013 | Moderate | Strong | Strong | Strong | Moderate | Strong | **Strong** | ✓ | ✗ | *n/a* | ✗ | *10* | ***Moderate*** |
| Sanchez et al. 2016 | Moderate | Strong | Strong | Moderate | Moderate | Strong | **Strong** | ✗ | ✗ | *n/a* | ✗ | *32* | ***Moderate*** |
| Sung, Chang and Abbey 2006 | Moderate | Moderate | Weak | Moderate | Moderate | Strong | **Moderate** | ✗ | ✗ | *n/a* | ✗ | *12* | ***Weak*** |
| Sung, Chang and Lee 2010 | Moderate | Moderate | Strong | Moderate | Strong | Strong | **Strong** | ✗ | ✓ | *n/a* | ✓ | *12* | ***Strong*** |

Table 5: Summary of study quality assessment

## 2.5 Discussion

As a result of systematically identifying and appraising the existing literature on the use of individualised music in caring for people with dementia experiencing agitated behaviours it is evident that individualised music has some effect on levels of agitation. There is significant learning to take from this review, as well acknowledging methodological limitations apparent in the studies reviewed.

The literature search and application of the inclusion and exclusion criteria elicited sixteen studies for inclusion in this review exploring the use of individualised music in caring for people with dementia. The majority of articles were published in the last decade, which reflects the change in practice over recent years from the reliance on medication to manage agitation to the use of non-pharmacological approaches to care. The searching of reference lists from the most recent papers did not bring about any further studies not already identified, so this gave confidence that all relevant research had been included in this integrated review, and that conclusions drawn from this review are based on all available evidence.

All bar one study exploring the use of individualised music in dementia care reported beneficial effect in using individualised music to improve levels of agitation in people with dementia. The finding of this review is similar to those of previous reviews in which certain non-pharmacological interventions such as aromatherapy, hand massage, rocking chair therapy, pet therapy, doll therapy, Snoezelen therapy and light therapy have been shown to have the potential to reduce unwanted behaviours in people with dementia (Kong, Evans and Guevara 2009, Livingston et al. 2014). It is also in line with the systematic review (Hulme et al. 2010) of non-pharmacological approaches for dementia that family carers might use, that found that music and music therapy has beneficial effects, and in particular playing preferred (favourite) music can reduce agitation. Similarly, a literature review by Sung and Chang (2005) also concluded that preferred music has positive effects on decreasing agitated behaviours in people with dementia, but also noted

limitations in the studies they reviewed and suggested further research was needed. The findings of this current review also support current national policy on the reduction in the use of pharmacological treatments to manage unwanted behaviour in dementia (Banerjee 2009), and a move to non-pharmacological approaches (Scottish Government 2013).

The majority of the studies were rated as strong or moderate when assessed for quality, but several methodological limitations are apparent within the reviewed studies. The following weaknesses should be carefully considered when using the findings to inform future practice.

The majority of the studies reviewed used a purposive sampling technique, a type of non-probability sampling. The size of samples ranged from four to sixty participants, with one exception of a randomised control trial with 120 participants. However, some studies, mainly using a controlled trial design, had very small samples of between four and eighteen participants. When this is the case, any findings should be interpreted cautiously as the external validity of these studies may be reduced, and may not be representative of the wider population of people with dementia. On the other hand one could argue they should be given more weight because they reduce bias through control. In addition, only three of the sixteen included studies detailed any description of how they determined their sample size. But positively, all relevant studies that involved randomisation, detailed their procedure for randomly allocating participants to the various interventions. The study settings of all included studies focused on people with dementia living either at home, or in a long term care facility, nursing home or day centre. The differences in these settings may alter the way the intervention is administered, received by the participant, and their response, and hence the outcomes achieved. It is also not possible to generalise the findings to other care settings such as hospital care. The more rigorous research design of randomised controlled trial tended to be that used by the more recently undertaken studies, and could be argued to provide a higher level of evidence of effectiveness that can be used to inform practice. All the randomised control trials included in this review were rated as ‘strong’ using

the Quality Assessment Tool for Quantitative studies. By chance, one study explored any qualitative element to using individualised music in dementia care, which was interesting to see as this provided useful triangulation of effect from the viewpoint of healthcare professionals and family members. The search strategy excluded qualitative studies, which explains why more qualitative data was not elicited by the integrated review.

All of the studies reviewed tested the intervention of individualised music. But there was variation in the length of time the participant listened to the music, and how many music sessions the participant received as part of the research protocol. Some studies administered the music at a specifically identified time, for example bath time or prior to peak levels of agitation, whereas other studies were not as precise in dictating this. The variation in all these elements across the included studies makes it difficult to compare outcomes across the studies or perform evidence synthesis with any confidence.

Only three studies used the nursing staff to deliver the individualised music intervention to the participants they were caring for. Alternatively this was carried out by research assistants in several studies. The latter, on a positive note, might provide greater adherence to the research protocol, but it does not provide a realistic picture of what it might be like to use individualised music in routine care.

The majority of the studies reviewed used previously validated and reliable observation rating scales to measure the behavioural outcome. However, three studies developed their own checklist of behaviours or developed a new rating scale, but they did not report on the validity or reliability of these. This is a weakness, and further testing of their self-designed tools would have added credibility to their findings. Several studies reported on the inter-rater reliability of their chosen measurement tool, and some studies went further and carried out inter-rater reliability testing of the evaluators within their actual study. Using a validated measurement tool and assessing inter-rater reliability within the study gives greater assurance that the

measurements are accurate, and the findings of the study are valuable. However, it is worth noting that the studies that developed their own measurement tools all carried out inter-rater testing and demonstrated high levels of reliability. There was no discussion of validity for any of the newly developed tools.

One concerning factor in this integrated review was the lack of blinding of the evaluators undertaking the measurement scales on participants in two studies, where it was feasibly possible. These studies compared individualised music with classical music. The music was played into the room of the participant which meant the evaluator was also exposed to it. A way to allow blinding would be for the participant to listen to the music through headphones so the evaluator cannot hear it. However the participant might not tolerate headphones which would make this method unsuitable. Another possibility would be for the evaluator to wear headphones which block any external noise, but this would also mean they would not hear any noise made by the participant which might be a sign of agitation. Day and Altman (2000) state that human behaviour is influenced by what we know or believe, and in research there is a particular risk of expectation influencing findings, most obviously when the there is some subjectivity in the assessment, leading to biased results. Studies where the evaluators were blinded to the intervention were more likely to eliminate this. Therefore caution should be taken when considering the findings in the studies where the evaluators were not blinded to the intervention. A possibility for future development would be to conduct meta-analyses of studies to see if the effect sizes are moderated by blinding or other study elements such as setting or length of intervention.

Several of the reviewed studies were cross over design where participants received a sequence of different interventions, namely individualised music and at least one other intervention. All studies utilising this design included a washout period in between interventions except one study by Clark, Lipe and Bilbrey (1998) who delivered one intervention immediately followed by another. A washout period is a time when the participants do not receive any

active trial intervention and is intended to prevent continuation of the effects of the trial intervention from one period to another (Bland 2017). This may not be significant in this study as there may not be any carry-over effect from the intervention. But as this is not known, the study would have been improved if a washout period had been included. Very importantly, the studies with a comparative intervention sometimes found that individualised music was not necessarily the best intervention; therefore for these results to be credible the reader needs to be assured that there was no continuation of effect of the previous comparative intervention, which would be achieved by having a washout period.

### 2.5.1 Implications for practice

The studies in this integrated review have reported the beneficial effects of individualised music on agitation levels in people with dementia, but the studies were limited in offering the music intervention to residents in nursing homes or long-term care facilities, day centre attendees or to individuals with dementia living in their own home. The use of individualised music in hospital settings is an unexplored area. Interestingly, although there is positive evidence on the use of individualised music dating over the past two decades, it is not 'routinely' offered within NHS Scotland as a non-pharmacological intervention to manage agitation. This might be due to financial constraints within NHS organisations, or because there is a lack of evidence to demonstrate its effectiveness in NHS settings. To date, no studies have explored the use of individualised music in people with dementia admitted to specialist hospital settings. Hospital admission can add greater stress to an individual with dementia, in addition to the underlying condition requiring treatment, leading to increased agitation. Therefore, strategies to help manage this are vital. Pharmacological management of agitated behaviours is used as a last resort; so the more we know and understand about therapeutic interventions such as individualised music, can help us deliver care that is safe, effective and person centred. Using the findings from this integrated review can help inform those who work in the

care of people with dementia of the importance of using individualised music to reduce levels of agitation, wherever the care setting. The findings should promote consideration of introducing this intervention into everyday dementia care. And if individualised music is beneficial for managing agitation in people with dementia, consideration should be given to see if the effects can be extrapolated to other patient groups who experience high emotional states such as people living with cancer and patients receiving palliative and end of life care. There is a need to test the use of individualised music in hospital settings in order to add to the growing body of evidence demonstrating the positive effects of individualised music in dementia care.

## 2.6 Limitations

This review has a number of limitations. Firstly the author is inexperienced in undertaking a review of this nature so her methodological expertise was learnt 'on the job'. Although every step of the process was supported by theoretical underpinning (Boland, Cherry and Dickson 2014), and guidance and supervision from the author's research supervisors, the inexperience of the author is arguably evident in the quality of the findings. Secondly, only English language studies were included in the review, which may limit the number of available studies. It is difficult to estimate how many articles may have been missed by this action as the author selected English language articles only at the database searching stage. One non-English article did come through this process however, but this may have been because the abstract was in English and the remainder of the article written in Korean. It was however a systematic review and meta-analysis of music therapy, and would not have been included in this integrated review. Another limitation is that the screening of the abstracts from the initial search was undertaken independently by the author, along with the screening of the full text articles. The selected articles for qualitative synthesis were checked by the research supervisors for suitability. This process could have been improved by including the supervisors earlier in the screening process. And finally, a more precise identification of the dependent variable in question would have made

the review more meticulous. As such, although the focus of the review question was agitation, the author allowed a wide interpretation of this phenomenon and included studies exploring aggression, anxiety, verbally disruptive behaviours and depression. Stricter adherence to the aim of the review would have elicited fewer studies and perhaps a higher quality review. Nonetheless, useful learning has taken place as a result of the review of the sixteen studies.

## 2.7 Conclusion and direction for further study

This integrated review has identified, appraised and synthesised the existing literature on the use of individualised music in the care of people with dementia. It has found it to be a beneficial therapeutic intervention in managing agitation that can be used as an alternative or alongside pharmacological strategies. However, the methodological limitations of the included studies should be considered. Future research should explore the use of individualised music in other settings such as hospital care. And research to elicit the views of healthcare professionals and family members in the implementation of individualised music for people with dementia should be undertaken. Relationships between the stage of dementia and the effects of individualised music should also be explored. Given that agitation is the most frequently manifested behavioural symptom of people with dementia (Kong, Evans and Guevara 2009), and that individualised music has the potential to provide a therapeutic approach to care that helps to reduce this, further investigation is warranted. This present study aims to build on research already undertaken; adding to the growing body of evidence on the use of individualised music in dementia care; and ultimately improving the quality of life for people with dementia,

The main research question is:

> *What are the effects of individualised music on levels of agitation in people with moderate to severe dementia being treated and cared for in a specialist mental health hospital setting?*

The research hypotheses are:

1. Individuals with dementia will display less agitation during daily periods of listening to 30 minutes of individualised music than when not listening to individualised music.
2. Individuals with dementia will display less agitation during weekly periods in which individualised music is implemented compared with weekly periods where it is not being implemented.

Additional research questions are:

1. How do healthcare professionals subjectively experience the process of facilitating individualised music to people with dementia in their care setting?
2. How do family carers subjectively experience the use of individualised music with their loved one whilst admitted to hospital?

| | *AUTHOR* | DESIGN | PARTICIPANTS | SITE | INTERVENTION | INSTRUMENT | ANALYSIS | FINDINGS |
|---|---|---|---|---|---|---|---|---|
| 1 | *Clark et al. (1998)* | One group experimental cross over design.<br>Aim of study was to examine the effects of recorded, preferred music in decreasing occurrences of aggressive behaviour among people with dementia during bathing time. | Dementia.<br>History of aggressive behaviours.<br>*n = 18*<br>Mean age 82<br>MMSE mean score 10 | Privately owned nursing facility | No music for 2 weeks and preferred music for two weeks at bathing time (10 episodes).<br>Either during full bath or partial bath. | Observational checklist for aggressive behaviours | Two tailed t-test | Decrease occurred in 12 of 15 aggressive behaviours during music (significant $p<0.05$).<br>All other top 5 individual behaviours looked at separately only showed significant decrease for hitting behaviours.<br>Mean length of bathing time did not differ significantly between music and no music condition.<br>Overall conclusion is that preferred, recorded music may be beneficial in reducing the total number of aggressive behaviours displayed by people with dementia during bathing time. |
| 2 | *Cohen-Mansfield et al. (1997)* | Cross over design. Aim of study is to assess effectiveness of different interventions on verbally disruptive behaviour. | 60 Nursing home residents with verbally disruptive behaviour (VDB) consented to take part. 7 died before any data collection, 5 died whilst completing the intervention, 11 became quiet, 3 refused to continue and 2 were restrained. 32 participants completed the study. Not all participants had dementia. (5 had unknown aetiology and 1 no diagnosis.<br>*n= 32* | Nursing home | i Medical intervention to ascertain causes of pain or discomfort causing VDB<br>ii Preferred music<br>iii Family videotape<br>iv 1:1 interaction<br>30 mins each session<br>One week washout period between interventions | i Tape recordings<br>ii Screaming Behavioural Mapping Instrument<br>iii CMAI focusing on VDB | MANOVA | A significant reduction in VDB was found for all three interventions:<br>1:1 interaction – 56%<br>Family videotape – 46%<br>Preferred music – 31%<br>No intervention – 16% |

| | *AUTHOR* | DESIGN | PARTICIPANTS | SITE | INTERVENTION | INSTRUMENT | ANALYSIS | FINDINGS |
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| 3 | *Garland et al. (2007)* | Randomised cross over design.<br>Aim of study was to compare the effectiveness of two individualised psychosocial treatments (simulated presence and music) in reducing frequency of physically and verbally agitated behaviours. | Dementia.<br>*n = 30*<br>MMSE mean score 2.5<br>Resided in nursing home for at least 3 months.<br>Rated on CMAI as having one or more significantly disruptive behaviours at least several time a day. | Nursing home | 15 minute audiotapes of simulated family presence; 15 minutes of preferred music, compared with a placebo neutral tape (reading from gardening book) and usual care.<br>Treatment x1 daily for 3 days during weeks 2,3,4. Participants rotated through all treatments during these 3 weeks with a 2 day washout period in-between each intervention. | Observation of 4 categories before, during and after treatment (total 45 minutes):<br>1. Physically aggressive agitation (spitting, hitting)<br>2. Physically non-aggressive agitation (pacing, unrobing)<br>3. Verbally aggressive agitation (swearing, cursing)<br>4. Verbally non-aggressive agitation (repetitive questions, screaming) | SPSS 11.5 two-way repeated measures multivariate analysis of variance (MANOVA) | Decline in physically agitated behaviours:<br>Simulated presence 30%<br>Music 25%<br>Placebo 15%<br>Decline in verbally agitated behaviours:<br>Simulated presence 33%<br>Music 18% (not significant)<br>Placebo 29%<br>Simulated presence and preferred music both proved effective in reducing counts of physically agitated behaviours. Simulated presence, but not preferred music, resulted in significantly reduced counts of verbally agitated behaviours. Placebo taped proved more beneficial than expected. |
| 4 | *Gerdner (2000)* | Experimental repeated measure pre/post test crossover design.<br>Aim of study was to compare immediate and residual effects of individualised music to classical 'relaxation' music on agitated behaviours in people with dementia | Alzheimer's Disease and related disorders.<br>*n = 39*<br>Scored between 3 and 7 on the Global Deterioration Scale (severe cognitive decline). | Long term care facility | Peak level of agitation identified.<br>Group A: 30 minutes preferred music (6 weeks) + washout (2 weeks) + 30 minute classical music (6 weeks)<br>Group B: reverse<br>30 minutes music x2days/week | Modified CMAI | Statistical Analysis System (SAS).<br>Fisher's Exact Test to compare categorical data.<br>T-test for the variable of age.<br>Wilcoxon Rank Sums Test for ordinal data from the GDS.<br>Repeated measures analysis of variance (ANOVA) | Significant reduction in agitation during and following preferred music compared to classical music. |

| | *AUTHOR* | DESIGN | PARTICIPANTS | SITE | INTERVENTION | INSTRUMENT | ANALYSIS | FINDINGS |
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| 5 | *Gerdner (2005)* | Mixed methodology: controlled trial and qualitative study.<br>Aim of the study was to evaluate the effectiveness of individualised music for the management of agitation in people with dementia when administered daily by trained staff and family. Also to explore the experiences of staff and family in administering individualised music. | Alzheimer's Disease and related disorders.<br>*n = 8*<br>Scored between 3 and 7 (mean 6) in the Global Deterioration Scale (severe cognitive decline). | Long term care facility | Peak level of agitation identified.<br>Baseline data collected for 4 weeks using Modified CMAI.<br>Education programme for staff and family members.<br>Individualised music for 8 weeks. 30 minutes daily preceding peak time of agitation. Also administered on an 'as needed' basis.<br>Modified CMAI completed on a weekly basis throughout 2 month intervention period. | Agitation visual analogue scale<br>Modified CMAI<br>Open ended interviews. | SAS/STAT procedure MIXED. Linear mixed model to analyse data from agitation VAS and Modified CMAI.<br>Interviews analysed using content analysis. | A statistically significant reduction in agitation was found during the presentation of music and an overall reduction in agitation was found on day shift during weeks 1-8 and on evening shift on weeks 5-8. Staff and family interviews provided convergent validity of findings. |
| 6 | *Guétin et al. (2009)* | Randomised controlled trial.<br>Aim of study was to assess the effects of a new music therapy on anxiety in patients with mild to severe dementia. Secondary was the effect on depression and the persisting effect up to 2 months after discontinuation. | Mild to moderate Alzheimer's Disease.<br>15 in each group<br>*n = 30 (6 did not complete the study)*<br>MMSE score between 12 and 25.<br>Hamilton Anxiety Scale score of at least 12. | Nursing home | Individual receptive music therapy.<br>Music selected on basis of personal preference.<br>Administered x1 weekly for 16 weeks.<br>Control group received rest and reading.<br>Music intervention, lasting 20 minutes, is broken into several phases that gradually bring a patient into a state of relaxation, followed by a re-enlivening phase (U sequence method). | Hamilton Scale for anxiety<br>Geriatric Depression Scale | Quantitative data: t-test or the Mann-Whitney test.<br>Qualitative data: $x^2$ test or Fischer's exact test.<br>ANOVA to study the overall changes in the endpoints measured during follow up. | Significant improvements in anxiety and depression were observed in the music intervention group as from week 4 and until week 16. The effect of music was sustained for up to 8 weeks after the discontinuation of the sessions between weeks 16 and 24. |

| | *AUTHOR* | DESIGN | PARTICIPANTS | SITE | INTERVENTION | INSTRUMENT | ANALYSIS | FINDINGS |
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| 7 | *Janata (2012)* | Randomised controlled trial. Aim of study was to examine the effects of a customised music programme on agitation and depression in people with moderate to severe dementia. | Dementia. *n = 38* (2 did not complete the study) | Assisted living facility | Baseline data collected for 2 weeks prior to intervention. Intervention comprised of 12 weeks of individualised music. Arousing music was played in the morning and calming in the evening. Music was played x4 daily. First and last programmes were 21-25 mins long and second and third were 50-65 mins. | NPI (Neuropsychiatric inventory) CMAI CSDD (Cornell Scale for Depression in Dementia) MMSE at beginning, middle and end of study. | ANOVA | Reductions in scores on the CMAI, NPI, and CSDD were rapid and sustained in both the intervention group and the control group. Distinction between the control and intervention group was blurred on account of the amount of exposure to music that the control group residents could receive incidentally by wandering around the facility or entering the rooms of residents whose music they liked. Groups better labelled as direct and indirect treatment groups. |
| 8 | *Park and Specht (2009)* | Controlled cohort study. The aim of this study was to examine the effects if individualised music on agitation in individuals with dementia who live at home. | Dementia. *n = 15* MMSE (mean 9.33) | Home | Preferred music played 30 minutes before peak agitation time. Study lasted for 8 weeks: 30mins music x2 weekly for 2 weeks, followed by no music for 2 weeks. This was repeated once. | Modified CMAI carried out by family caregiver 30 mins before, during and after listening to music) during the intervention weeks and no intervention weeks. | ANOVA | Findings show the mean agitation levels were significantly lower while listening to music than before listening and remained at a lower than peak level even after the music listening. No difference was found in the effect of music intervention on agitation between the music weeks and no music intervention weeks in this study. Individuals had chances to listen to music even during the no music intervention weeks, which may have confounded the study results. |
| 9 | *Park (2013)* | Controlled trial. The purpose was to test the effect of individualised music on agitation for home dwelling individuals. | Patients with dementia. Mean MMSE score was 8.08 *n*=26 | Home dwelling. | Listening to preferred music for 30 mins prior to peak agitation time x2 weekly for a total of four sessions. | Modified CMAI | t-test | Agitation level decreased while listening to music in all four sessions compared with baseline but the agitation level increased back when the music was removed. |

| | *AUTHOR* | DESIGN | PARTICIPANTS | SITE | INTERVENTION | INSTRUMENT | ANALYSIS | FINDINGS |
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| 10 | *Raglio et al. 2013* | Crossover study<br>The study aimed to assess the effects of active Music Therapy with those of Individualised Music on BPSD in people with dementia.<br><br>(Published in the Letters to the Editor section of the journal) | Dementia – DSM-IV criteria.<br>*n=17*<br>MMSE (18 or less)<br>Moderate to severe dementia | Unknown | x30 individual bi-weekly session (15 weeks) of Music Therapy or Individualised Music.<br>30 mins per session<br>2 month washout in between | Bedford Alzheimer Nursing Severity Scale (BANNS) and MMSE at baseline only.<br>Neuropsychiatric Inventory (NPI)<br>Cornell-Brown Scale for QOL in Dementia<br>Cornell Scale for Depression<br>Cohen Mansfield Agitation Scale (CMAI)<br>Music Therapy Rating Scale | Not detailed | No statistical difference between Music Therapy and Individualised Music.<br>Music Therapy did show improved BPSD symptoms.<br>Music Therapy and Individualised Music both showed improved CMAI scores.<br>QOL scores improved in music therapy but not individualised music. |
| 11 | *Raglio et al. (2015)* | Randomised Controlled Trial<br>To assess the effectiveness of active music therapy and individualised music on BPSD in people with dementia against standard care | People with moderate to severe dementia.<br><br>Dementia – DSM-IV criteria.<br>MMSE (18 or less)<br>*n=120* (22 did not complete the study) | Nursing Homes and Day Centres | i Standard care.<br>ii Standard care and 20 music therapy session delivered bi-weekly (10 weeks)<br>iii Standard care and 20 individualised music delivered bi-weekly (10 weeks) | Bedford Alzheimer Nursing Severity Scale (BANNS) and MMSE at baseline.<br>Neuropsychiatric inventory (NPI)<br>Cornell-Brown Scale for QOL in Dementia<br>Cornell Scale for Depression<br>Music Therapy Check List – Dementia | ANOVA | The addition of music therapy or individualised music to standard care did not have a significant effect on BPSD in people with dementia.<br>All groups showed a reduction over time in NPI global score but not of significance. |

| | *AUTHOR* | DESIGN | PARTICIPANTS | SITE | INTERVENTION | INSTRUMENT | ANALYSIS | FINDINGS |
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| 12 | *Ragnesko g et al. (2001)* | Controlled trial.<br>Aim of study was to investigate whether individualised music could be used as a nursing intervention to reduce symptoms of agitation in patients with dementia. | Dementia – DSM-IV criteria.<br>MMSE<br>GBS rating scale.<br>Show signs of agitation.<br>*n = 4* | Nursing home. | Four periods:<br>1. Control period without music.<br>2. Control period – pre-recorded general music played<br>3. Individualised music<br>4. Individualised music<br>Each session started with 5-10 mins without music to observe the patient to find out their mood, followed by 30mins of music, followed by 5-8mins without music.<br>Carried out 4-5 times in each patient. | Video recording.<br>Systematic observations using Facial Action Coding System (FACS) | Author watched all videos. These were divided into 1 min segments analysed using systematic observations and FACS | For the two patients most affected by dementia the noticeable effect of music was minimal. The music reduced agitation (and amounts of shouting) in two of the patients. These two patients became agitated several times when the music was stopped. |
| 13 | *Sakamoto et al. (2013)* | Randomised controlled trial.<br>The aim of this study was to examine differences in the short and long term effect of passive and interactive approaches using individualised music associated with special memories. | Alzheimer's type dementia – severe.<br>*n = 39*<br>MMSE | Four group homes and a special dementia hospital. | Non-intervention control group.<br>Passive music group – listened to individualised music passively.<br>Interactive music group – listened to individualised music and also participated with interactive activities e.g. clapping, singing, dancing, guided by a facilitator.<br>30 mins x1 weekly for 10 weeks. | Short term effects: measured indices of behavioural and psychological symptoms of dementia (BPSD) 5 mins before and 5 mins after each intervention using the autonomic nerve index and the FACES Scale.<br>Long term effects: the Behavioural Pathology in Alzheimer's Disease (BEHAVE – AD) Rating Scale. | Short term effects: Autonomic changes were analysed using ANOVA and Wilcoxon signed rank test.<br>Tukey's Honestly Significant Difference test.<br>For the FACES scale – Wilcoxon signed rank test and for comparisons the Mann-Whitney U test was used followed by the Bonferroni correction.<br>Long term effects: Wilcoxon signed | Passive and interactive music interventions caused short-term parasympathetic dominance (rest, healing, rebuilding, positive thinking) as opposed to sympathetic dominance (nervousness, stress, feelings of panic). Interactive intervention caused the greatest improvement in emotional state. Greater long-term reduction in BPSD was observed following interactive intervention, compared with passive music intervention and a no-music control group. |

| | *AUTHOR* | DESIGN | PARTICIPANTS | SITE | INTERVENTION | INSTRUMENT | ANALYSIS | FINDINGS |
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| | | | | | | | rank test and for comparisons the Mann-Whitney U test was used followed by the Bonferroni correction. | |
| 14 | *Sanchez et al. (2016)* | Randomised Controlled Trial<br>To compare the effects of multisensory stimulation environment (MSSE) and individualised music on agitation, emotional and cognitive status, and dementia severity in people with dementia | People with severe dementia<br>*n=22* (4 did not complete the study) | Residents in a specialised dementia elderly centre | i MSSE<br>ii Individualised music<br>Both groups had bi-weekly 30 min sessions over 16 weeks. | Agitation – CMAI<br>Mood – Cornell Scale for depression<br>Anxiety – RAID<br>Cognitive function – Severe MMSE<br>Severity of Dementia – Bedford Alzheimer Nursing Severity Scale (BANNS) | ANOVA | MSSE group showed improvements in anxiety (RAID) and BANNS pre-post trial.<br>MSSE and individualised music groups both showed improvements in agitation during the intervention with no significant difference.<br>Results suggest that MSSE could have better effects on anxiety symptoms and dementia severity in comparison with individualised music. |
| 15 | *Sung, Chang and Lee (2010)* | Controlled trial. One unit within the home was randomly assigned as the experimental group and the other the control group.<br>The aim of the study was to evaluate a preferred music listening intervention for reducing anxiety in older adults with dementia. | Dementia – moderate to severe cognitive decline with a GDS score of 4-6.<br>*n = 52*<br>*n = 29 in experimental group*<br>*n = 23 control group* | Nursing home | 30 mins preferred music mid afternoon x2 weekly for 6 weeks (12 sessions)<br>Control group – care as usual. | Anxiety was measured using the Rating Anxiety in Dementia (RAID) tool. Measured at baseline and at week 6. | Analysis of co-variance (ANCOVA) | Preferred music intervention has a positive impact by reducing the level of anxiety in older people with dementia. Older adults who received the preferred music intervention had a significantly lower anxiety score at 6 weeks compared to those who received usual standard care with no music. |

| | *AUTHOR* | DESIGN | PARTICIPANTS | SITE | INTERVENTION | INSTRUMENT | ANALYSIS | FINDINGS |
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| 16 | *Sung, Chang and Abbey (2006)* | Controlled trial. One building complex within the residential care facility was randomly assigned as the experimental group and the other the control group. The aim of the study was to evaluate a preferred music listening intervention for reducing anxiety in older adults with dementia. | Dementia – moderate to severe cognitive decline with a GDS score of 4-6. *n = 57* *n = 32 in experimental group* *n = 25 control group* | Residential care facility | 30 mins preferred music mid afternoon x2 weekly for 6 weeks (12 sessions) Control group – care as usual. | CMAI | t-test | A significant reduction was found on overall CMAI and physically non-aggressive behaviours in the experimental group in comparison to those in the control group, indicating that preferred music significantly decreased the overall agitation and physically non aggressive behaviours of people with dementia in long term care settings. |
| *MMSE: Mini mental state exam; GDS: Global Deterioration Scale; BPST: Brief Psychosocial Therapy; BPSD: Behavioural and Psychosocial Symptoms in Dementia* | | | | | | | | |

Table 6: Summary of the studies of individualised music on agitated behaviours in people with dementia

# Chapter 3: Methodology and Design

This main element of this pilot study was to explore the effects of individualised music on levels of agitation in people with moderate to severe dementia being treated and cared for in a specialist mental health hospital setting. Additionally it explored the experiences and opinions of healthcare professionals and family carers of using individualised music to manage agitation.

## 3.1 Choice of research methodology

It is important to acknowledge the ontological and epistemological underpinnings of this pilot study which gave rise to the methodological approaches used to address the research questions. A mixed methods approach was adopted. The research followed a positivist paradigm and an interpretive paradigm as driven by the specific objectives of the study. A positivist paradigm is grounded in the ontological belief that there is a single truth or reality, which epistemologically can be objectively measured and known using reliable and valid tools. This methodological approach uses quantitative methods to ascertain the reality, often using experimental techniques. An interpretative paradigm believes that there is no single truth or reality; that reality is created by an individual and has to be interpreted so that underlying meaning of events and experiences can be discovered. Qualitative methods are used to do this such as interviews, case studies, narratives and observations.

In deciding the methodological approach of this pilot study a ‘bottom up’ approach was used to decide where the research was positioned. The research questions were decided, and then the best methods to elicit the ontology were chosen. This resulted in two paradigms being naturally selected. A positivist approach was used to gain knowledge of the effects of individualised music on levels of agitation. Epistemologically an objective

scientific method of enquiry was used to allow the measurement of data that was observable and quantifiable. Using an experimental approach allowed the researcher to uncover a single reality or truth of the effect of the music on levels of agitation for each research participant.

The theoretical orientation of the research questions exploring the experience of healthcare professionals and family carers followed an interpretative paradigm. The researcher used an interpretative methodology aimed at providing a depth of understanding through exploring perceptions, beliefs and feelings. Interviews and focus groups were used to elicit data that could be analysed and themed to construct underlying meaning.

## 3.2 Design of study

This pilot study was a mixed methods study, divided into two parts. The main part of the study was the quantitative experiment that measured the effect of individualised music on levels of agitation levels in people with moderate to severe dementia being cared for in a specialist mental health setting. An additional smaller part to the study was the qualitative exploration of the experiences of healthcare professionals and family carers. The two arms of the study are represented in Figure 3 below.

Using multiple methods or perspectives to collect and interpret data about a phenomenon, in order to obtain an accurate representation of reality, is known as triangulation (Polit and Beck 2007). Although combining quantitative and qualitative approaches can be complex due to the different epistemological and ontological positions, using the triangulation method can be give a richer and more comprehensive picture of the issue under investigation (Foss and Ellefsen 2002). In this study, the quantitative element of the study was used as the preliminary inquiry, and the qualitative aspects undertaken as a secondary supporting line of inquiry. However data elicited from the interviews with family carers and healthcare professionals gave richness by providing illustrations, elaborating understanding and other

knowledge that would not have been gained by undertaking the quantitative study alone.

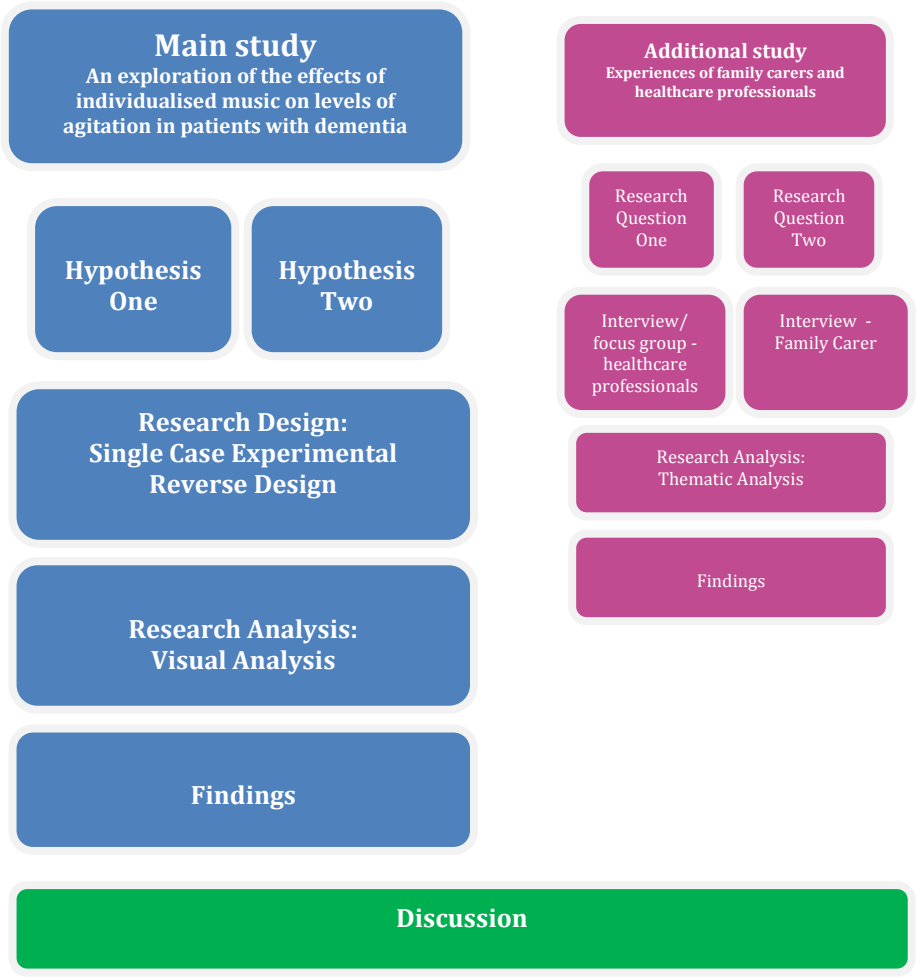



Figure 3: Two arms of the research study

### 3.2.1 Study setting

The study took place in two specialist dementia wards in a community mental health hospital in a rural health board in NHS Scotland.

### 3.2.2 Main study – People with dementia

As the reality of using music to influence levels of agitation could be measured using valid and reliable tools, a positivist approach to the study

was employed. A single case experimental reversal design was used (A-B-A-B). Each participant served as his or her own control. Such a design employs multiple (in this case two) baselines to ascertain whether the intervention in question has a replicable effect. It is widely used in situations where there are limited research subjects and funds for research (Rassafiani and Sahaf 2010) and when subjects are highly heterogeneous (Geist and Hitchcock 2014) as is the case with people requiring hospitalisation due to complex behavioural and psychological symptoms of dementia. In such cases, the vast diversity in individual presentation precludes designs using group data. Further, such designs are employed when the intervention is innovative or new and where there is a lack of evidence for its effectiveness.

In single case experimental reverse design studies, the experimenter systematically introduces and withdraws control and intervention conditions and then assesses the effects of the intervention on behaviour across replications of these conditions within and across participants (Dallery, Cassidy and Raiff 2013).

In this pilot study, the reverse design was used whereby the intervention was introduced after a baseline period. Following the intervention period, the baseline period was reintroduced, hence the 'reversal' design. There was a minimum of three alternations in order to document experimental control (see Figure 4).

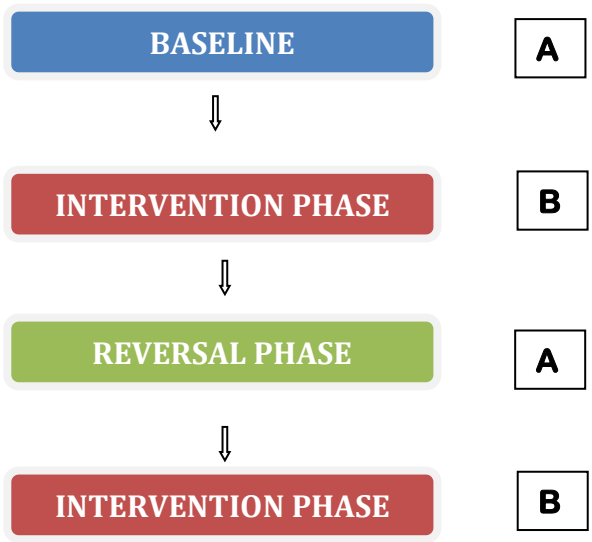



Figure 4: Flow diagram of experimental reversal design

This research design was chosen because it allows evidence to be generated that demonstrates cause and effect when an intervention is introduced and withdrawn. This fitted well with the introduction and withdrawal of the intervention of individualised music in the described study. In an ideal world more rigorous research designs would be used, for example a randomised controlled trial, but the feasibility and logistics of this was not possible given the scale of the project. Therefore given the setting and the goal of the proposed study, the single case reverse design study suited the research question, and could be accomplished with a small sample size. This research design has previously been found to be appropriate for studying music therapy interventions (Geist and Hitchcock 2014).

### 3.2.3 Additional study - Healthcare Professionals and Family Carers

As there is no single reality or truth when exploring experiences and beliefs of individuals, an interpretative approach was used in this study to construct the reality and discover underlying meaning of the experiences of healthcare professionals and family carers. A qualitative research design was used to elicit experiential data from healthcare professionals caring for the participants with dementia, and from the family carers. A focus group or one-to-one semi-structured interview (see Appendix 3) was conducted at the end of the data collection period with the healthcare professionals involved in the study, and one to one interviews with family carers (see Appendix 4). The purpose was to elicit their experience of participating in an individualised music programme for people with dementia experiencing agitation. Identification of positive and negatives outcomes were sought along with potential factors that might shape and constrain implementation of individualised music.

## 3.3 Measures to ensure rigour, trustworthiness and quality control

A researcher always endeavours to bring new understanding and knowledge to their area of study, and for that to be seen as credible and valued, they must ensure it is trustworthy and verifiable. To determine the strength of evidence derived from research the methodological rigour must be evaluated (Brown et al. 2015). In quantitative research, this means demonstrating the validity, reliability, replicability, and generalisability of the findings (Brown et al. 2015); and in qualitative research, providing evidence of credibility, transferability, dependability and confirmability (Lincoln and Guba 1985).

The following section will outline the quality control measures that were used for the present study:

- Validity – this refers to how well a test measures what it is reported to measure. In the quantitative part of this research study two measures were used to measure levels of agitation (Agitated Behaviour Scale and Cohen-Mansfield Agitation Inventory). Both these measures were selected because their validity has been widely reported (See section 3.10.1 and 3.10.2).
- Reliability – this refers to the degree to which a measurement tool produces stable and consistent results. As above, measurement tools were selected for the study with reported high levels of reliability. Further to this an inter-rater reliability assessment was undertaken on the use of the Agitated Behaviour Scale within the current study to assess inter-rater reliability (See Section 3.10.1).
- Replicability – this refers to the research study being replicable, which means the study gives enough detailed information that the research can be repeated or replicated. A comprehensive account of the procedure undertaken by the researcher was provided to enable the reader to replicate the study if desired (See Section 3.11).
- Generalisability – this refers to the extent to which research findings can be applied to settings other than that in which they were originally carried out. This was a more difficult concept to demonstrate in the current study.

It was addressed by providing detailed information about the setting and the sampling process (Section 3.6), participant inclusion and exclusion criteria for the study (Section 3.7 and 3.8), and the participant characteristics (Section 4.1). Thus allowing the reader to consider if the findings could fit to other contexts outside the study situation.

- Credibility – this refers to establishing that the results of qualitative research are credible or believable from the perspective of the participant in the research. This was achieved by audio-recording the interviews and focus groups and transcribing them word for word. The use of participant quotes in the findings also adds credibility. The themes from the analysis were shared with the research supervisors and discussed during a supervision session. Although the participants were not asked to comment on the final themes, they were all offered an executive summary of the research study once completed.
- Transferability – this is synonymous with generalisability, or external validity, in quantitative research as described above. Again, it was difficult to demonstrate, but a thick description of the setting and participant characteristics of the current study were provided. Along with this, a detailed and explanative narrative of the themes elicited from the interviews was supplied. By doing this it is left to the reader to judge the quality of the findings and decide if they contextually fit to other settings.
- Dependability – this refers to the stability or consistency of the inquiry process. This was achieved by provided a clear description of the research procedure for undertaking the interviews and focus group (Section 3.11.3 and 3.11.4), and the process for analysing the data (Section 3.13.2 and 3.13.3).
- Confirmability – this refers to how the researcher influences data interpretation. From the outset of the study the researcher acknowledged her personal position, interests and values regarding the topic under investigation, and openly recorded these in the section on researcher reflexivity (Section 3.4). Openness and transparency in this manner was important so that readers could see how the researcher's perspective shaped the interpretation of the data.

## 3.4 Researcher reflexivity

As a researcher it is important to be aware of one's particular values, assumptions, and biases, and how these may affect the research process. The method, known as reflexivity, is introspection on the role of subjectivity in the research process (Palaganas et al. 2017). It is essential that the researcher makes explicit their position so that the reader can understand what they may bring to the process of analysis. The next section details the position of the researcher in the current study.

My motivation to research this particular topic arose from personal reading and personal use of individualised music in dementia care, and questioning its perceived benefits in relation to my own clinical practice of caring for people with dementia in hospital settings.

I am a consultant nurse for dementia in a Scottish NHS Health Board. The nature of my post means I am viewed as an expert in the care of people with dementia, and my opinion on best practice is regularly sought. It is essential that the advice and information I give is based on the best available evidence.

I first learnt about the benefits of using individualised music in dementia care through reading the book *'Where Memories Go'* by the broadcaster and writer Sally Magnusson, and through exploring the website of the charity she founded called Playlist for Life©. I was very struck by the simplicity of using music that was familiar and meaningful to an individual to help reduce levels of agitation.

Music has always been a significant part of my own life. I play the piano, guitar and clarinet, and I studied music academically at school. I enjoy listening to many genres of music, but I have certain types of music, certain artists, and certain tracks that are meaningfully significant to me for the welcoming memories and positive emotion they arouse in me when I listen to

them. I therefore instantly related to the idea of using individualised music in dementia care to generate a ‘feel good’ effect in people living with dementia. I have recently had firsthand experience of seeing the positive effect of listening to individualised music through my father-in-law who has mild cognitive impairment. He was recently diagnosed with a terminal cancer and given a very short time to live. My husband and I created a playlist of all his favourite music for him to play on his iPad, and we have been able to share many special moments with him as he joyfully reminiscences whilst listening to this music.

In my clinical role as a nurse consultant for dementia I could easily accept the perceived benefits of individualised music, and as an expert in my field, recommend to my Health Board that we introduce individualised music as an intervention to manage agitation in people with dementia when in hospital. However making this recommendation would be naïve, unprofessional and likely detrimental as it is not based on robust clinical evidence. My professional reputation lies in the recommendations and decisions I make, therefore it is essential they are based on sound clinical judgement informed by high level evidence.

This led me develop this research study - I wanted to know if individualised music is beneficial for managing agitation in people with dementia when in hospital? As the researcher it was important that I separated my own perceptions of the benefits of individualised music from the study, and not let these influence in any way. This was more easily achieved in the main study as the data collection was based on experimental measurements and was gathered by healthcare professionals rather than me. A possibility had been for me to measure the agitation scores but this would have been less impartial, and not reflective of everyday practice, the feasibility of which I was trying to assess.

The qualitative part of the study was more difficult for me to position myself as I was interviewing the participants, analysing the data, and drawing conclusions. It was vital I put any preconceived assumptions I had about

individualised music in dementia care to one side, and let the participant's voice be heard. As I knew I would be making recommendations for clinical practice based on the findings of my research study, I had a vested interest to protect my professional reputation by ensuring I achieved credible findings. The only way to do this was to set aside any of my own ideas and preconceptions and listen to the narrative of the participant. I was conscious that the participants might tell me what they thought I wanted to hear, so I deliberately questioned in an open and transparent way to elicit the real experience of the participants, encouraging them to give real life examples where appropriate. In analysing and theming the data, I tried as best as possible to bracket off my prior held beliefs and experiences, and worked with what was before me in the transcripts, immersing myself in the experience of the participants, their beliefs, and their thoughts.

It is not possible to eliminate all bias in interpretative research, but being aware of the possibilities for bias, and taking the necessary steps to address it, is paramount. I have attempted to be as rigorous, and trustworthy, as possible in presenting the findings of this study.

## 3.5 Ethics and regulatory issues

### 3.5.1 Ethical concerns

The design of the study involved withdrawing a potentially helpful intervention (individualised music) for the purposes of the study. While it was true that the intervention was withdrawn in week 3, it was argued there is currently insufficient evidence that it is effective with this patient group and in this setting. As a result it was maintained that individuals remained in equipoise at the point at which withdrawal occurred since it was uncertain whether any reduction in agitation was due to the intervention. From this perspective, withdrawal of the intervention offered the opportunity to verify its utility upon introduction after one further week. At that point the experimental

part of the study ceased and the individual was free to continue with individualised music.

If the person with dementia appeared upset or distressed at any point, proceedings were paused to ascertain if they wish to continue participating in the research. If it appeared they did not, everything was stopped and it was taken that they had withdrawn their consent. This could take place at any stage during the study. If they wished to continue with the individualised music out with the study, this was facilitated.

### 3.5.2. Ethical approval

The study was sponsored by University of Abertay. The research was conducted in accordance with Research Governance Framework for Health and Social Care. Application through the Integrated Research Application System was undertaken and ethical approval was granted from Scotland A NHS Regional Ethics Committee and the local NHS Research and Development Department (see Appendix 21 and Appendix 22). Alongside this application was made to the University of Abertay Research Ethics Committee and approval given (see Appendix 23).

## 3.6 Sample

A non-probability sampling strategy was used to identify a total of five persons with dementia, and five healthcare professionals located within specialist mental health wards in a hospital setting. Five family carers of people with dementia (one for each research participant) were identified after recruitment of the person with dementia.

The Senior Charge Nurse (SCN) from each ward was responsible for identifying potential research participants in accordance with the inclusions and exclusion criteria.

The Consultant in Old Age Psychiatry was responsible for assessing the capacity of the person with dementia and eligibility to take part in the research project in line with the Adults with Incapacity (AWI) (Scotland) Act 2000 (Part 5: medical Treatment and Research). All patients were required to have a completed 'NHS Fife Capacity Document' which detailed the individuals' capacity and welfare attorney/guardian and corresponding evidence to include the Certificate of Incapacity under Section 47 of the Adults with Incapacity (Scotland) Act 2000.

## 3.7 Inclusion criteria

Criteria for selecting the participants were as follows.

3.7.1 Person with dementia

- Age 18 years and over
- Clinical diagnosis of moderate to severe dementia
- History of agitated behaviour as identified by the nursing staff and/or medical team
- Minimum expected hospital stay ≥ 4 weeks
- Able to hear normal speaking voice at a distance of 0.5metre
- Able to express personal music preference or a family member is able to express the participant's opinion/preference
- Participant does not have capacity and is unable to provide informed consent. In accordance with the Adults with Incapacity (Scotland) Act 2000 consent will be obtained by proxy from the person's welfare power of attorney or guardian in the first instance or nearest relative in the absence of such person.

3.7.2 Healthcare Professional

- Age 18 years or over
- Able to provide informed consent
- Responsible for the care/treatment of the person with dementia included in the study
- Place of work: Specialist Mental Health Wards

3.7.3 Family Carer

- Age 18 years or over
- Able to provide informed consent
- Able to act as proxy for the person with dementia they care for if required
- Appointed and confirmed as (unpaid) carer for the person with dementia

## 3.8 Exclusion criteria

Criteria for excluding participants were as follows.

3.8.1 Person with Dementia

- Judged by the aforementioned Consultant in Old Age Psychiatry to be too unwell to participate/reason for hospital admission prevents participation
- Participant has capacity to provide informed consent
- Has severe hearing impairment
- Participant and family member unable to identify personal music preferences
- Participant actively appears to dislike the intervention
- Non-English speaking

3.8.2 Healthcare Professional

- Participating member of the project steering group
- Non-English speaking

3.8.3 Family Carer

- Judged by Senior Charge Nurse to be too unwell to participate
- Non-English speaking

## 3.9 Recruitment and Consent Procedures

Once potential participants had been identified the following procedures were followed.

3.9.1 Persons with Dementia

In accordance with the Adults with Incapacity (Scotland) Act 2000 (Part 5: Medical Treatment and Research) the member of the ward team firstly contacted the individual's welfare power of attorney/guardian or nearest relative using the preferred mode of contact provided. The member of the ward team arranged a suitable date and time to discuss the research and the nature of the individual's (person with dementia) participation (should they consent to take part). At this initial meeting each individual was provided with an invitation pack and a brief verbal explanation of the study. The invitation pack contained a copy of the invitation letter (Appendix 5), a copy of the Participant Information Sheet (Appendix 6) and corresponding Consent Form (Appendix 7) for the nearest relative/guardian or welfare power of attorney. To eliminate any potential coercion, the member of the ward team informed the individual that the research was being conducted by a researcher external to the ward and the participation of the individual with dementia in the research study would not impact upon their clinical care and treatment. If the individual's welfare attorney/guardian or nearest relative consented to

themselves and the person with dementia being approached by the Chief Investigator to discuss the research further, the member of the ward team arranged a suitable date and time for the Chief Investigator to visit both individuals on the ward. With the exception of both individual's first names, no further personal data regarding either individual was provided to the Chief Investigator at this stage and the member of the ward team explained that the Chief Investigator will simply be informed that the individual meets with the criteria for inviting that person to participate in the research as demarcated in the participant information sheet. Verbal consent for this information to be passed to the Chief Investigator and to arrange a meeting with the Chief Investigator was agreed. Finally the member of the ward team explained to the individual that the person with dementia was not obliged to consent to take part and they would be free to change their mind at any time. Individuals were informed that should they change their mind at any point they should alert any member of the ward team. Contact details were provided for the purpose of doing so via the Participant Information Sheet. Paramount to these proceedings, the member of the ward team sought to ascertain the participants prior wishes to consent to partaking in such research (where possible) with the proxy.

From there, the Chief Investigator met with both individuals to discuss participation. To guide this process the Chief Investigator provided a verbal explanation of the study to both individuals and both individuals were afforded ample time to review the invitation pack and accompanying consent form (24 hours), to discuss the nature of the study and their participation with the Chief Investigator, and to ask any questions regarding the research and their potential involvement. The Chief Investigator ensured that the individual (person with dementia) was provided with an opportunity to express his/her wishes / raise any concerns / ask questions regarding the research and once again the proxy was encouraged to vocalise the individual's prior wishes to consent to partaking in such research.

Attention to verbal or non-verbal (behavioural) indications of the person's wishes to decline participation was also considered crucial here. If an

individual showed an expression to not take part in the study, irrespective of agreement to participate by the proxy, the Chief Investigator would have terminated these proceedings, thanked both individuals for their time and refrained from recruiting the participant. Reasons for this decision would have been provided to the proxy. Likewise, if the proxy indicated that they did not wish for the individual to participate, the Chief Investigator would have thanked both individuals for their time and refrain from recruiting the participant. If the person with dementia did not display any verbal/non-verbal indications that he/she did not wish to take part in the study, and the proxy was happy to consent on behalf of the person with dementia, the Chief Investigator obtained written consent by proxy; the consent form was signed and dated by the individual's welfare power of attorney/guardian/nearest relative and the Chief Investigator (Appendix 7). The person's welfare power of attorney/guardian/nearest relative retained all documents contained with the invitation pack, with the exception of the consent form which was stored separately from all other study data in a locked filing cabinet within the office workspace of the Chief Investigator at her office. A copy of the consent form was given to the individual's welfare power of attorney/guardian/nearest relative. At this stage, all participants were reminded of their right to withdraw from the study at any point and, following completion of, the study.

### 3.9.2 Healthcare Professionals

The Senior Charge Nurse's from the wards were responsible for the identification of 5 healthcare professionals, in accordance with the inclusion and exclusion criteria for healthcare professionals. From there, the Senior Charge Nurse approached all potential participants who were eligible for participation to explain the nature of the study and provided them with an invitation pack including a NHS Fife headed cover letter (Appendix 8) and participant information sheet (Appendix 9). To eliminate any potential coercion, the Senior Charge Nurse informed the participant that the research was being conducted by a researcher independent to the ward and thus their decision to participate will not impact upon their employment on the ward. If

the individual consented to being approached by the Chief Investigator to discuss the research further, the Senior Charge Nurse sought to seek consent to allow the Chief Investigator to visit the individual on the ward at a suitable date and time.

Other than the individuals name, no personal data regarding the individual was provided to the Chief Investigator at this stage, unless the individual consented to providing a contact telephone number and/or email address. If so, the Senior Charge Nurse explained to the individual that this information will only be used by the researcher to arrange a suitable meeting time and will be subsequently destroyed afterwards. If the individual did not wish to provide contact details, the Senior Charge Nurse arranged a suitable date and time for the participant to meet with the Chief Investigator. Verbal consent for this information to be passed to the Chief Investigator and to arrange a meeting with the Chief Investigator was obtained. Finally the Senior Charge Nurse reminded the individual that they were not obliged to consent to taking part and were free to change their mind at any time. All individuals were informed that should they change their mind at any point they should alert the Senior Charge Nurse to inform the Chief Investigator. Names of all potential participants were provided to the Chief Investigator alongside a suitable date and meeting time and/or contact details.

The Chief Investigator then met with the individual, provided a verbal explanation of the study and allowed ample time for the individual to review the invitation pack and accompanying consent form (24 hours), to discuss the nature of the study and their participation and for the Chief Investigator to answer any questions regarding the research and their potential involvement. To eliminate any potential coercion the Chief Investigator acted alone throughout these proceeding and all participants were reminded that their decision to partake in the research will not impact upon their employment within the ward.

If an individual indicated that they did not wish to take part in the study, the Chief Investigator thanked the individual for their time and refrained from

recruiting the participant. If the individual indicated that he/she would like to take part in the study, written consent was obtained (Appendix 10). The participant retained all documents contained within the invitation pack, with the exception of the consent form which was stored separately from all other study data in a locked filing cabinet within the office workspace of the Chief Investigator at her office. A copy of the consent form was given to the healthcare professional. At this stage, all participants were reminded of their right to withdraw from the study at any point during and, following completion, of the study.

### 3.9.3 Family Carers

A member of the ward team was responsible for the identification of 5 family carers (individual's welfare power of attorney/guardian or nearest relative). These individuals were contacted in the first instance by the Senior Charge Nurse to explain the nature of the study, who provided them with an invitation pack including a NHS Fife headed cover letter (Appendix 11) and participant information sheet (Appendix 12). To eliminate any potential for coercion, the Senior Charge Nurse informed the participant that the research was being conducted by a researcher independent to the ward and thus their decision to participate will not impact upon the care and treatment of the individual with dementia.

If an individual consented to being approached by the Chief Investigator to discuss the research further, the member of the ward team sought consent to allow the Chief Investigator to visit the individual on the ward at a suitable date and time or to contact the individual to arrange a meeting. If the individual was the same person responsible for providing consent to participate (by proxy) for the person with dementia, the member of the ward team arranged for the Chief Investigator to meet with the individual immediately following completion of these proceedings. If the individual was not responsible for providing consent on behalf of the individual with dementia as they are not the person's welfare power of attorney/guardian but

fits with the criteria as the person's 'carer', an alternative date and time was proposed or the individual was asked to provide preferred contact details so that the Chief Investigator can contact the individual.

With the exception of the individual's name, no further personal data regarding either individual was provided to the Chief Investigator at this stage unless the individual was happy to provide contact details to allow the Chief Investigator to contact this person for the purposes of arranging a meeting. If so, the member of the ward team informed the individual that the contact details shall only be used for this purpose and destroyed thereafter. In addition, the member of the ward team explained that the Chief Investigator will simply be informed that the individual meets with the criteria for inviting that person to participate in the research demarcated in the participant information sheet. Verbal consent for this information to be passed to the Chief Investigator and to arrange a meeting with the Chief Investigator was obtained. Finally, the member of the ward team reminded the individual that the carer is not obliged to consent to taking part and that they are free to change their mind at any time. Individuals were informed that should they change their mind at any point they should alert any member of the ward team. Contact details were provided for the purpose of doing so via the participant information sheet.

The Chief Investigator then meet with the individual, provided a verbal explanation of the study and allow ample time for the individual to review the invitation pack and accompanying consent form (24 hours), to discuss the nature of the study and their participation and for the Chief Investigator to answer any questions regarding the research and their potential involvement. To eliminate any potential coercion the Chief Investigator acted alone throughout these proceedings and all participants were informed that their decision to partake in the research would impact upon the care and treatment of the individual with dementia at the hospital.

If an individual indicated that they did not wish to take part in the study the Chief Investigator thanked the individual for their time and refrained from

recruiting the participant. If the individual indicated that he/she would like to take in the study, written consent was obtained (Appendix 13). The participant retained all documents contained within the invitation pack, with the exception of the consent form which was stored separately from all other study data in a locked filing cabinet within the office workspace of the Chief Investigator at her office. A copy of the consent form was given to the carer. At this stage, all participants were reminded of their right to withdraw from the study at any point during and following completion of the study.

Following consent to participate, all individuals were then assigned a non-identifiable participant number for the purposes of data collection.

## 3.10 Measures

### 3.10.1 Agitated Behaviour Scale[1]

The Agitated Behaviour Scale was used to assess agitation levels over a 30 minute period on a daily basis throughout the study, during baseline weeks and intervention weeks. The Agitated Behaviour Scale was originally developed for use in patients following traumatic brain injury (Corrigan 1989). Its primary purpose is for repeat assessment of agitation by healthcare professionals who want an actual measure on the course of a patient's agitation levels. It is particularly useful when interventions are being attempted to decide effectiveness (Bognor 2000). It has also been found to be useful for use in patients with other neurological conditions such as dementia (Tabloski, McKinnon-Howe and Remington 1995, Corrigan, Bogner and Tabloski 1996). The Scale comprises of 14 items, with each item scored from 1 to 4 (1 being the behaviour is absent to 4 being the behaviour is present to an extreme degree). The minimum score is 14 and the maximum score is 56. Zun and Downey (2008) divided the scores from the scale into

[1] Permission was given to use the Agitated Behaviour Scale by John Corrigan and Jennifer Bogner

no agitation (<21), mild agitation (21-28), moderate agitation (29-35) and severe agitation (≥36).

The Agitated Behaviour Scale has high inter-rater reliability and high internal consistency when used in dementia care. In a study focussing on the reliability of the scale in a long term care facility with residents that primarily had a diagnosis of dementia (Bogner et al. 1999), the Pearson correlation co-efficient of 0.906 and Chronbach's Alpha ranging from 0.740 to 0.80, suggest that the Agitated Behaviour Scale is a reliable instrument for measuring agitation in people with dementia. The validity of the Agitated Behaviour Scale has been widely reported (Nott et al. 2010, Bogner et al. 2000, Corrigan 1989).

The Agitated Behaviour Scale was selected for this study because of the qualities described above and because it is easy and straight forward to use. However, the main reason for selecting this particular tool was it allowed serial assessment of agitation over a selective time interval of thirty minute periods. This suited the research design of the study. Other measurement tools considered for the study were designed to measure agitation over much longer time periods, and would have required modification prior to use, and hence affected the reliability and validity of the tool.

To assess the competency of administration of the Agitated Behaviour Scale in this particular study and to give an indication of inter-rater reliability of the healthcare professionals using the tool, a written scenario was given to staff to score (see Appendix 20). The scenario was developed and scored by The Ohio State University (www.ohiovalley.org/informationeducaton/agitation/abs/). The results of this, presented in Table 7, highlight that the healthcare professionals over-scored and under-scored levels of agitation in the scenario case. Scoring ranged from 68% to 110% of the correct score. This suggests that the reliability of agitation scoring using the Agitated Behaviour Scale in this study was not particularly strong.

| | Scenario score | Score given by HCP[2] | Percentage of score | Level of scoring |
|---|---|---|---|---|
| Healthcare professional 1 | *No longer working on the ward when scenario scoring carried out* | | | |
| Healthcare professional 2 | 38 | 28 | 74% | Under |
| Healthcare professional 3 | 38 | 40 | 105% | Over |
| Healthcare professional 4 | 38 | 26 | 68% | Under |
| Healthcare professional 5 | 38 | 42 | 110% | Over |

Table 7: Scoring of scenario case using the Agitated Behaviour Scale

### 3.10.2 Cohen-Mansfield Agitation Inventory

The Cohen-Mansfield Agitation Inventory was used to assess frequency of agitated behaviours in the participants on a weekly basis throughout the study. The Cohen- Mansfield Agitation Inventory was originally developed for research purposes but it is now widely used for clinical purposes in nursing homes, by healthcare professionals as well as family carers (Cohen-Mansfield 1991). Ratings usually pertain to the two weeks preceding the assessment, but in the instance of this study it was carried out on a weekly basis. The Inventory comprises 29 agitated behaviours, each rated on a 7-point scale of frequency (1 being the behaviour never happened to 7 being the behaviour occurred several times an hour). The minimum score is 29 and the maximum score is 203.

Testing of the Cohen-Mansfield Agitation Inventory has shown it to be a valid and reliable tool for assessing agitation in people living in an aged care facility, which was confirmed by positive correlations with two other behavioural measurement tools (Finkel et al. 1992 cited in Brett et al. 2016). Gerdner (2000) found a mean of 92.7% inter-rater agreement when using the Cohen-Mansfield Agitation Inventory in her study, and 95% in a later study (Gerdner 2005).

The Cohen-Mansfield Agitation Inventory was used in this study to add a longitudinal measurement of agitation in the participants over the four week study period. This was to supplement the Agitated Behaviour Scale

[2] HCP Healthcare professional

measurement that gave a short term measurement over a defined 30 minute period. As a result of the two measurements of agitation, the immediate effect of individualised music could be assessed, as well as any longer term effect on levels of agitation.

## 3.11 Procedure

### 3.11.1 People with dementia

An initial interview was held by the Chief Investigator with the person with dementia and/or family member for the purposes of identifying participant characteristics, background musical preferences and personally meaningful music.

Nursing staff were educated in the use of the Agitated Behaviour Scale, the Cohen Mansfield Agitation Inventory, and in the administration of the individualised music intervention. This was delivered by the researcher to the nursing staff on either a one to one basis or small group teaching. The supporting documentation for the study was explained to nursing staff and a folder provided for each participant with all the necessary forms.

Each participant had a named nurse who oversaw the implementation of the music intervention and measurements for that particular participant, but this responsibility was delegated to other members of the nursing team when that nurse was not on duty.

The agitation level of participants was measured at baseline using the Agitated Behaviour Scale. This measurement was taken over a 30 minute period on a daily basis at the same time each day for a minimum of 7 days. The time of this measurement was the time that the participant was thought to be most agitated and was decided by the nursing staff based on their knowledge of the person and the routines of care for that person. A weekly measurement of frequency of agitated behaviours was also recorded using

Cohen Mansfield Agitation Inventory designed to measure agitation over a longer period.

Following this the participant received a daily music intervention of 30 minutes of individualised music. This was delivered just prior to the previously identified peak time of agitation, supporting Gerdner's mid-range theory of individualised music intervention for agitation (Gerdner 1997), and was administered at the same time each day for 7 days. A member of nursing staff administered the intervention. Agitation levels were measured during this 30 minute period. If participants wanted to listen to the music intervention more frequently this was facilitated. The music intervention was limited to 30 minutes because of limited attention span in persons with dementia (Gerdner 2013). Any verbal and non-verbal behaviours were also noted. A weekly agitation measurement was also recorded.

Following the intervention week a further week of no intervention followed. However a member of nursing staff was instructed to spend time in social interaction with the participant in the same way as he/she did when administering the music (but without the music). The reason for this was to make every effort to ensure all variables remained constant other than the experimental intervention of individualised music. Levels of agitation during this 30 minute period were measured, and also a weekly agitation measurement.

Finally, a further week of intervention (administered as previously detailed) followed with daily and weekly agitation levels measured. (See Table 8 for an overview of the study design).

| Day 1 - 7 | Day 8 – 14 | Day 15 – 21 | Day 22 - 28 | Day 29 onwards |
|---|---|---|---|---|
| • Baseline data measurement of agitation levels (daily and weekly) | • Administration of music intervention<br>• Measurement of agitation levels (daily and weekly) | • Social interaction<br>• Measurement of agitation levels (daily and weekly) | • Administration of music intervention<br>• Measurement of agitation levels (daily and weekly) | • Return to usual care<br>• +/- individualised music if desired |

Table 8: Overview of the study design

Throughout the four week study period a record of Pro Re Nata (PRN) (as needed) medications were recorded.

### 3.11.2 Music intervention and music equipment

An individualised music intervention was created by identifying personally meaningful music to the participant. The music was identified using the approach of Playlist for Life©. Personally meaningful music, that being music that was rich in memories for the participant was identified through interview by the Chief Investigator and the participant and/or family member. A minimum of 10 pieces of music were identified and recorded on the Music Selections Form (see Appendix 2). This music was downloaded on to a MP3 player and listened to by the participant through headphones or via a speaker. If the participant chose to listen to the music via the headphones a splitter cable and an additional set of headphones were provided to allow the healthcare professional or family member to listen to the music with the participant. The financial cost of the equipment and associated purchase of the music was funded by a donation from the NHS Fife Healthy Harmonies Staff Choir.

### 3.11.3 Healthcare professionals

A focus group and a one to one semi-structured interview (see Appendix 3) was carried out to discuss the healthcare professional's experience of facilitating the individualised music intervention, their perception of the outcomes of this intervention, and recommendations for an individualised music intervention for persons with dementia in specialist mental health setting. Due to personal commitments some healthcare professionals who wanted to participate in the research were not able to attend the focus group or be interviewed. Therefore written questions were emailed to the participants for them to answer. Although this method of eliciting data was disadvantageous in that it did not allow the researcher to explore issues in

depth, it did allow experiences and thoughts to be captured that otherwise would not have been documented. A qualitative thematic analysis of this data was carried out.

### 3.11.4 Family Carer participants

A one to one semi-structured interview (see Appendix 4) was used to discuss the family carers experience of being involved in the use of an individualised music intervention for the person they care for, their perception of the outcomes of this intervention, and recommendations for an individualised music intervention for persons with dementia. A qualitative thematic analysis of this data was carried out.

## 3.12 Data Measures

Data was collected as detailed below.

### 3.12.1 Persons with dementia

Participant characteristics:

- Age
- Sex
- Marital status
- Educational attainment
- Date of diagnosis of dementia
- Diagnosis sub-type
- Measure of cognitive impairment using Montreal Cognitive Assessment Version 7.1 (MoCA) – (Appendix 14) or similar tool as indicated by the medical team
- Current medical and non-medical treatment
- Living arrangements

- Reason for hospital admission and expected length of stay in ward

This was recorded in the Participant Background Questionnaire (see Appendix 15).

Background music preferences were recorded in the Background Music Questionnaire (see Appendix 1).

Music selections were recorded in the Music Selections Form (see Appendix 2).

Baseline measures undertaken by the nursing staff:

- Agitated Behaviour Scale (ABS) – this scale was used to obtain a daily measure of agitation at a set time each day for a 30 minute period. Every effort was made to ensure this was measured at the same time each day. It assessed the nature and extent of agitated behaviours at baseline pre-test, 7 days prior to commencing the intervention (see Appendix 16)
- Cohen Mansfield Agitation Inventory (CMAI) Long form – this was undertaken at the end of the baseline data collection period (7 days) giving a measurement of frequency of manifestations of agitated behaviours for the whole week (see Appendix 17)
- Baseline measurement of the administration of PRN (when needed) medication for agitation was recorded. This data was gathered from the prescription chart and corresponding nursing notes. This information was recorded in the 'Medication Form' (see Appendix 18)

Experimental measures undertaken by the nursing staff:

- As per baseline measures
- The healthcare professional was further asked to record engagement and enjoyment of the music, and any observed, non-verbal behaviours and verbal interactions/ utterances during the music intervention in the 'Music Session Documentation' form (see Appendix 19).

## 3.13 Analysis of data

### 3.13.1 Persons with dementia

Daily agitation scores were analysed using visual analysis to present the findings. The data was converted into graphs and figures, and trends and changes during baseline, intervention and follow up period was examined. Interpretation took place of whether the intervention had any influence on the outcome.

This method of analysis was used as it allowed the researcher to easily answer two questions:

- Did behaviour change in a meaningful way?
- To what extent can that change in behaviour be attributed to the independent variable?

Lane and Gast (2014) state “the primary goal of visual analysis is to identify if a functional relationship exists between the introduction of an intervention and change in a socially desirable behaviour, as well as replicate effects across multiple participants”. They argue that “visual analysis is sensitive to changes in behaviour and allows researchers to analyse each participant’s behaviour through repeated measurement and evaluation, allowing observation of abrupt, as well as subtle changes over time” (Lane and Gast 2014 p 460). The use of visual analysis fitted well with this particular study as it was a pilot study with a small sample size; hence this type of analysis was achievable whilst at the same time provided meaningful results.

As single case design studies use the individual ‘case’ as their own control, the results for each participant are presented separately. The process of visual analysis, namely looking at the graph of data points, is used to determine if the intervention has changed the participant’s pre-intervention patterns of scores. Three concepts were used to facilitate the process of visual analysis: level, trend and variability (Bulté and Onghena 2011, Cosgrove 2017, Engel and Schutt 2017, Lane and Gast 2014, Todd 2017).

Level: does inspection of the data points reveal a change, upwards or downwards, in amount or magnitude? To simplify this process the median was presented for each participant through each phase of the study. The median was used rather than the mean as some data points were outliers and one or two extreme scores can greatly alter the mean (Bulté and Onghena 2011, Engel and Schutt 2017).

Trend: a trend refers to the direction or pattern of the data points as a complete series and can be an increasing or decreasing pattern, even though individual data points may not always conform to the trend. A linear trend-line was presented to support the visual analysis of this concept.

Variability: Understanding of the visual analysis of the data points might depend on the variability or stability of scores. This means how different or divergent the scores are within the baseline and intervention phases. Range lines were presented to demonstrate the variability in the visual analysis.

Additional data collected through the weekly agitation measurements, the assessment of the degree of engagement and enjoyment each participant experienced from the individualised music sessions, and additional comments or observations noted by the healthcare professional of the participants behaviour, body language or verbal utterances were analysed by recording frequency of certain behaviours and detailed descriptions of behaviours witnessed. This data was illustrated through graphical and tabular presentation. The administration of PRN medication for agitation was analysed by also looking at frequency of need and presented in table format.

### 3.13.2 Healthcare professionals

The focus group and individual interviews were analysed using the process of thematic analysis. Braun and Clarke (2006) describe thematic analysis as a method for identifying, analysing and reporting patterns (themes) within

data. An essentialist or realist method was applied to report experiences, meanings and reality of participants. A ‘bottom-up’ approach was used to analysing the data, where the researcher had no pre-existing coding frame or theoretical stance that she was trying to fit the data to. This inductive method means the themes identified are strongly linked to the data from the interviews.

The process for the thematic analysis started with the transcription of the interviews/focus groups. The researcher undertook the transcription of all interviews and focus groups. They were transcribed verbatim to word document and pseudonyms applied for the purposes of anonymity. The transcription was a time-consuming process but allowed the researcher to become totally familiar with the data, and early interpretation and meanings were formed. Transcripts were read and re-read to facilitate continued familiarisation with the data.

The next stage was the generation of initial codes within the data set. A line by line analysis was undertaken of each interview and any features in the data, ideas or interesting narrative that had significance on the research questions were identified and marked with a highlighter pen. During this process common description, accounts, or examples began to develop and were thus coded. Utmost care was taken to treat each interview separately, and not be influenced by previous transcripts.

The next step in the thematic analysis involved bringing together all the codes from each separate interview. A mind map was created to provide a visual representation of the codes to help sort them into potential overarching themes. These themes were then reviewed and refined until a final theme was reached which could be defined, and the essence of that theme described. In analysing the data in this way the researcher was trying to grasp the essential meaning of the data (van Manen 1997) in order to allow interpretation and culminating in a description of the phenomena for each theme.

### 3.13.3 Family carers

A thematic analysis approach was employed in the same manner as described above for healthcare professionals.

## 3.14 Study withdrawal

Participants were able to withdraw from the study at any time for any reason. In the event of this happening, a reason for withdrawal would be sought, but participants could chose to withdraw without providing an explanation. If a participant decided to withdraw it would not affect the normal care they received. Data collected prior to withdrawal would be used in the analysis unless consent for this was specifically withdrawn.

# Chapter 4: Results

Using the strategy outlined in the previous Methods chapter, five people with dementia were recruited to the experimental part of the study. Four family carers and five healthcare professionals were recruited to the qualitative element of the study.

## 4.1 Participant characteristics

### 4.1.1 Persons with dementia

The sample comprised five adults with a diagnosis of dementia, all hospitalised for medical care and treatment of their condition. One person from the sample died before completing all the interventions (Participant 4).

The mean age of participants was 70.6 years (standard deviation 9.3), ranging from 56-84 years. Over half of the sample were male (60%) and four of the five participants were married. One participant was a widower. This participant lived in a care home prior to hospital admission. All other participants lived at home. All participants had received formal education – one to primary school level, two to secondary school level and two had attended university and obtained undergraduate degrees. See Table 9 for summary of participant characteristics.

### 4.1.2 Healthcare professionals

The sample comprised five healthcare professionals. All participants had been involved in the delivery of the individualised music intervention during the experimental phase of the study. The sample were all registered mental health nurses in either staff nurse or senior charge nurse positions.

| | Participant 1 | Participant 2 | Participant 3 | Participant 4 | Participant 5 |
|---|---|---|---|---|---|
| Age | 74 | 66 | 56 | 73 | 84 |
| Sex | Female | Female | Male | Male | Male |
| Marital status | Married | Married | Married | Widower | Married |
| Educational attainment | Primary school | University | University | Secondary school | Secondary school |
| Date of diagnosis of dementia | Not known | June 2015 | August 2014 | Not known | November 2015 |
| Diagnosis sub-type | Lewy body dementia | Alzheimer's Disease | Young onset Alzheimer's Disease | Vascular dementia | Mixed dementia – Alzheimer's Disease and Vascular Dementia |
| MoCA or equivalent | Moderate cognitive decline | Severe cognitive decline | Severe cognitive decline | Severe cognitive decline | Moderate cognitive decline |
| Current treatment | Medication Nursing interventions | Medication Nursing interventions | Medication Nursing interventions | Medication Nursing interventions | Medication Nursing interventions |
| Living arrangements | Home (with husband and daughter) | Home (with husband) | Home (with wife and son) | Care home | Home (with wife) |
| Reason for admission | Decline in mental health – agitation, hallucinations, falling. Family unable to cope. | Decline in mental health. Family unable to cope. | Decline in mental health. Aggression towards wife. Family unable to cope (young child at home) | Aggression towards care home staff. Resistance during personal care. | Decline in mental health. Family unable to cope. |
| Expected length of stay | >4 weeks | >4 weeks | >4 weeks | >4 weeks | >4 weeks |

Table 9: Summary of participant characteristics for persons with dementia

### 4.1.3 Family carers

Due to the death of one of the participants with dementia only four family carers were recruited. All of the carer participants were the spouse and next of kin for the person with dementia, and all held Welfare Power of Attorney status for the individual.

## 4.2 History of music involvement and music preferences for persons with dementia

Music preferences were assessed by the Chief Investigator for each participant in the experimental study. This was done by interviewing the participant and his/her family carer. Participant's favourite types of music, methods of listening to music, and musical backgrounds were identified by the participants or family carers. The most favourite type of music was popular music, and most common method of listening to music was using a compact disc player. Four participants (80%) viewed music as being important, and one (20%) viewed music as being very important in their life. Only one participant played a music instrument although she had stopped this two to three years previously. All participants required help to use a music playing device, although for one participant this was a relatively new situation. Four participants (80%) listened to music for enjoyment and one participant listened to music to relieve boredom. This participant lived in a care home facility. See Table 10 for a summary of participant music preferences.

| | Participant 1 | Participant 2 | Participant 3 | Participant 4 | Participant 5 |
|---|---|---|---|---|---|
| How important is music in your life | Important | Very important | Important | Important | Important |
| How often do you listen to music | Once or twice per day | As often as I can | Most days | Some days | Most days |
| How many hours per day listening to music (average) | 2 hours | 4-6 hours | 1-2 hours | 1 hour | 1 hour<br>Sometimes listens to radio overnight |
| What technology do you use to listen to music<br>*used most | Radio<br>CD Player*<br>Cassette player<br>Record player | Radio*<br>CD player<br>Sonos<br>Record player | MP3<br>Cassette player<br>Radio<br>CD Player<br>Laptop/ Computer* | CD Player* | Radio<br>CD Player* |
| Do you require assistance to use device | Yes<br>12 months ago could manage | Yes<br>8 months ago could manage | Yes<br>Starting to need help | Yes<br>Does not remember how to use | Yes<br>Has macular degeneration so unable to see |
| With whom do you listen to music | Mostly on my own | Mostly on my own | With family | With family | With family |
| What is the main reason for listening to music | To enjoy the music | To enjoy the music | To enjoy the music | To relieve boredom | To enjoy the music |
| Do you play an instrument | No | No<br>Stopped 2-3yrs ago | No | No | No |
| Have you ever played an instrument | No | Yes<br>Piano | No | No | No |
| How long have/did you play this instrument | n/a | 50yrs+ | n/a | n/a | n/a |
| Have you had formal music training | n/a | Yes<br>Piano lesson | n/a | n/a | n/a |
| 3 types of music most listened to | Pop<br>Opera<br>Classical | Classical<br>Pop<br>Vocal jazz | Pop<br>Punk<br>Classical | Country and Western<br>50's<br>60's | Ballads<br>Light classical<br>Jazz |
| Do you participate in musical activities e.g. choir, dance group, band | WI Choir<br>Hymns at church<br>(both not currently) | No | No | Enjoyed dancing in youth | No |

Table 10: Summary of participant music preferences for persons with dementia

## 4.3 Effectiveness of individualised music intervention on daily levels of agitation

### 4.3.1 Participant One

Data in Figure 4 represents the agitation scores for Participant One throughout the four week experimental study. Agitation levels were measured daily as per the study protocol. This represents a 100% adherence with the study protocol. Over the 28 days, six data points measured within the range of 21 and 28, indicating the participant experienced mild agitation, and there was one data point recorded within the range of 29 and 35, which meant the participant experienced a moderate level of agitation. In week one the participant showed mild agitation on one day, in weeks two and three she experienced two days of mild agitation, and in week four she experienced moderate agitation on one day and mild agitation on another.

#### 4.3.1.1 Level

The summary line (median) between week one and week two did not alter suggesting that the music intervention did not have any effect on agitation levels for Participant One. (See Figure 5 Graphs a and b). The median went up by one data point between week two and week three when the participant returned to a no music week (see graphs b and c). From week three to week four the biggest effect was noted when the median lowered from 19 to 15 (see graphs c and d), suggesting that the intervention may have improved levels of agitation.

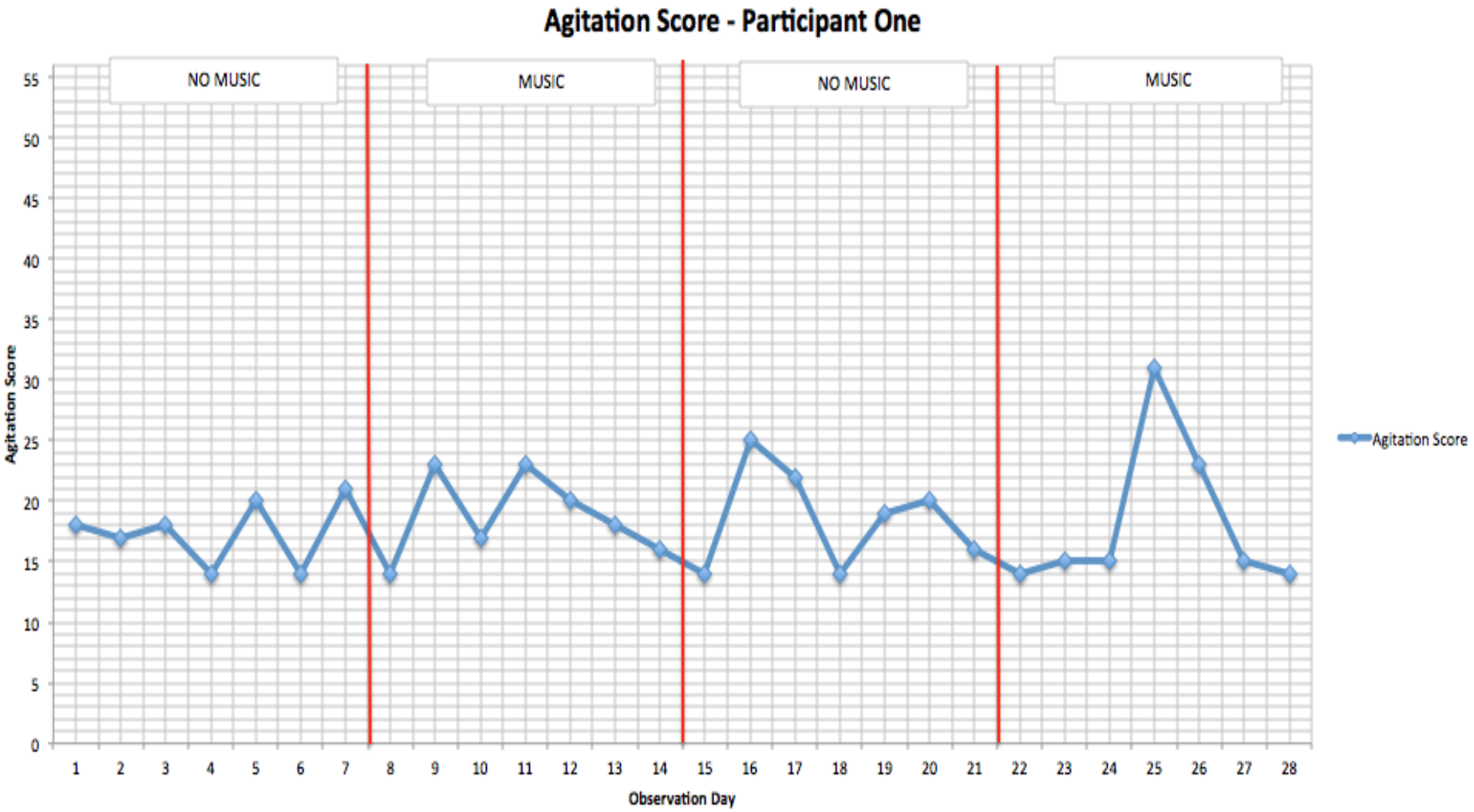


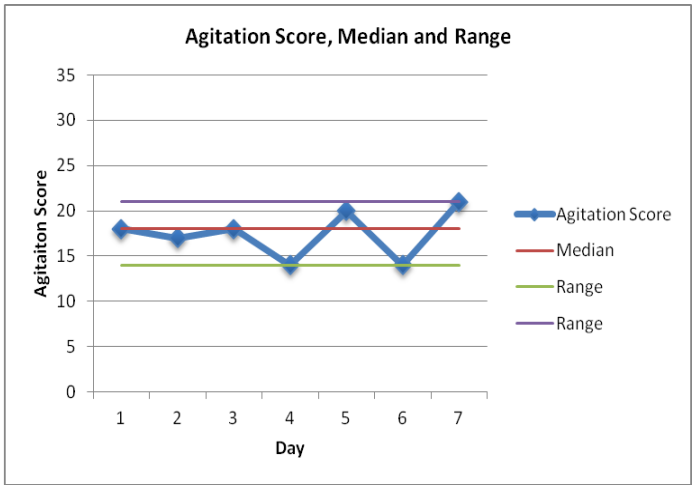

Figure 5: Daily agitation scores for Participant One

#### 4.3.1.2 Trend

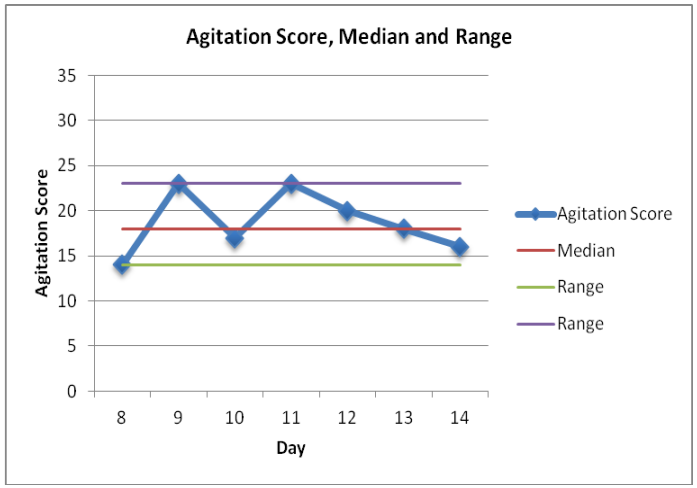
The linear trend-line was plotted for each week of the study as presented in Figure 6 graphs a-d. In week one, the trend-line shows a very gentle slope upwards, whereas in week two the trend-line is straight, suggesting the intervention did not improve levels of agitation but at the same time did not make them worse. In week three, a no music week, there is a very gentle sloping downwards of the trend-line suggesting a slight improvement in agitation levels, whereas the trend-line starts to gently slope upwards again in week four when the music intervention was reintroduced, suggesting that agitation levels slightly deteriorated during this week. This is contrary to the results found when analysing the median for this week. However the two-outlier results of 30 and 23 may explain this, and if these results were excluded the trend-line would demonstrate a downward direction supporting the improvement of agitation levels for that week.

#### 4.3.1.3 Variability

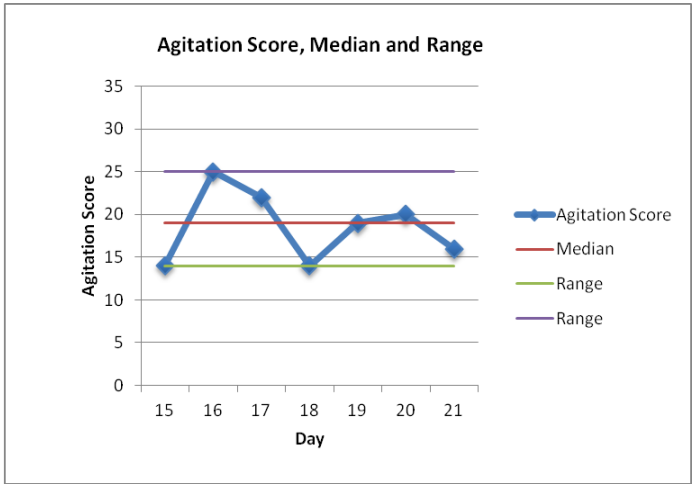
The variability of the scores gradually increased over the four weeks of the study: the range was 7 data points in week one; 9 data points in week two; 11 data points in week three; and a significant increase in week four to 17 data points. A wide range as demonstrated in week four makes any assessment of effectiveness of the intervention difficult. Again, it is two outlying scores that affected the range in this week. If these scores were removed the variability of scores would be one data point, showing stability and potentially resulting in more confidence in the results.



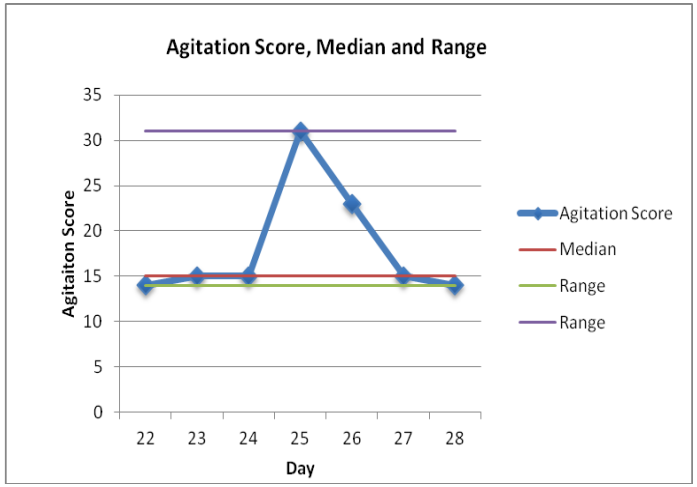

a




b

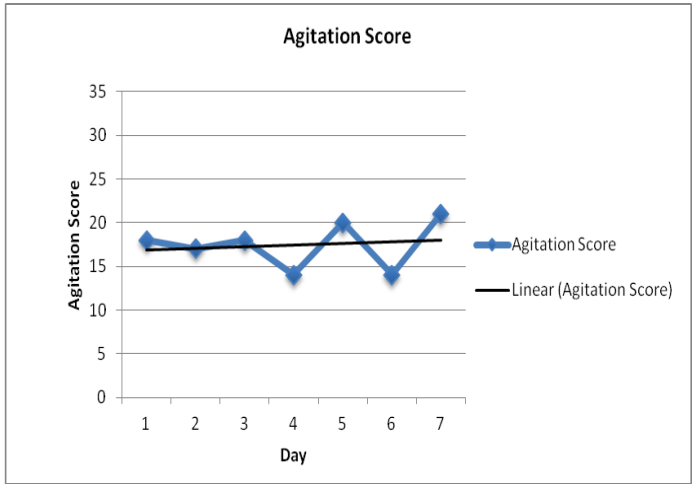



c

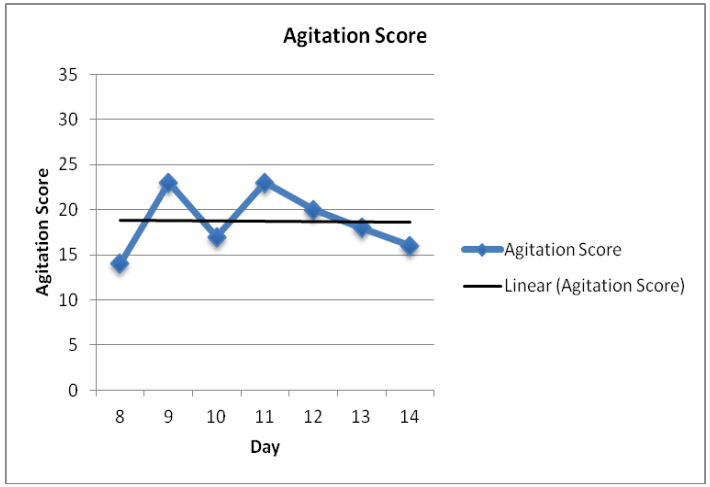



d

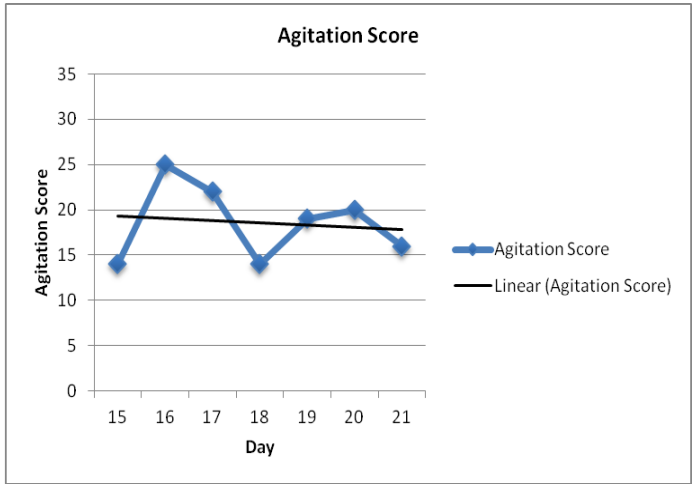
Figure 6: Agitation Scores, Median and Range for Participant One




a




b

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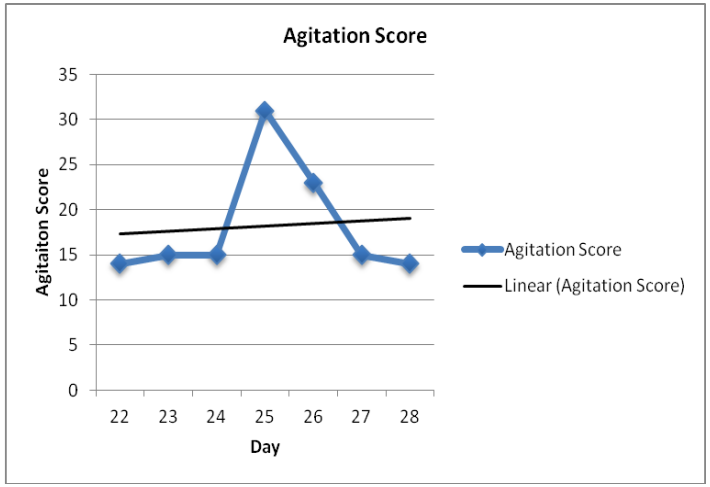



d

Figure 7: Agitation Scores with Linear Trend-line for Participant One

### 4.3.2 Participant Two

Data in Figure 7 represents the agitation scores throughout the four week experimental study for Participant Two. Agitation levels were measured as per the study protocol in week one and week two, but the intervention was not administered on day 21, day 26 and day 28 resulting in no data for these days. This represents an 89% adherence to the research protocol. There were 21 data points over the 28 days that measured within the range of 21 and 28, indicating the participant experienced mild agitation. There were three data points recorded within the range of 29 and 35, which meant the participant experienced moderate levels of agitation. And one data point that measured over 35, which indicated the participant experienced severe levels of agitation. In week one the participant experienced mild agitation on all seven days of the study. In week two the participant experienced mild agitation on six days and severe agitation on one day. In week three the participant experienced mild agitation on six days and moderate agitation on one day. In week four the participant experienced mild agitation on two days and moderate agitation on two days, and no agitation on the remaining day of the intervention being administered.

#### 4.3.2.1 Level

The summary line (median) between week one and week two did not alter suggesting the music intervention did not have any effect on agitation levels for Participant Two. (See Figure 8 Graphs a and b). The median went up by three data points between week two and week three when the participant returned to a no music week (see graphs b and c) indicating levels of agitation slightly increased when the music was withdrawn. From week three to week four the median went up by a further data point, suggesting the music intervention had no effect on levels of agitation.

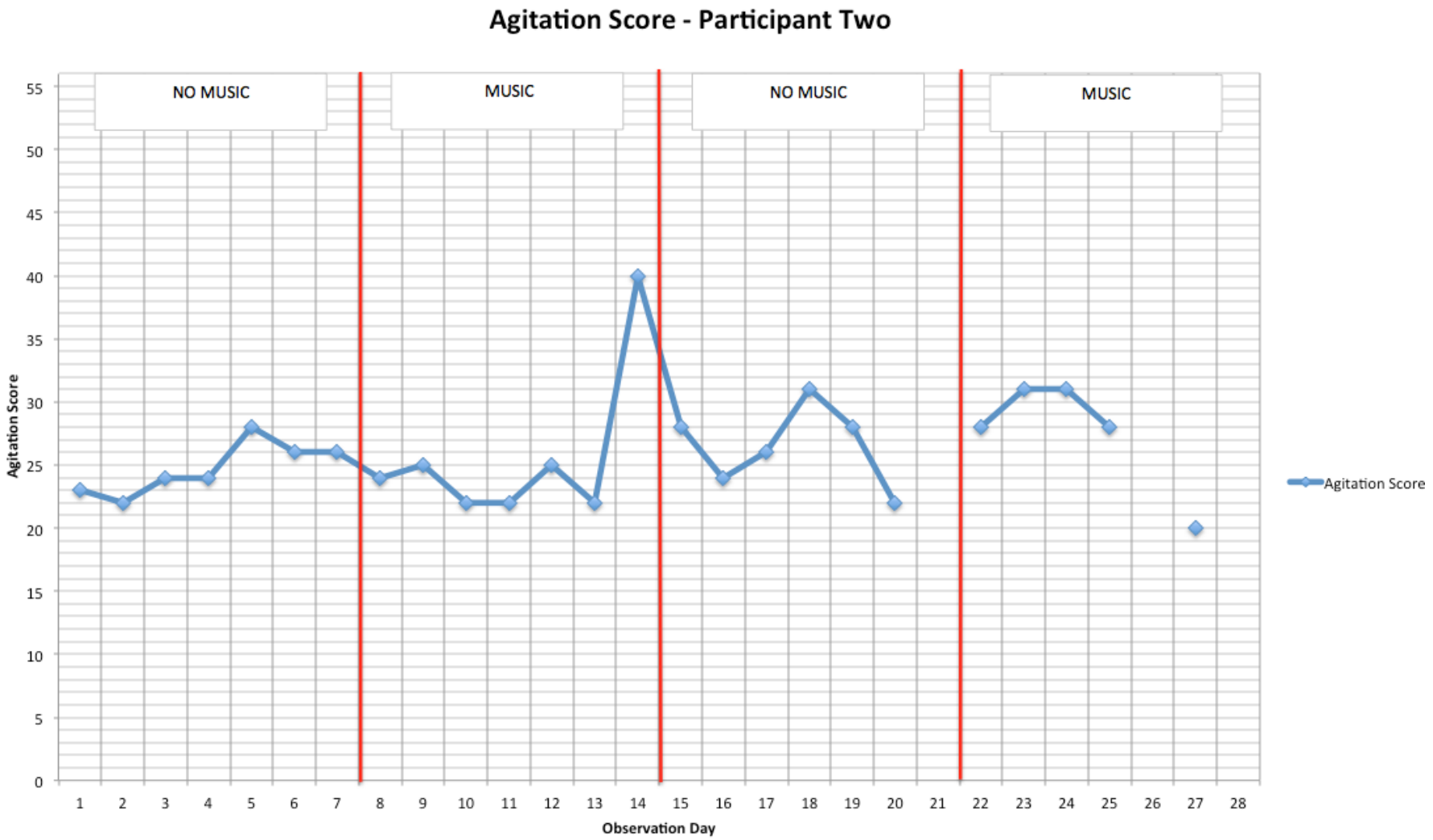
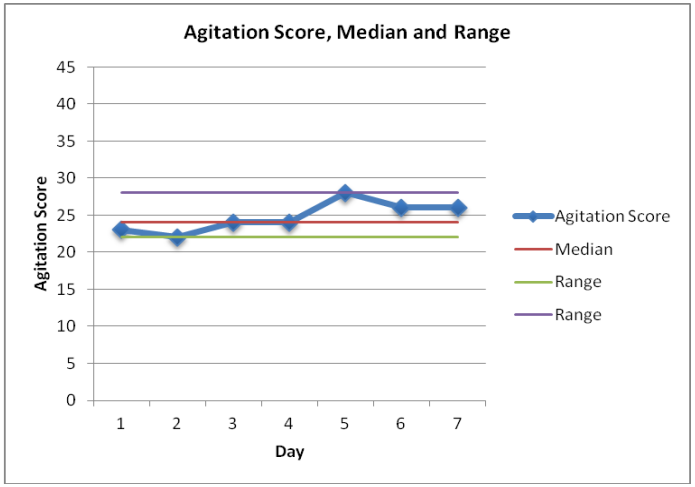
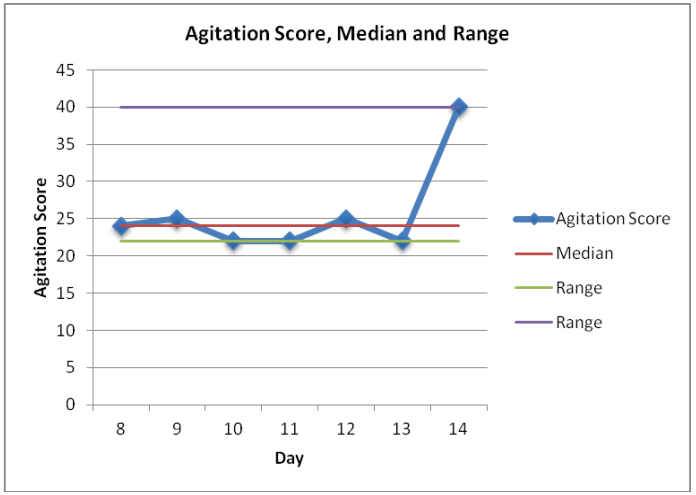


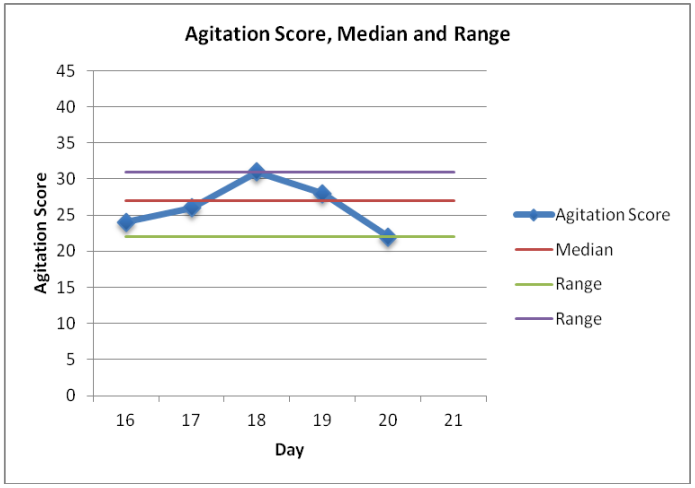

Figure 8: Daily agitation scores for Participant Two



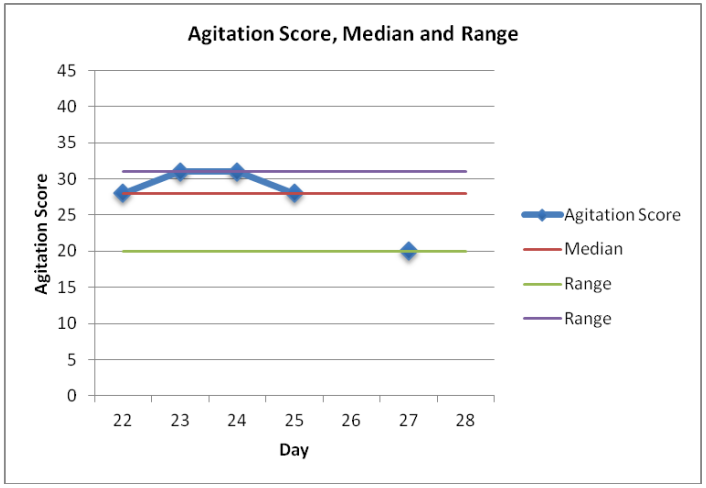

a




b

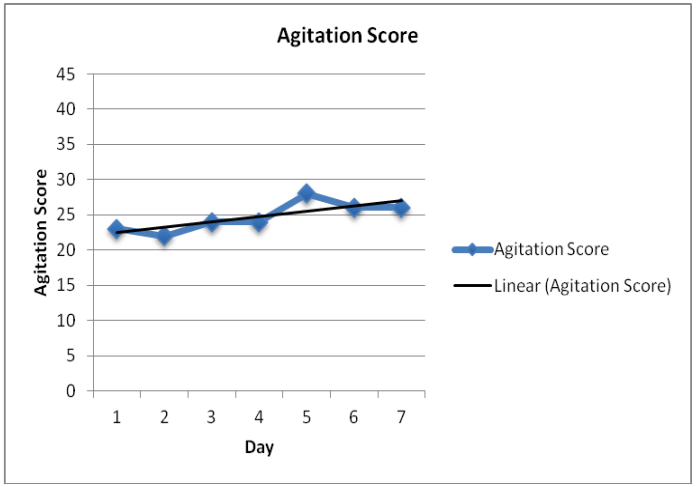



c

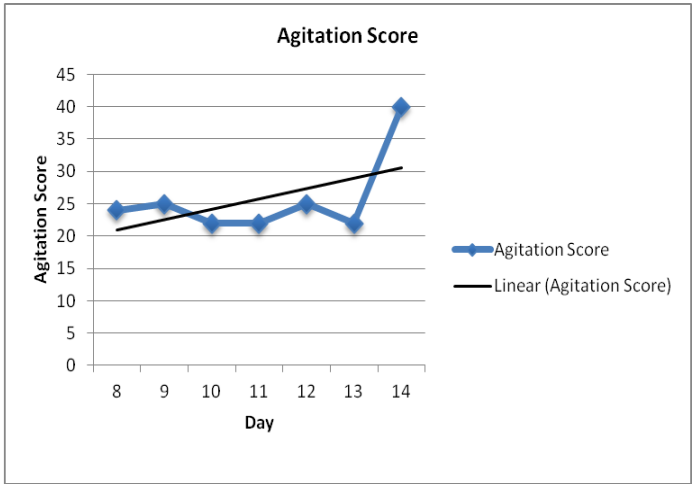



d

Figure 9: Agitation Scores, Median and Range for Participant Two




a

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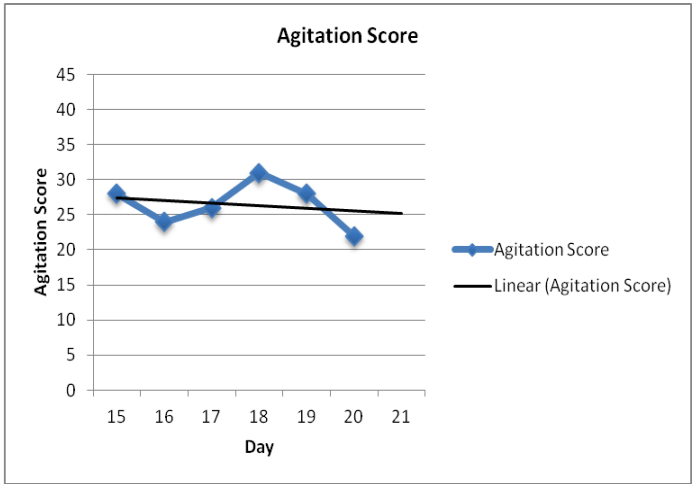


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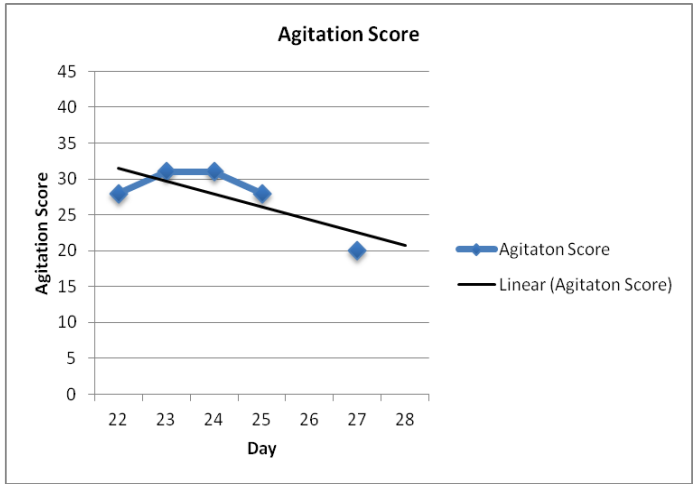



d

Figure 10: Agitation Scores with Linear Trend-line for Participant Two

4.3.2.2 Trend

The linear trend-line was plotted for each week of the study as presented in Figure 9. In week one the trend-line shows a gentle slope upwards. This trend continued in week two, the music intervention week, and the rate of increase is greater suggesting the music did not have any effect on levels of agitation, and possibly made them worse (graph b). It is worth noting however that one outlier score caused this upward trend, and if this score is removed from the calculation the trend-line becomes very slightly sloping downwards indicating a neutral, or a very slight positive effect on agitation levels during this week (see Figure 10) below.

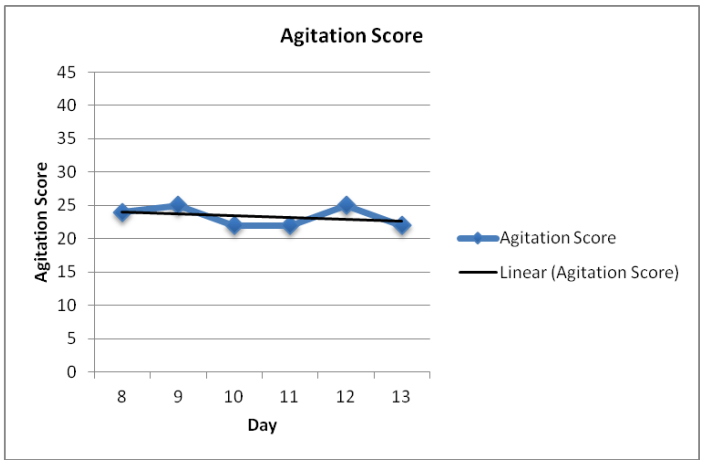



Figure 11: Agitation Scores with Linear Trend-line for Participant Two (Week 2 with outlier score removed)

In week three, a no music week, there is a gentle sloping downwards of the trend-line suggesting a slight improvement in agitation levels over the week (see graph c). In week four, a music week, the trend-line continues to slope downwards at an increasing rate, indicating agitation levels improved (see graph d). However, like before, a single outlying data point may explain this and not represent a true situation. When this data point is removed the trend-line is straight suggesting the music intervention did not improve agitation levels but also did not make them worse (see Figure 11). This supports the data presented in section 4.3.2.1 on the median line where there was no improvement in agitation levels.

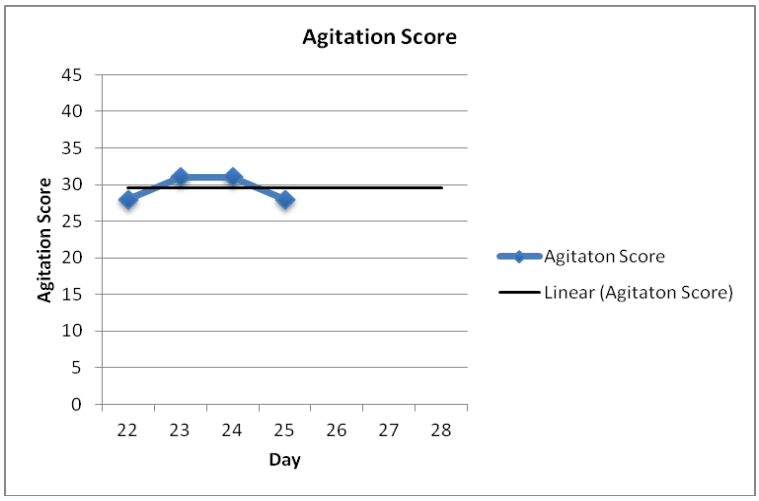



Figure 12: Agitation Scores with Linear Trend-line for Participant Two (Week 4 with outlier score removed)

#### 4.3.2.3 Variability

The variability of the scores fluctuated over the four weeks of the study: the range in week one was 6 data points; 18 data points in week two; 9 data points in week three; and 11 data points in week four. Such wide variation makes it difficult to ascertain firm conclusion from the data. Again, single outlying data points greatly contributed to the variation in the range of scores, and if these were removed from the equation the range in both week two and week four would be three. Greater stability such as this would promote greater confidence that the changes in agitation scores are due to the application of the intervention. As such it is not possible to make that conclusion.

### 4.3.3 Participant Three

Data in Figure 12 represents the agitation scores for Participant Three throughout the four week experimental study. Agitation levels were measured daily in week one. The intervention was not administered on day 13 in week two and day 22 in week four, hence missing data on these days.

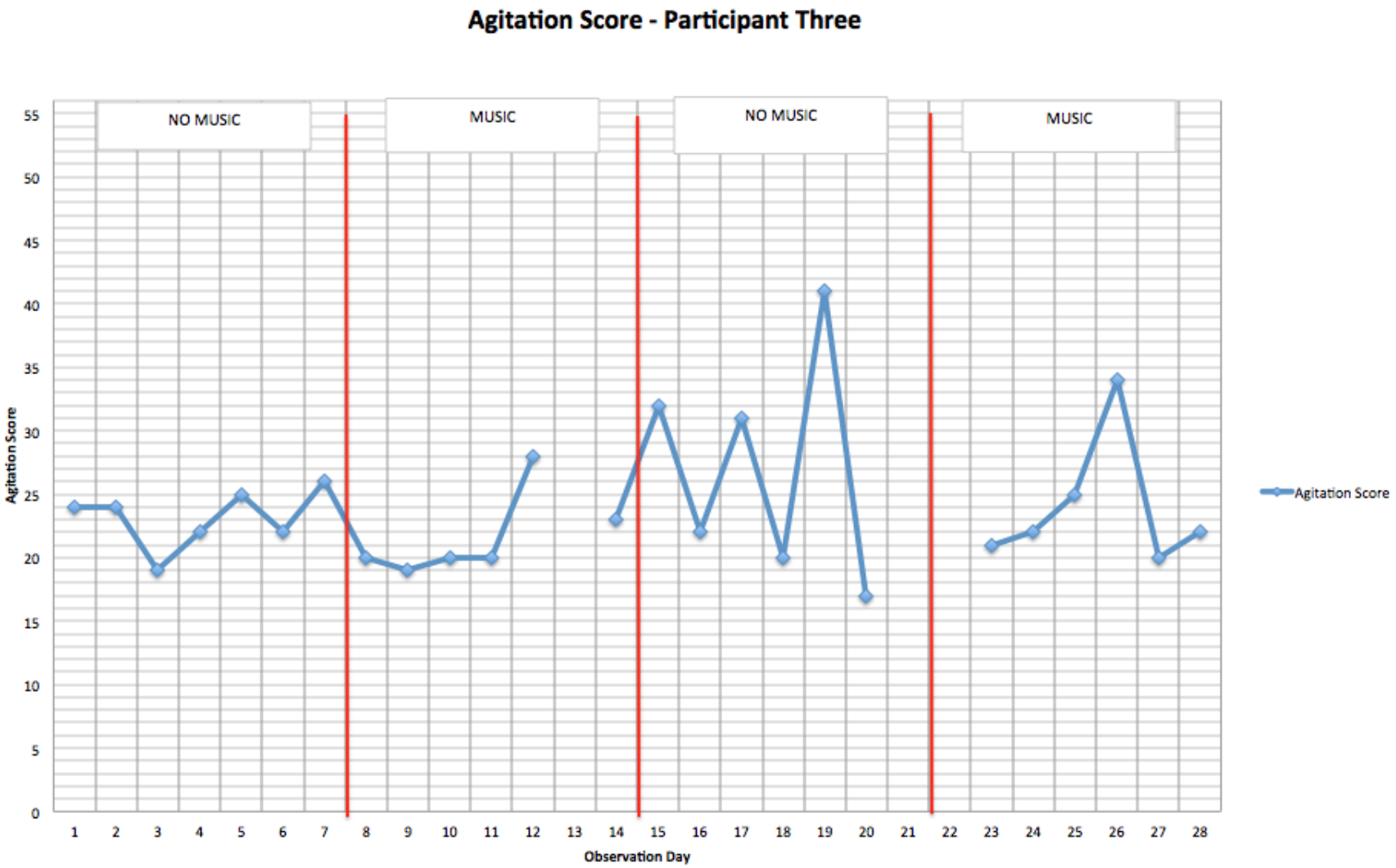
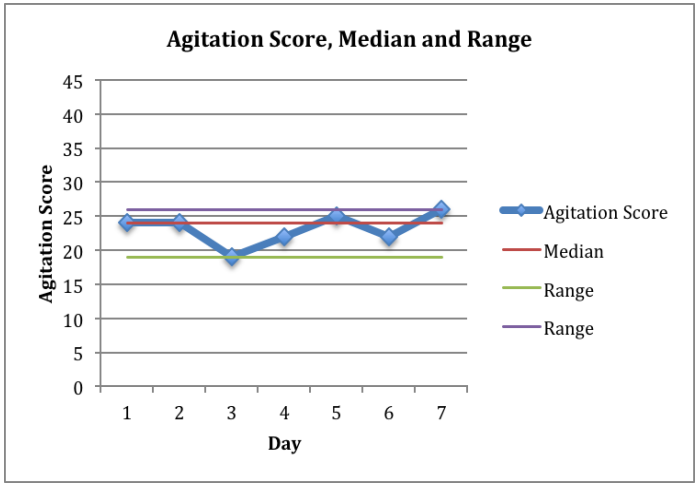
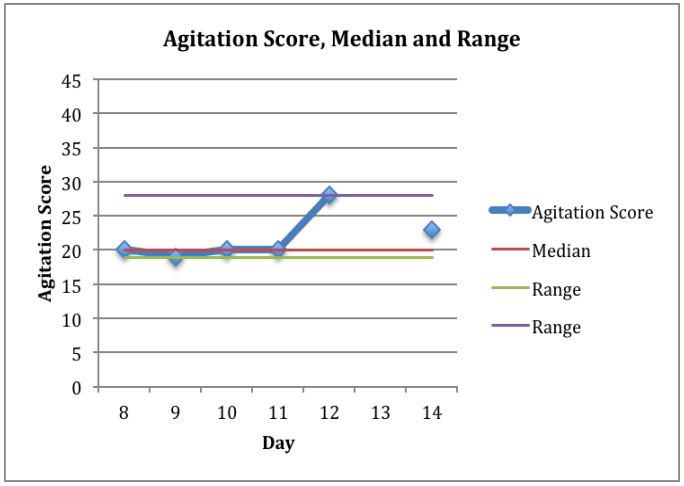


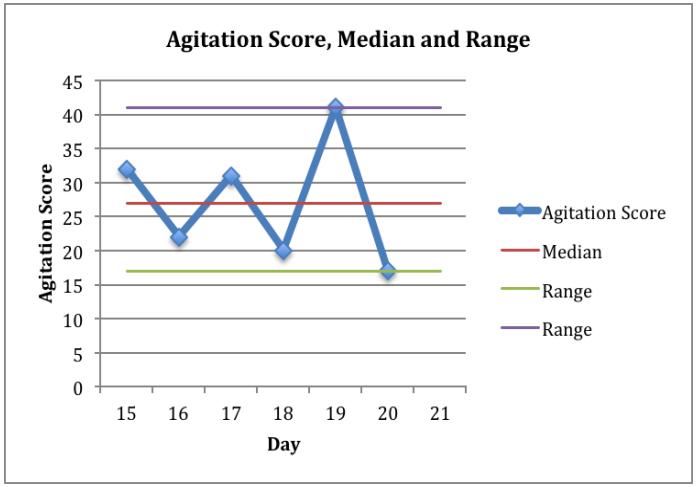

Figure 13: Daily agitation scores for Participant Three



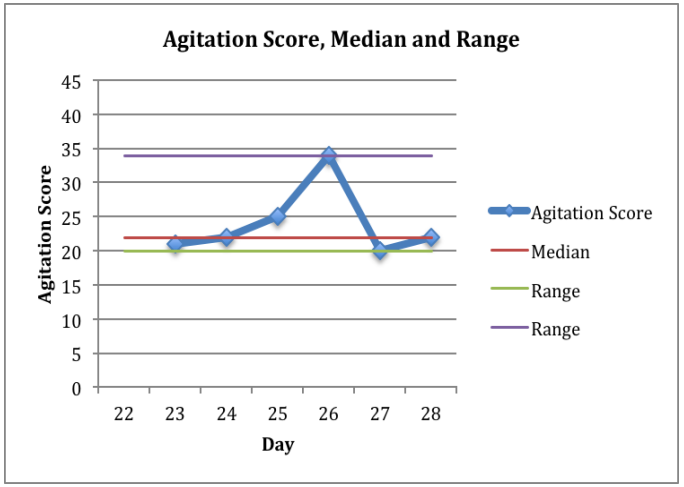

a




b




c




d

Figure 14: Agitation Scores, Median and Range for Participant Three

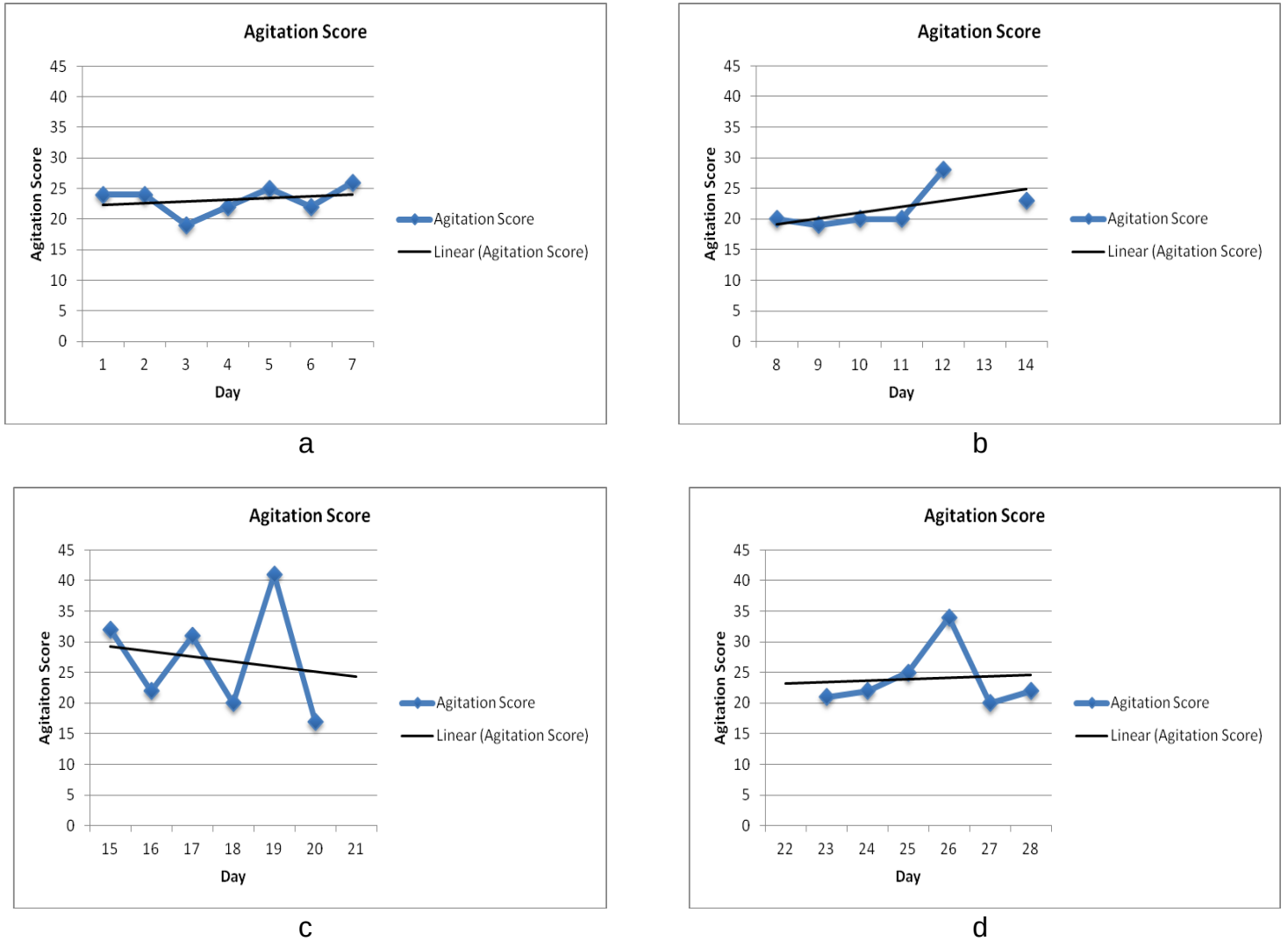



Figure 15: Agitation Scores with Linear Trend-line for Participant Three

No measurement was undertaken on day 21, a no intervention week. This represents an 89% adherence to the research protocol. There were 13 data points over the 28 days that measured within the range of 21 and 28, indicating mild agitation experienced by the participant. There were three occasions when the participant experienced moderate agitation, and one occasion when he experienced severe agitation. In week one, the participant showed mild agitation on all days except day three when he displayed no agitation. In week two he displayed no agitation until day 12 and 14 of the study when he experienced mild agitation. In week three the participant experienced no agitation on two days, mild agitation on one day, moderate agitation on two days and severe agitation on one day. In the final week of the study the participant experienced no agitation on one day, mild agitation on four days, and moderate agitation on one day.

#### 4.3.3.1 Level

The summary line (median) was higher in week one than in week two indicating that there might be some association between the intervention and the levels of agitation. (See Figure 13 Graphs a and b). This is supported by the increase in the median in week three when the music was removed (see Figure 13 graph c), and the further decrease in median when the music was re-introduced (see Figure 14 graph d).

#### 4.3.4.2 Trend

The linear trend-line was plotted for each week of the study as presented in Figure 14 graphs a-d. In week one, the trend-line shows a very gentle slope upwards. This trend continued in week two, the music intervention week, and the rate of increase is slightly greater suggesting the music did not have any effect on levels of agitation, and possibly made them worse (graph b). In week three, a no music week, there is a gentle sloping downwards of the trend-line suggesting an improvement in agitation levels (graph c). The trend-

line starts to very slightly slope upwards again in week four (graph d), a music week, indicating that the intervention potentially made the levels of agitation worse. As in previous participants, there is an outlier agitation score on day 26 which if removed the trend-line would very gently slope downwards indicating a small improvement in agitation levels.

#### 4.3.3.3 Variability

The variability of the scores fluctuated over the four weeks of the study: the range in week one was 7 data points; 9 data points in week two; 24 data points in week three; and 14 data points in week four. The scores in week three were extremely variable. Such wide variation makes it difficult to ascertain firm conclusion from the data. Again, single outlying data points greatly contributed to the variation in the range of scores, and if these were removed from the equation the range in week two would be four, and in week four would be five. Greater stability such as this would promote greater confidence that the changes in agitation scores are due to the application of the intervention. As such it is not possible to make that conclusion.

### 4.3.4 Participant Four

Data in Figure 15 represents the agitation scores throughout the four week experimental study for participant four. Agitation levels were only measured on 6 occasions in week one, day 7 being the omitted measurement. During week 2, the intervention was not administered on day 11 and day 14 resulting in no data for these days. A single final agitation score was completed in week three, on day 15 of the study, before the participant became unwell and subsequently passed away. There were 2 data points over the 15 days that measured within the range of 21 and 28, both in week one, indicating the participant experienced mild agitation. The measurement on all remaining days was 17 or below meaning the participant did not display agitation.

#### 4.3.4.1 Level

The summary line (median) between week one and week two reduced from 15.5 to 14. (See Figure 16 Graphs a and b). This is suggestive that the intervention did have an effect on lowering levels of agitation, however both medians equate to no agitation.

#### 4.3.4.2 Trend

The linear trend-line was plotted for week one and two of the study as presented in Figure 17 graphs and b. In week one, the trend-line shows a steep slope downwards, whereas in week two the trend-line is straight. This suggests the intervention did not alter agitation levels, which in this case was no agitation, but at the same time did not make agitation levels worse.

#### 4.3.4.3 Variability

The variability of the scores differed greatly between the two weeks. In week one the range was 13 data points whereas in week two it was 3 data points. Wide scores at baseline make assessments of intervention more difficult. If the two outlying scores are removed from week one, the range of scores between the two weeks would be the same, indicating stability in the scores. The stability of the scores in week two could be a positive indicator that the intervention was having a positive effect on agitation levels.

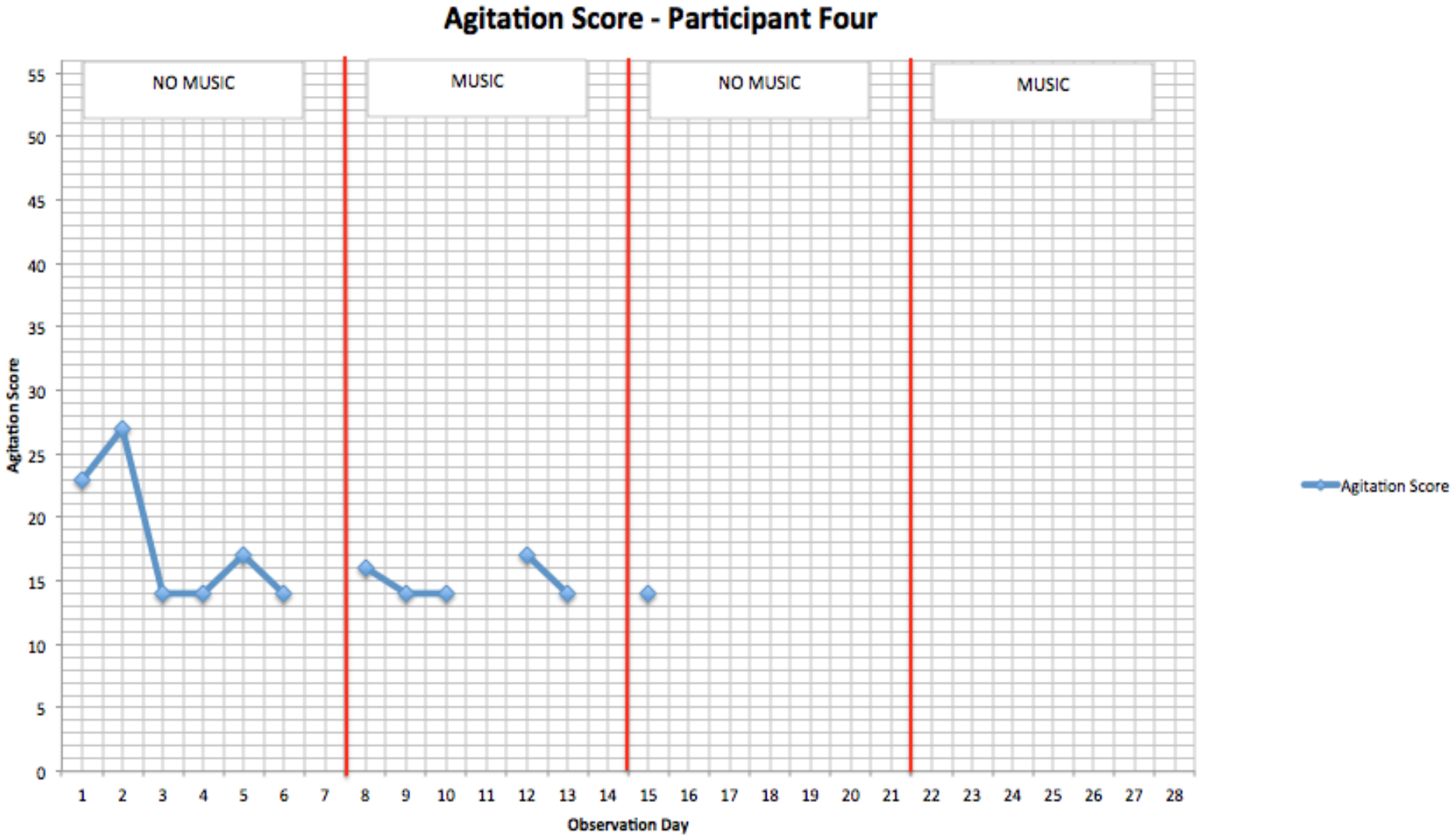
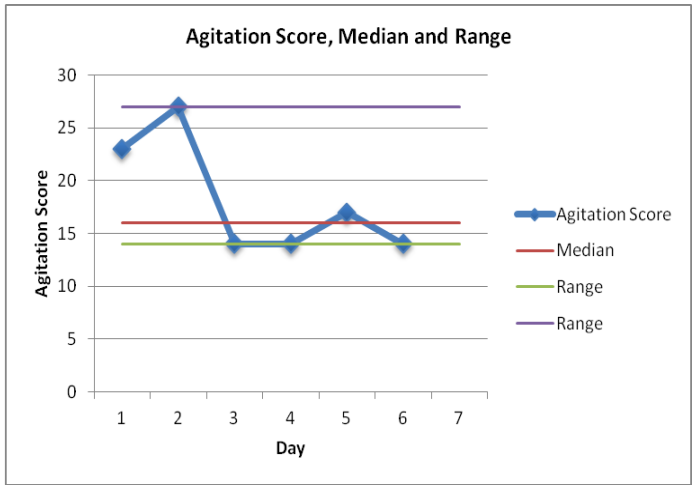
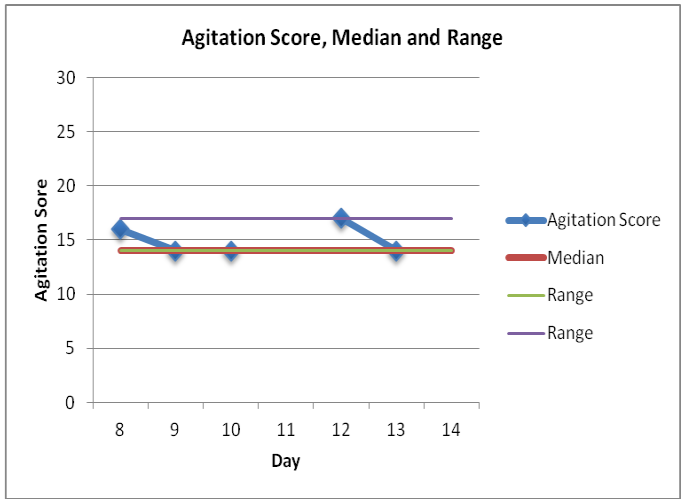



Figure 16: Daily agitation scores for Particpant 4

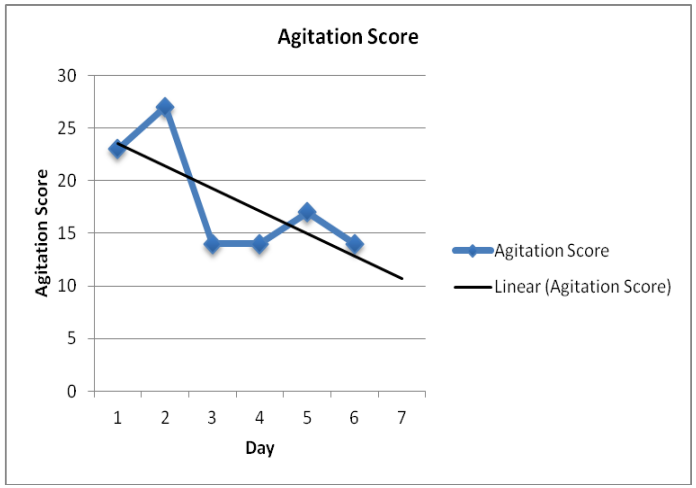



a

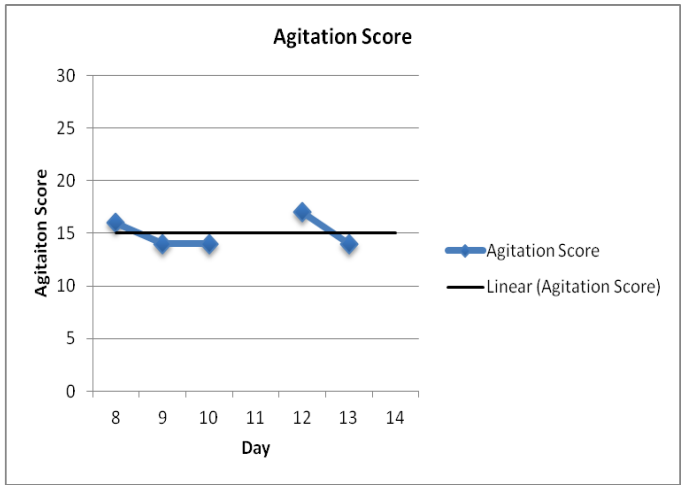



b

Figure 17: Agitation Scores, Median and Range for Participant Four




a




b

Figure 18: Agitation Scores with Linear Trend-line for Participant Four

### 4.3.5 Participant Five

Data in Figure 18 represents the agitation scores for participant five throughout the four week experimental study. Agitation levels were measured for every day of the study as per the protocol except for days 27 and 28 when the intervention was not administered. This represents a 93% adherence to the research protocol. Although this participant was identified by the medical and nursing team as someone who had a history of agitated behaviour, the participant only exhibited mild agitated behaviour on three occasions – day 10, day 11 and day 23. The remaining time he was not agitated.

#### 4.3.5.1 Level

The summary line (median) went from 16 to 18 between week one and week two suggesting that agitation levels were slightly worse during the intervention week. (See Figure 19 Graphs a and b). The median returned to 16 in week three, a no music week, indicating that agitation levels improved in this week (graph c). In week four, the median lowered to 14, suggesting the intervention may have improved levels of agitation (graph d). However it is worth noting that all these scores are indicative of no agitation.

#### 4.3.5.2 Trend

The linear trend-line was plotted for each week of the study as represented in Figure 20 graphs a-d. In week one, the trend-line is straight, whereas in week two the trend-line slopes upwards. This was an intervention week therefore indicating levels of agitation increased during the week with the music. The trend-line continues to gently slope upwards in week three (no music) signifying continued levels of agitation. In week four, the trend-line slopes downwards, suggesting agitation levels were improved during this week with the music intervention.

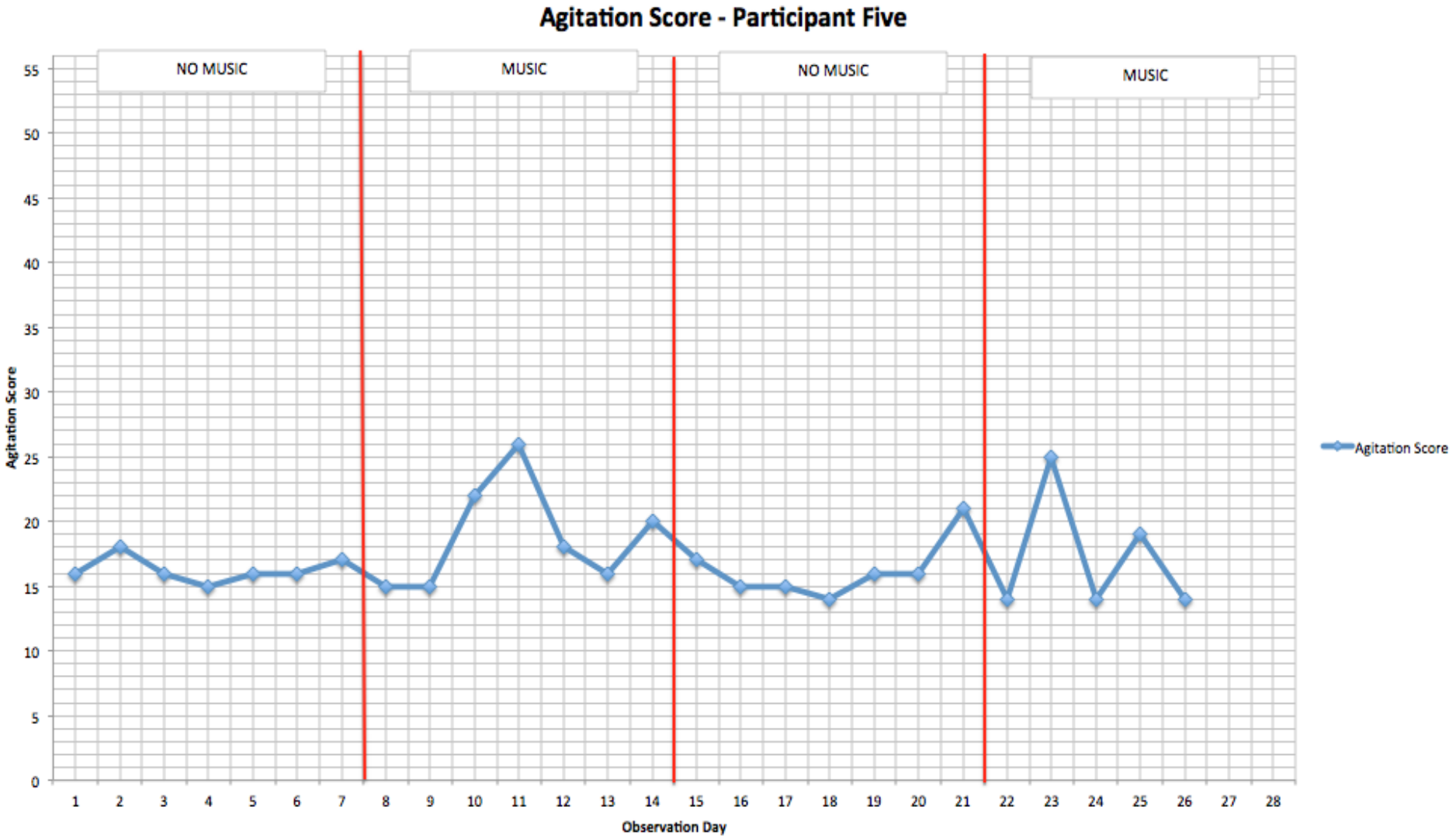
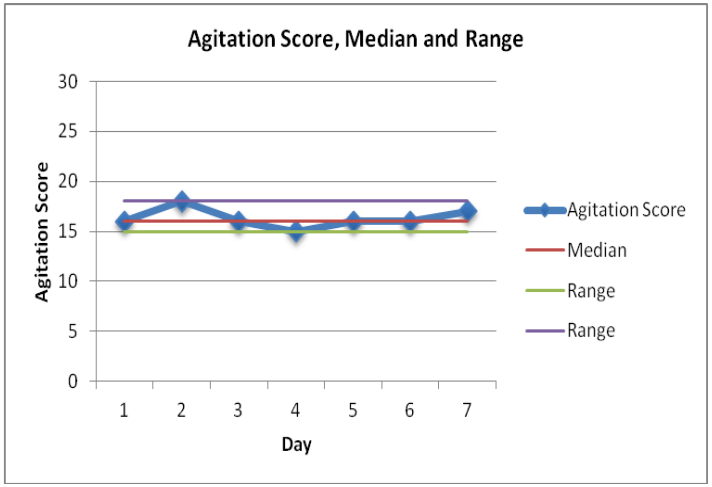
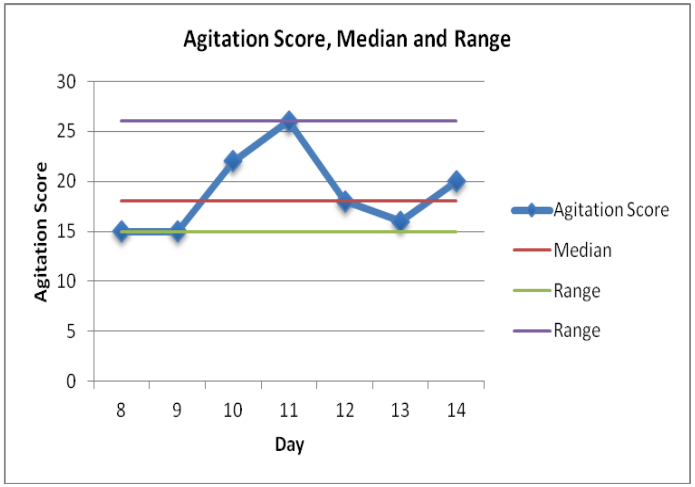



Figure 19: Daily agitation scores for Participant Five




a

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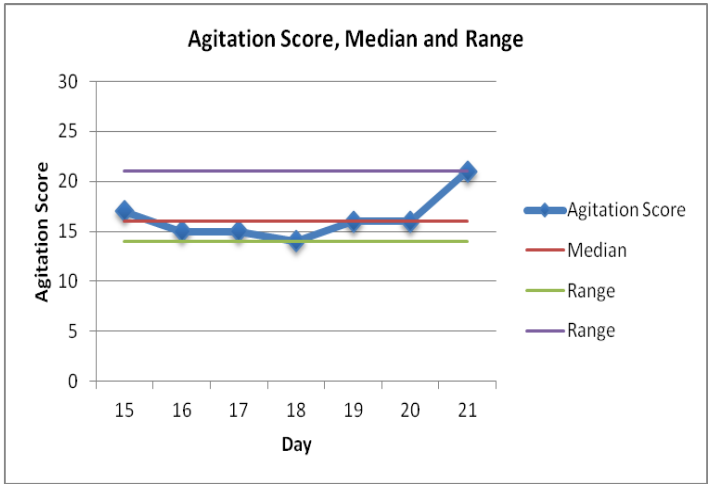
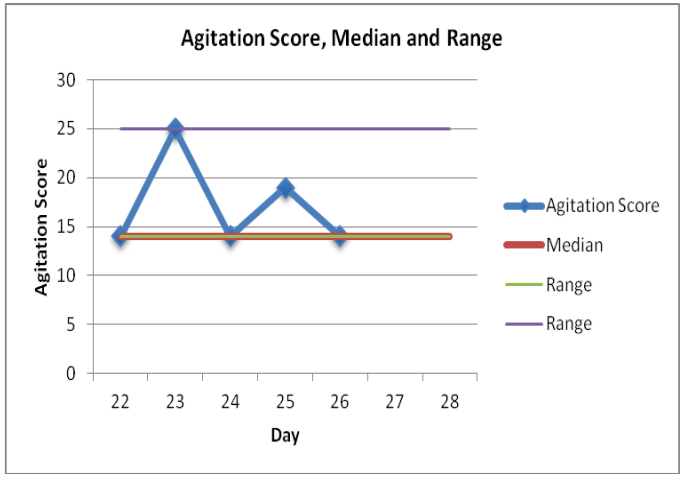
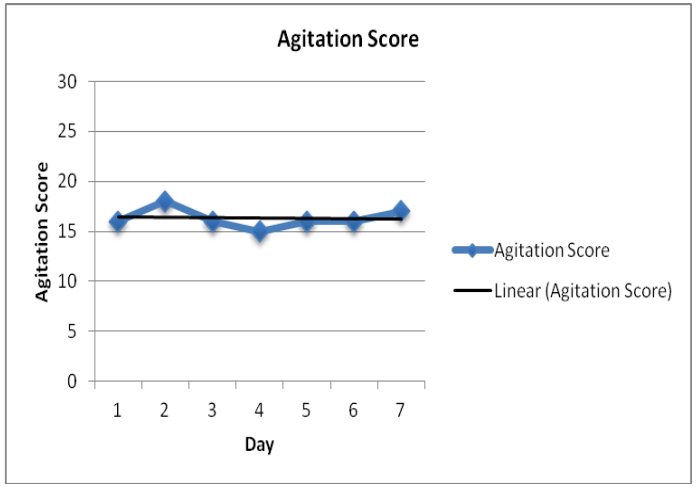



c

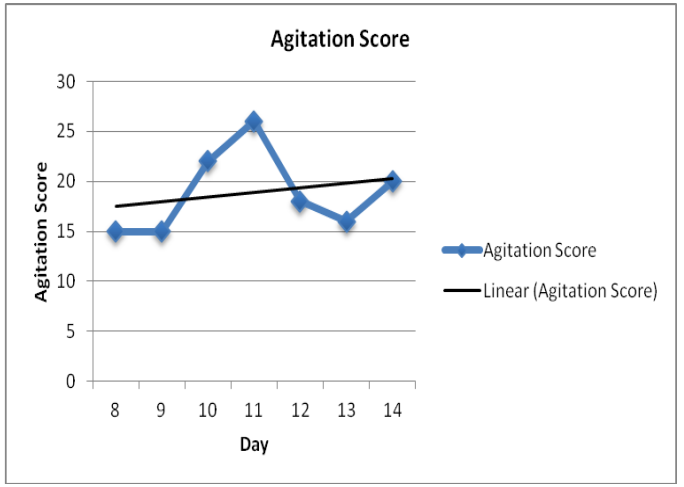



d

Figure 20: Agitation Scores, Median and Range for Participant Five




a

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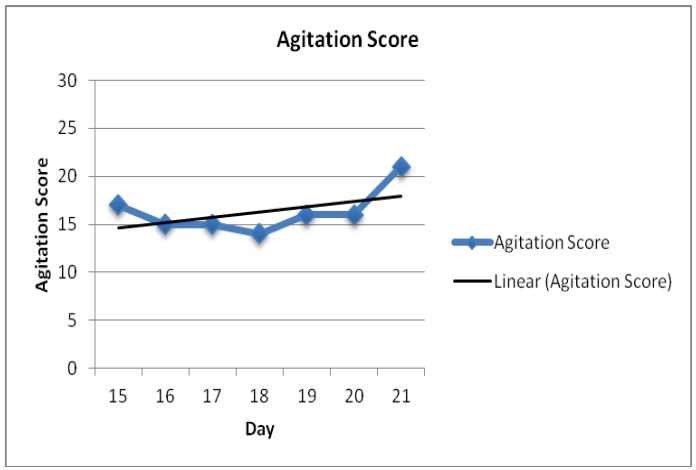


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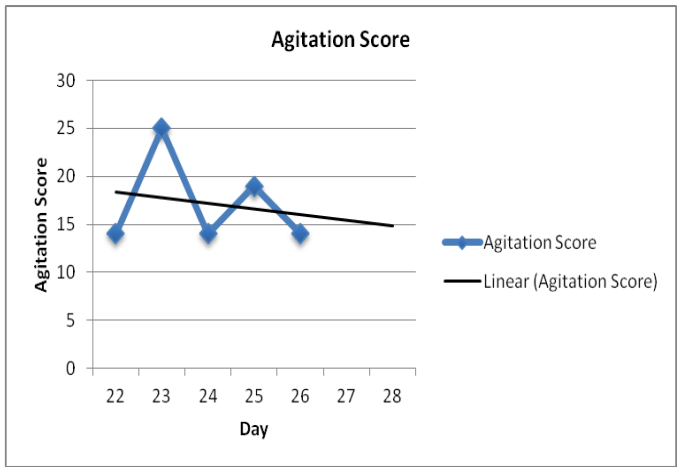


d

Figure 21: Agitation Scores with Linear Trend-line for Participant Five

#### 4.3.5.3 Variability

The variability of the scores flucated over the four weeks of the study: the range in week one was 3 data points; 11 data points in week two, 7 data points in week three; and 11 data points in week four. Such fluctuation makes it difficult to ascertain firm conclusion from the data. The variability of the scores in week two and week four, the intervention weeks, would suggest that the music did not have a sustained effect on agitation levels in this participant. Greater stability would promote greater confidence that the changes in agitation scores are due to the application of the intervention. As such it is not possible to make that conclusion.

### 4.3.6 Study hypotheses

Review of the above results is inconclusive in relation to the hypothesis that individuals with dementia will display less agitation during daily periods of listening to individualised music. As the results were so varied between participants, and also between the different weeks for the same participant, Table 11 presents a breakdown of hypothesis support or non support for each participant and for each intervention week.

| Hypothesis 1 | Individuals with dementia will display less agitation during daily periods of listening to 30 minutes of individualised music than when not listening to individualised music | |
|---|---|---|
| | First music week | Second music week |
| Participant 1 | Neither supported or unsupported | Supported |
| Participant 2 | Not supported | Not supported |
| Participant 3 | Neither supported or unsupported | Neither supported or unsupported |
| Participant 4 | Neither supported or unsupported | - |
| Participant 5 | Not supported | Supported |

Table 11: Breakdown of support or non support of study hypothesis one

## 4.4 Effectiveness of individualised music intervention on weekly levels of agitation

Table 12 shows an overview of the agitated behaviours displayed by each participant as assessed using the Cohen-Mansfield Agitation Inventory. The behaviours that occurred several times a week or more are listed. Unfortunately there is missing data for several participants which makes analysis between the baseline and intervention weeks difficult.

### 4.4.1 Participant One

Participant One displayed seven different agitated behaviours over the four week study period. The most common behaviours displayed were pacing/aimless wandering and general restlessness. No baseline measurement was recorded for week one, but week two saw the greatest number of agitated behaviours during a week. This was a music intervention week. The number of agitated behaviours displayed during the second no music week (week three) reduced, and then increased by one behaviour in week four. This suggests that the music intervention did not help to reduce levels of agitation, but in fact may have made them worse.

### 4.4.2 Participant Two

The number of agitated behaviours displayed several times a week or more by participant two was consistently the same number of behaviours each week of the study, although the behaviours differed slightly each week. No data was recorded for week four. Pacing/aimless wandering and general restlessness were again the most common behaviours displayed by the participant. The consistency in the number of behaviours displayed in week one through to week three indicates that the music did not help to reduce the levels of agitation, but at the same time did not make them worse.

| | | Number of agitated behaviours occurring several times a week or more | Description of behaviour |
|---|---|---|---|
| Participant 1 | Week 1 | Missing data | |
| | Week 2 | 7 | Pacing, aimless wandering<br>Inappropriate dress or disrobing<br>Cursing or verbal aggression<br>Hitting (including self)<br>Scratching<br>Trying to get to a different room e.g. out of the room, building<br>General restlessness |
| | Week 3 | 3 | Pacing, aimless wandering<br>Inappropriate dress or disrobing<br>General restlessness |
| | Week 4 | 4 | Pacing, aimless wandering<br>Inappropriate dress or disrobing<br>Hitting<br>General restlessness |
| | | | |
| Participant 2 | Week 1 | 4 | Pacing, aimless wandering<br>Trying to get to a different room e.g. out of the room, building<br>Hoarding things<br>General restlessness |
| | Week 2 | 4 | Pacing, aimless wandering<br>Throwing things<br>Tearing things or destroying things<br>General restlessness |
| | Week 3 | 4 | Pacing, aimless wandering<br>Throwing things<br>Strange noises<br>General restlessness |
| | Week 4 | Missing data | |
| | | | |
| Participant 3 | Week 1 | 8 | Pacing, aimless wandering<br>Inappropriate dress or disrobing<br>Cursing, verbal aggression<br>Trying to get to a different room e.g. out of the room, building<br>Handling things inappropriately<br>Hiding things<br>Performing repetitive mannerisms<br>General restlessness |
| | Week 2 | 5 | Pacing, aimless wandering<br>Inappropriate dress or disrobing<br>Cursing, verbal aggression<br>Trying to get to a different room e.g. out of the room, building<br>General restlessness |

| | | | |
|---|---|---|---|
| | Week 3 | 8 | Pacing, aimless wandering<br>Cursing, verbal aggression<br>Trying to get to a different room e.g. out of the room, building<br>Complaining<br>Handling things inappropriately<br>Hoarding things<br>Performing repetitive mannerisms<br>General restlessness |
| | Week 4 | 10 | Pacing, aimless wandering<br>Inappropriate dress or disrobing<br>Cursing, verbal aggression<br>Hitting (including self)<br>Pushing<br>Screaming<br>Trying to get to a different room e.g. out of the room, building<br>Hurting self or other<br>Handling things inappropriately<br>General restlessness |
| | | | |
| Participant 4 | Week 1 | Missing data | |
| | Week 2 | Missing data | |
| | Week 3 | Missing data | |
| | Week 4 | Missing data | |
| | | | |
| Participant 5 | Week 1 | 3 | Pacing, aimless wandering<br>Repetitive sentences or questions<br>General restlessness |
| | Week 2 | 4 | Pacing, aimless wandering<br>Repetitive sentences or questions<br>Negativism<br>General restlessness |
| | Week 3 | Missing data | |
| | Week 4 | 1 | Repetitive sentences or questions |

Table 12: Results from the Cohen-Mansfield Agitation Inventory

### 4.4.3 Participant Three

Participant three displayed the most number of weekly agitated behaviours during the study of all participants, totalling 14 different agitated behaviours.

The most common behaviours occuring several times a week or more were pacing/aimless wandering, trying to get to a different room e.g. out of the room or building, and general restlessness. As data was recorded for all four weeks of the study for this participant some comparison can be made between baseline and intervention weeks. The number of agitated behaviours displayed during the baseline week and the first music intervention week decreased, and then increased again during the return to a no music week. This suggests that the music intervention may have contributed to the less frequent display of agitated behaviours during week two. However during week four, a music week, the participant displayed an even greater number of agitated behaviours, indicating that during this week the music intervention did not help to improve levels of agitation, and potentially made them worse.

### 4.4.4 Participant Four

No data was collected for participant four.

### 4.4.5 Participant Five

Participant five displayed four different agitated behaviours over the four week study period. The most common agitated behaviour displayed was repetitive sentences or questions. There were three agitated behaviours displayed during week one, which rose to four during week two, the music week. This suggests the music did not help to reduce agitated behaviour. Data was missing for week three. The number of agitated behaviours displayed during the final week of the study (music week) dropped to only one, suggesting the music may have contributed to the reduction in agitated behaviour.

### 4.4.6 Study hypotheses

Review of the above results is inconclusive in relation to the hypothesis that individuals with dementia will display less agitation during weekly periods of listening to individualised music. As the results were so varied between participants, and also between the different weeks for the same participant, Table 13 presents a breakdown of hypothesis support or non support for each participant and for each intervention week.

| Hypothesis 2 | Individuals with dementia will display less agitation during weekly periods in which individualised music is implemented compared with weekly periods where it is not being implemented | |
|---|---|---|
| | First music week | Second music week |
| Participant 1 | Not supported | Not supported |
| Participant 2 | Neither supported or unsupported | *Missing data* |
| Participant 3 | Supported | Not supported |
| Participant 4 | *Missing data* | *Missing data* |
| Participant 5 | Not supported | Supported |

Table 13: Breakdown of support or non support of study hypothesis two

## 4.5 Engagement and enjoyment of the individualised music session

### 4.5.1 Participant One

Participant one experienced enjoyment and engaged with the music in the majority of the individualised music sessions (see Figure 21). Table 14 details the comments made by healthcare professionals when observing participant one listening to the music. The majority of remarks highlight a positive experience, such as the participant dancing, singing, smiling, and tapping her feet. There were occasions when she appeared not to enjoy the music, which was demonstrated by her trying to leave the room or not being able to focus on the music.

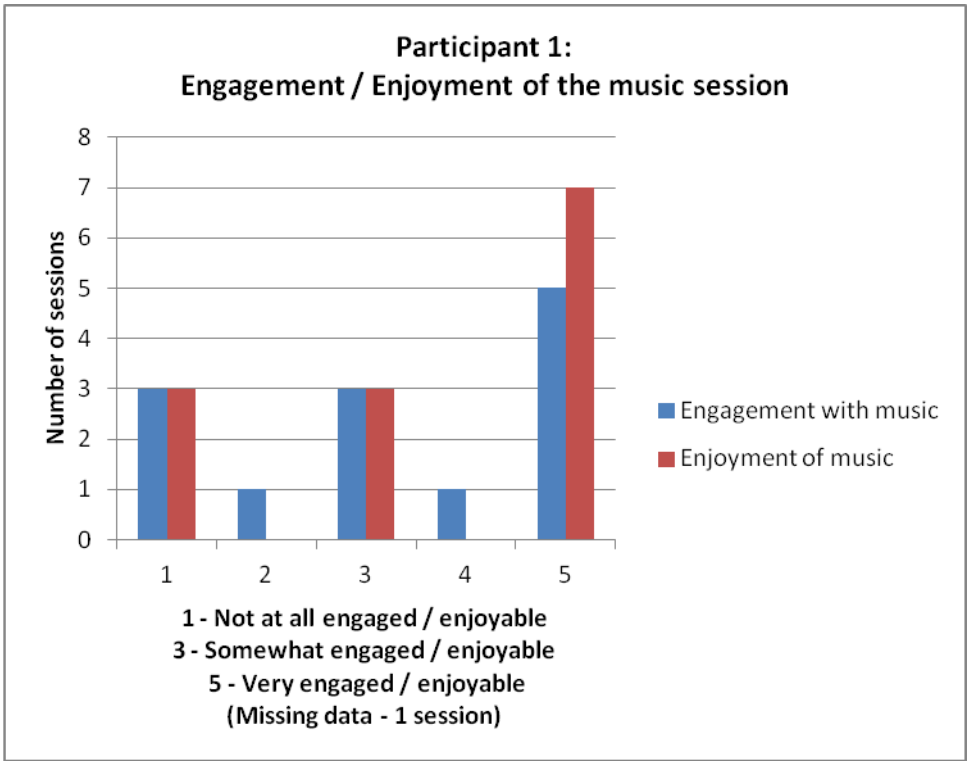


Figure 22: Engagement and enjoyment of the music sessions for Participant One

| **Participant 1 (P1)** |
| --- |
| P1 enjoyed the music a lot, this was observed as she was enjoying to sing, dance, smile and also did interact with others by dancing |
| At 10am, out with time allocated, music was played from playlist as P1 appeared quiet and low in mood. P1 instantly started to sing and dance – a lot of enjoyment. At 11.40am music played again as P1 enjoys this a lot. 8.15-8.45pm P1 unsettled and stripping off. Reaction evident on recognition of songs and singing along, however constant moving and unable to sit and concentrate and repeatedly stripping off top. |
| Instant enjoyment evident as soon as music began. Only concerns she had was that music wasn't loud enough for all the patients to hear. Compliant during personal care following music session. |
| P1 was listening to the music for 30 mins; she appeared irritable in mood and was exploring the ward environment. She appeared pre-occupied with touching objects in the day room and was distracted. With encouragement from staff she sang along to one of the songs and danced with staff |
| P1 sat down in the lounge with her daughter. She listened to the music and got emotional at one point stating that the song reminded her of her own mum – who died when P1 was very young, however she was able to talk about it without getting distressed. |
| P1 enjoyed the music, singing along and tapping her feet to the music. |
| Unable to sit for any length of time, trying to leave the room. |
| Prior to the music session P1 appeared very restless and unsettled. P1 was pacing around the ward environment and responding to visual hallucinations. On commencement of the music playing P1 instantly appeared more relaxed and was able to sit on her bed, smiling and singing along. P1 fell asleep after around 25 mins. |
| P1 was in a clear good mood when the music was playing and was even dancing for most of the session. She was able to recognise the songs that came on stating "Cliffy baby" and was also able to recognise who sang them with minimal prompting. |
| P1 had just been changed and she was highly agitated. She was distressed at the first song, classical music, so changed to Rod Stewart. All P1 would do was trying to get out of the door and pulling at her clothes. |
| P1 was very agitated in session, not participating in activity. |
| Appears to have really enjoyed the session, very settled and calm throughout and was becoming agitated prior to session starting. Slightly tearful throughout but states happy tears. |
| P1 engaged very well in playlist for life, singing and tapping foot throughout. |

Table 14: Comments and observations on music sessions for Participant One

### 4.5.2 Participant Two

Participant two did not experience any enjoyment or engagement with the music in the majority of the individualised music sessions (see Figure 22). She was somewhat engaged in 46% of the sessions, and only somewhat enjoyed 23% of the sessions. Table 15 details the comments made by healthcare professionals when observing participant two listening to the music. All the commentaries detail a negative and highly emotional experience for the participant, with only one description of a positive reaction to the music. This involved hand tapping to music, and recognition of music.

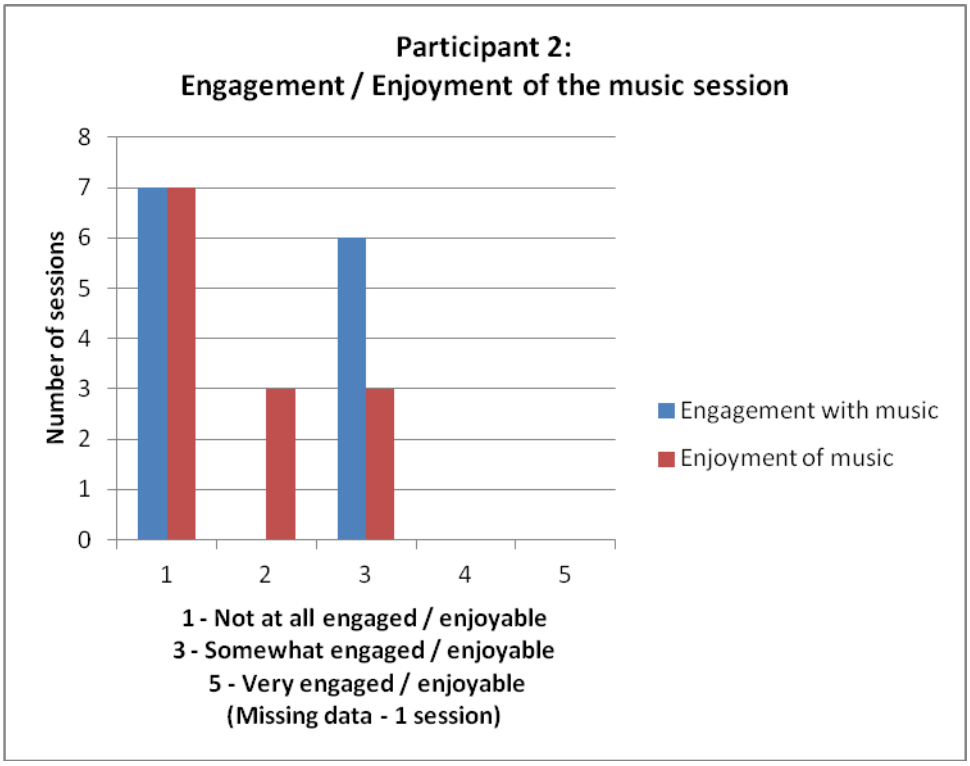


Figure 23: Engagement and enjoyment of the music sessions for Participant Two

| **Participant 2 (P2)** |
| --- |
| During the time from 2.00pm it was attempted 3 times for P2 to listen to the music but she kept taking the headphones off. She was pacing the ward at this time. |
| P2 sat down with her husband listening to the music for approximately half an hour. She attempted to leave the room on a few occasions. It was evident that P2 recognised some songs as she was tapping her hand listening to the music. No other emotions displayed throughout this. |
| Music played influenced by number of people in room. It would be better if only one person was present. Influenced outcomes. |
| As per previous session, additional visitor made it difficult to engage P2 significantly with regards to music. |
| Charge ran out so session only lasted 15 mins. Tearful episodes at times but showing more emotion. |
| P2 instantly started crying and left the room after a few minutes. Clearly unhappy and had an angry look on face, kept walking in and out bed space room. Music switched off due to level of distress caused – after 10 mins. |
| During the 30 mins, P2 cried and was constantly coming and going in and out of room but when asked if she wanted me to stop music she replied no! |
| Unable to determine whether or not P2 actually enjoyed the music session as she cried throughout the whole time. However when asked if she wanted me to switch it off she replied with a no! P2 spent the whole session coming in and out of her bedroom, crying throughout and did throw a pencil case across the room at the start of the session in an aggressive manner. At the end of the session, P2 took the speaker and attempted to switch if off herself. |
| Instantly started excessively crying and walked out room, clearly distressed by this. Changed song to see if that helped but same presentation on return to room. Session stopped after 5 mins due to distress. |
| P2 cried within a couple of minutes of the music playing and left her room. P2 returned and sat with staff for a time with the music on (few minutes only) but started to cry. When asked if she enjoyed the music P2 replied no. Due to obvious distress caused to P2 session was stopped. |
| Due to the accelerated behaviour and the loss of sleep P2 has been suffering during this week if was decided to ask P2 if she wanted to listen to the music. She said no. |
| P2 not tolerant of music session. Kept leaving the room, not appearing interested at all. |

Table 15: Comments and observations on music sessions for Participant Two

### 4.5.3 Participant Three

Participant three also experienced minimal enjoyment and engagement with the individualised music sessions (see Figure 23). He enjoyed just one of the sessions, and somewhat enjoyed a further three sessions. He was somewhat engaged in less than half of the individualised music sessions. The comments made by the healthcare professionals when observing participant three listening to the music, detailed in Table 16, reflect his difficulty engaging with the music. They noted that at times he did appear to recognise and enjoy the music, but had difficulty remaining connected to this and hence would only tolerate for short periods.

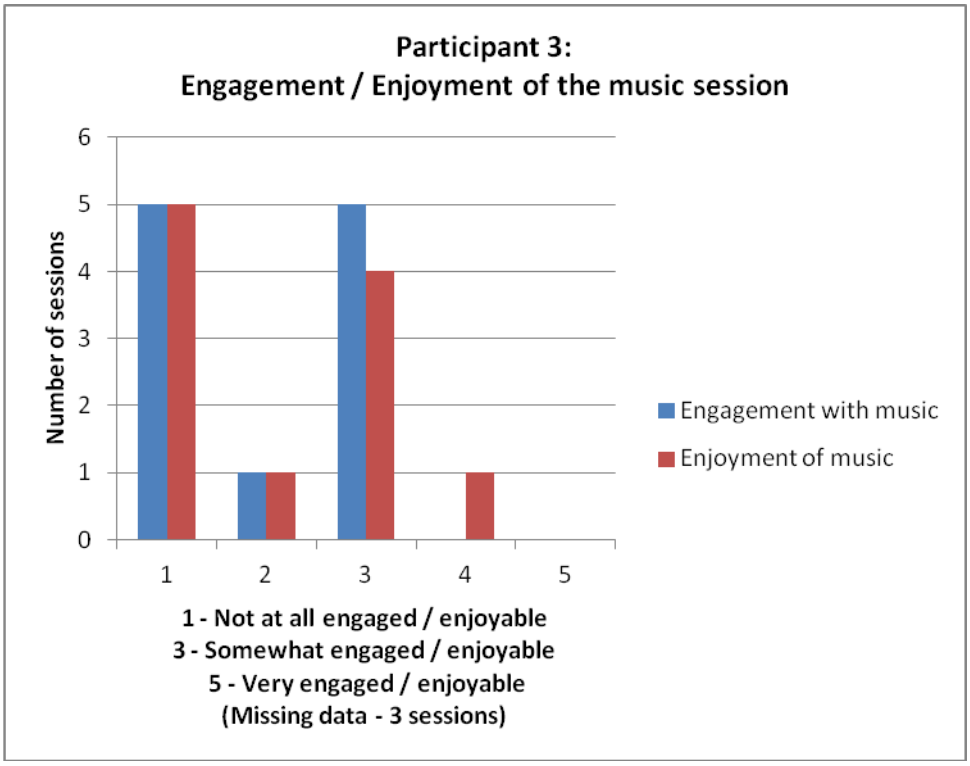


Figure 24: Engagement and enjoyment of the music sessions for Participant Three

| **Participant 3** |
| --- |
| P3 was only able to tolerate the music for 5 mins approx before he left the area. However, when the music was first played his mood brightened instantly and he indicated that he recognised the song. |
| P3 was initially was given the iPod with earphones when sitting on the sofa. P3 sat down listening to the music for around 5 mins and then wandered the ward the remainder of the session. P3 took the earphones off after 20 mins, the session was then stopped. However during the 20 minute session P3 took these off a few times but put them back on. |
| P3 engaged in playlist for life for a short spell but just repeatedly put the music down and walked away from it. Staff tried to get him re-engaged but P3 was not interested. |
| ***Session not possible today due to workload pressures on the ward*** |
| Was keen to walk away from music |
| Did not seem interested |
| P3 had received as required medication for agitation in morning for severe agitation. Then slept for approx 4-5 hours. On rising, paced ward constantly, unable to stay still for any period of time. Appeared accelerated and unable to concentrate. |
| Appeared to enjoy the music and recognised the songs, but agitation prevented him from remaining in the room for long periods of time. |
| Appeared to enjoy the music initially but unable to concentrate for any length of time. currently under clinical review due to deterioration in presentation. |

Table 16: Comments and observations on music sessions for Participant Three

### 4.5.4 Participant Four

Data was recorded for only one session for participant four which showed on that occasion he did not engage or enjoy the music (see Figure 24 and Table 17).

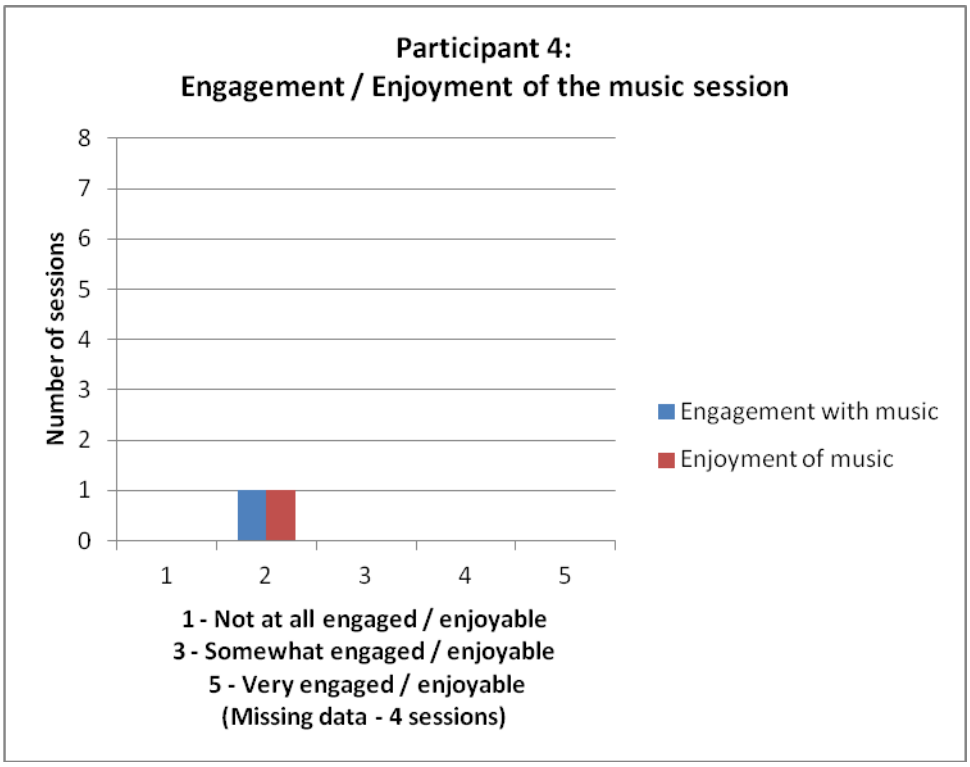


Figure 25: Engagement and enjoyment of the music sessions for Participant Four

| **Participant 4** |
|---|
| No data |
| *Session not possible today due to workload pressures on the ward* |
| *Session not possible today due to workload pressures on the ward* |

Table 17: Comments and observations on music sessions for Participant Four

### 4.5.4 Participant Five

The results for participant five highlight a diverse range of experiences in relation to the individualised music. He found some sessions enjoyable and engaged with the music, but he also experienced the opposite effect at times. (See Figure 25). The remarks provided by the healthcare professionals in Table 18 reflect this 'mixed response'. They documented instances when he sang along to the music, relaxed to the music, tapped his fingers to the music, and asked questions about the artists, but also described him being unsettled and distracted, and not gaining benefit from the session.

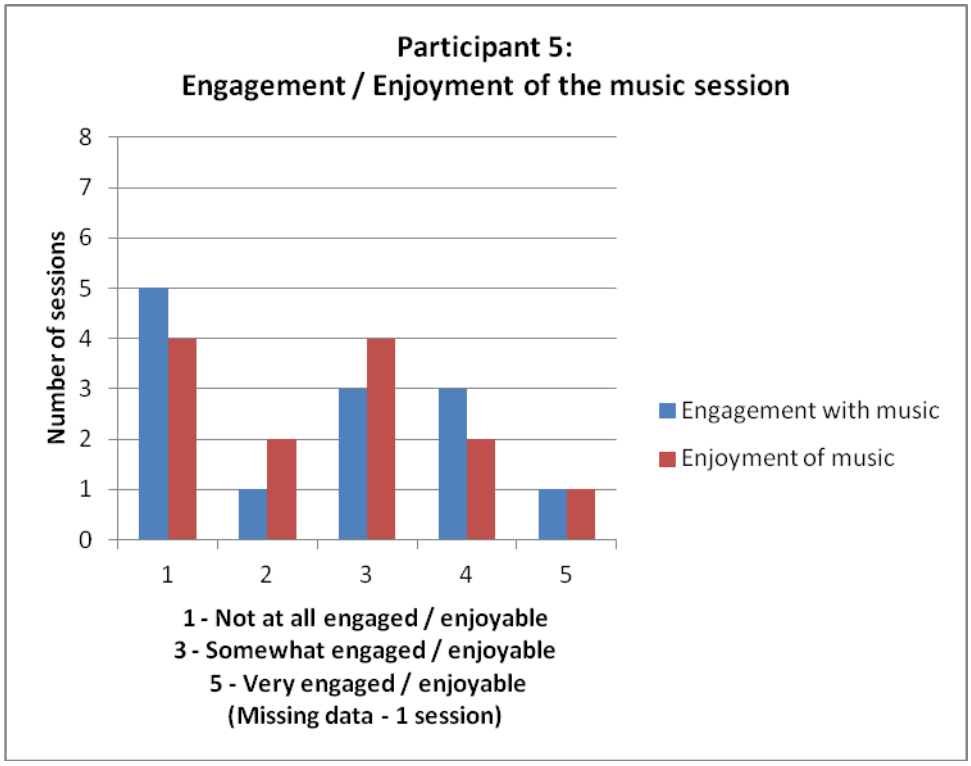


Figure 26: Engagement and enjoyment of the music sessions for Participant Five

| **Participant 5 (P5)** |
| --- |
| Prior to session P5 was a little agitated, repeating same questions – why am I here? What's wrong with me? P5 lay on top of bed during session, tapping fingers engaging well in session, eyes closed. Unsure at the beginning why he was doing this. Did not ask any questions thereafter. 5 mins before end of session, P5 sat up and asked why am I here? Did say he enjoyed the session. |
| P5 stated before the session his nerves were bothering him and asked for medication. Accepted to give music a try instead of medication. Appeared relaxed. Did ask a few questions throughout. Encouraged P5 to think of good memories associated with the songs. Tapped fingers throughout. Singing along nearer the end. |
| Had had Lorezepam 0.5mg for anxiety/agitation earlier in day. Feeling drowsy before session. Asking what this was all about a number of times. Acknowledged they were bits of music he knew. I felt I was a distraction as kept asking questions about he was here and where wife was and not engaging much with music. Becoming more unsettled during session. Terminated after 20 mins. Feeling frightened at his short term memory loss. |
| P5 not keen to participate. Would not sit down, paced room, talking over music, asking why he was in hospital, not happy with answers, becoming increasingly agitated and angry. Quite firmly asked to put off music after 10 mins. Session terminated. Required as required medication for agitation after session. Session was held later today because of staffing issues. |
| P5 unable to relax into session today. Asking numerous questions throughout – why am I here? Why can't I do this at home? Session terminated after 20 mins. P5 singing along with music for a few mins. |
| P5 had his family visiting at time of session, sitting in quiet room. Asked a few questions throughout but appeared quite relaxed. Nearer the end of session P5 asked for music to be turned off as this was a distraction due to him wanting to spend time with his family. Session terminated. Family pleased with P5's progress on the ward. |
| P5 anxious prior to session, asking to phone son and medication for nerves. Attempted to use music for distraction, however unable to do so. Session only lasting 5 mins. No benefit from session. Phone call to son made and medication administered. |
| P5 missed one occasion due to him being too agitated. It appeared the music was making him more irritable, therefore session was stopped. As required medication given to ease the agitation. |
| P5 was asleep lying on bed prior to session. Agreed to session, appeared very relaxed, only asked a few questions but relaxed afterwards, eyes closed and lifting his arms into the air. |
| Staff Nurse A allocated to do session today by family have asked for only female staff to do session as feel he is more settled with them. P5 off ward at normal session time for another therapy.<br>P5 repetitive saying "my nerves are too bad". Restless initially however managed to sit for a short period and listen to music. P5 able to identify singers/songs. Shallow breathing and making an exhale noise with every breath. Informed myself that this activity would be more enjoyable if his wife was here. Nodding his head and singing to last song. Appeared much more relaxed at end of session. |
| Staff Nurse B first time doing playlist for life. P5 asked lots of questions – is that |

| |
|---|
| Max Bygraves? Whatever happened to Judy Garland? Sat with eyes closed for most of session, singing along at times but also asking about where he was? And where was his wife? Seemed fed up throughout the session but relaxed. Seemed to engage more with faster songs – Baby Face, Love and Marriage – sang throughout ?more familiar. Much quieter towards end – appeared relaxed. |
| Staff Nurse C - first time doing playlist for life. P5 unsettled, restless and pre-occupied about using the phone. Sat through half of one song. Leaving room despite encouragement to remain in room and relax. |
| P5 sat in chair relaxed. Asked a few questions – why am I here? What's wrong with me? Sat with eyes closed, tapping fingers on the table. Playlist earlier today due to cognitive therapy at usual time of playlist. Generally P5 does appear more relaxed at this time of the morning. Remainder of playlist P5 relaxed, no questions asked. |

Table 18: Comments and observations on music sessions for Participant Five

## 4.6 Administration of Pro Re Nata Medication

Table 19 shows the number of occasions per week when the administration of PRN (when needed) medication for agitation was required for each participant. Participant one did not require any additional medication for agitation throughout the study. Participant two required three administrations during the first no music week, and one administration during the first music intervention week. This suggests she was less agitated during this week. However, she did not require any PRN medication during week three, but needed two administrations during the final music intervention week, indicating she was more agitated during this final week with music. Participant three required no PRN medication for agitation in the first baseline week, but required four administrations during week two when he received the music intervention. This signifies he was more agitated during the music week. On return to a no music week in week three of the study, he required seven administrations on PRN medication, suggestive of high levels of agitation. He only required one administration in the final music week of the study, indicative of being less agitated during this final music week of the experiment. No data was recorded for participant four and participant five.

| Week | Participant One | Participant Two | Participant Three | Participant Four | Participant Five |
|---|---|---|---|---|---|
| **One** | 0 | 3 | 0 | No data | No data |
| **Two** | 0 | 1 | 4 | | |
| **Three** | 0 | 0 | 7 | | |
| **Four** | 0 | 2 | 1 | | |

Table 19: Number of occasions when PRN medication for agitation was required

## 4.7 Findings from the interviews with family carers

An addition to the main study was the exploration of the experiences of family carers. Although an add-on to the main experimental part of the study, the researcher felt it was important to elicit the experiences of family carers to give a wider understanding of the use of individualised music in hospital settings.

Interviews were held with four family carers. The interview process invited family carers to describe their personal experience of the use of individualised music with their loved one whilst in hospital. The researcher sought to understand the personal meanings that family carers attributed to their experience. Although there were many shared experiences described by family carers, every effort was made to consider each separate account and draw meaning from this.

The analysis of the four interview transcripts from the interviews held with the family carers elicited two main themes. The themes were deduced from the transcripts and were not actually described verbatim by the participants. A range of thematic statements taken from the transcripts are presented to convey aspects of the thematic analysis to promote understanding and recognition of the distinct themes. The thematic statements from all four interviews are included in Appendix 24.

The two main themes identified were:

- Theme 1: Unrealised engagement
- Theme 2: Therapeutic effect

### 4.7.1 Theme 1: Unrealised engagement

The theme of unrealised engagement is threaded through the experiences of family carers. The theme refers to a sense that family carers wanted full engagement with the use of individualised music, to see it work therapeutically with their loved ones, but their actual reality did not reflect their hopes and expectations. Unrealised engagement of the family carer, unrealised engagement of the healthcare professional, and unrealised engagement of the person with dementia were all common experiences encapsulated in the interviews with family carers. The experiences described by family carers relate to how engagement with the intervention of individualised music was important to them, but not fully achieved during the period of the study.

Family carers wanted to be fully engaged with the intervention of using individualised music with their loved one. For them, there was a need and desire to have a contributory role in the process of developing a playlist and using the individualised music with their loved one. For family carers to feel engaged, they wanted to be involved at a practical level and participate when using the music was being played to their loved one. This was not always fulfilled as factors inhibited this from being possible on many occasions. All family carers shared a strong desire to be involved with the use of individualised music, as involvement would help them feel like they were doing something to help their loved one get better, which was important to them.

The importance of engagement in the use of individualised music with a loved one was reflected in family carers sharing experiences of contributing in some way to the process. Family carers reported the positive effect they felt from being able to contribute to the care of their loved one by identifying the meaningful music and creating the playlist. One carer shared how this made them feel:

*"It's let me feel like I'm doing something to help her too. Even though I've not had chance to be part of the music yet, just meeting with you, with [participant 1], to identify the music was enjoyable in itself. Reminiscing about old times and talking about fond memories was so enjoyable. It was a lovely afternoon we all had together identifying the songs. I've felt like I've done something to help [participant 1] and I'm just looking forward to listening to the music with [participant 1]."*

*Carer 1*

Engagement in this process gave family carers a sense of usefulness, that they were doing something to aid the recovery of their loved one, or improve the experience of being in hospital.

For family carers, engagement also equated to them being present when the person with dementia listened to the individualised music. But this was not always possible, and lack of involvement was frequently voiced by family carers as a disappointment. Due to the nature of the research protocol the healthcare professionals were asked to administer the individualised music intervention at a time just before the person was known to become agitated, and at the same time each day. For some family carers this meant they were not present when the intervention was being administered, and therefore did not get opportunity to participate in the delivery of the intervention or observe their loved one listening to the music. Several family carers shared their disappointment in this situation:

*"I tend to visit in the afternoon, about this time usually, but the nurses were giving her the music in the evening, as this is when she usually becomes more unsettled. So I missed it sadly. I would've really liked to have been here."*

*Carer 1*

*"I think it would have been difficult, and it's not a criticism in any way… but staff are busy, and sometimes I can't be there at certain times and it would be difficult to try and tally when we were both…when it was mutually agreeable for the staff and the ward and for me to be in here. But yes I would have liked to have been here."*

*Carer 3*

Only one family carer described being actively involved when his spouse was listening to the music. All other family carers expressed disappointment at

not having the chance to witness or be involved in the delivery of the intervention. Although this was not intentional, and was due to the timing of the music not coinciding with when the family carer was visiting, it was a significant issue voiced by many and led them to feel they were not fully engaged with the intervention.

It was also important for family carers to feel that healthcare professionals were engaged with the use of individualised music with their loved one. On the occasions when this did not occur, the lack of engagement of the healthcare professional towards the individualised music intervention was noticed by family carers, and was understandably viewed negatively. Some family carers identified that some healthcare professionals were not enthusiastic about administering the music and suggested that they were perhaps reticent about benefit of the music:

> *"But I don't think he [healthcare professional] really believed in…or erm…saw any benefit in the music."*
>
> *Carer 5*

> *"You really need people who are committed, believe in what they are doing in a way that you would do, to make sure that the results that you get are credible results."*
>
> *Carer 2*

Engagement of the person with dementia was something that family carers spoke about. Although family carers knew they had no control over how engaged their loved one might be with the music, they desperately wanted to witness or be told that there was a therapeutic effect from the music. On the occasions when the person with dementia did not have a positive reaction to the music the family carer often rationalised why the lack of engagement may have occurred by giving explanatory reasons. One family carer reported that they felt that the music had a reminiscent effect for the individual, which they felt prevented them from engaging with the music:

> *"Well I'll have to admit that the music would have triggered memories. There was a resistance to it."*
>
> *Carer 2*

One family carer suggested that their loved one possibly still had some insight, some understanding and sense of the situation or occasion, and the triggering of the memory by the music, albeit a positive memory, was a reminder of lost ability, function and purpose. This in turn prevented that person engaging with the music:

> *"I just wonder whether the music is a reminder to him of past times… that he's realising what he can't do anymore. Would that explain why he only seems interested in the music for a short time? I think it might be bringing back memories for him that he would much rather not recall."*
>
> *Carer 3*

Other family carers shared their belief that the underlying medical condition of the participant was considered to influence their ability to engage with the music. One carer described that she felt her husband was too unwell to benefit from the individualised music. She recounted that she thought the medical condition necessitating the admission to hospital was such that it was not the right time to engage in such an intervention.

> *"I just wonder whether [participant 5] is really too unwell for the music at this time. He was admitted to hospital because of his nerves….and I don't think they've really got them sorted yet. I just think that when he is a bit more settled he might get more benefit from the music. At the moment he is just so distracted by everything I really don't think he can focus on the music properly."*
>
> *Carer 5*

Another carer identified that unrecognised and untreated pain in her husband affected his levels of agitation, and hence his ability to engage with the music:

> *"Those weeks was when his behaviour became really unsettled (weeks 3 and 4 of the study). He became more restless and was pacing a lot more round the ward, and was really angry at times. He hadn't been like that for a while. Eventually they realised he was in pain, from his back. They have just changed his pain killers and he is more settled."*
>
> *Carer 3*

### 4.7.2 Theme 2 – Therapeutic effect

The theme of therapeutic effect refers to the experiences described by family carers of when the individualised music intervention had a positive effect on reducing levels of agitation for their loved one, or facilitated a feeling of happiness or musical enjoyment for them. Family carers were keen to share these stories. But interestingly, the majority of the family carers had not seen their loved one firsthand listening to the music so had not actually witnessed the scenarios they retold to the researcher. Regardless of this, family carers were enthusiastic in recounting the therapeutic effects experienced by the person with dementia. These were usually experiences reported to them by the nursing staff or by other family members who had witnessed the intervention being administered. One example of this is:

> *"I rang in after the first time she'd had the music, they said its great… they said 'last night as soon as we put it on, [participant 1] was singing and she was wanting other patients to sing along' and their description was that it was a delightful reaction."*
>
> *Carer 1*

The positive effects described by family carers included their loved one singing, dancing, smiling, more relaxed, calmer, less agitated, and more person centred as demonstrated by this family carer:

> *"There is one thing that I remember…it wasn't when [participant 3] was having the music but it was when another patient had their music playing…[participant 3] was walking about the ward, pacing quite a lot, backwards and forwards around the ward….the other patient had their music playing through the little speaker and [participant 3] went over to her and became interested in her music….the lady was up on her feet…dancing a bit… and [participant 3] joined in with her…not exactly dancing but listening along to her music. It only lasted a couple of minutes but it was nice to see him do that."*
>
> *Carer 3*

*"Without a doubt, from what everyone has told me, the nurses, my daughter, when [participant 1] has been listening to the music she has been calmer, more relaxed, engaged with the music, interacting with others. This has only been beneficial. What negatives are there to identify? It's just amazing that something so simple…such a simple idea…can have such a positive impact."*

*Carer 1*

The therapeutic effect of the individualised music was favoured by family carers as a better way to manage agitated behaviour as opposed to sedative medication:

*"If music can help someone become less agitated then that has to be better than pumping them full of drugs to dampen their behaviour. I would guess just about everybody has some music that triggers a memory. Surely this has to be better than medication. Music lightens the soul…brightens the day. I would much rather [participant 3] gets to listen to his favourite music than giving him prn medication – any day."*

*Carer 3*

Pharmacological management of agitated behaviour is utilised as a last resort as the person can experience side-effects from the medication such as drowsiness and falls. The family carers involved in this study viewed the use of 'drugs' to help with agitated behaviour as a negative thing, and saw the individualised music as a preferred strategy to manage agitated behaviour in their loved ones.

*"If it means that the doctors don't need to give as many drugs to calm people down, to relax them more, then that has to be good. I would much rather [participant 5] listened to music to relax him than be given drugs."*

*Carer 5*

All family carers involved in the study unanimously voiced that they wanted their loved to continue using the individualised music intervention as a therapeutic intervention to manage agitation.

*"I know it was a trial here, and you were doing it under research conditions, but I'd like her to have it more frequently, whenever she wants to listen to it…..whenever she starts to become a little agitated I'd like the nurses to try it to see if it calms her down. So use it as much as we can."*

*Carer 1*

*"I think it will be great if she can take this with her to the care home."*

*Carer 1*

This even applied to those individuals who had not had such a positive effect from listening to the music. One carer when asked if the music should be continued with her loved one even though they had not had such a positive response to it replied:

*"Yes… oh yes…. Definitely. I really think that [participant 3] might get more from it as he becomes more advanced."*

*Carer 3*

The desire to continue with the music was voiced even when the carer had not witnessed the intervention being administered:

*"I really hope that the nurses continue using it with [participant 5] and I really hope I get chance to be involved with it more. I want to give it a fair chance to see if it is going to work."*

*Carer 5*

### 4.7.3 Summary

Engagement with the individualised music intervention was important to family carers, but this was often not realised. It was evident that family carers had high hopes for being involved with the music intervention, and their expectations were not always met in the reality of its use. Family carers were disappointed by the poor engagement of some healthcare professionals towards using the music, and also the limiting factors that prevented their loved ones fully engaging with the intervention. Nonetheless, the family

carers all spoke highly of the therapeutic benefit of using individualised music and although not always witnessed firsthand, they were committed to its ongoing use with their loved one as a non-pharmacological strategy to manage agitated behaviour.

## 4.8 Findings from the interviews with healthcare professionals

A further addition to the main study was the exploration of the experiences of healthcare professionals. Although another add-on to the main experimental part of the study and the exploration of the experiences of family carers, the researcher felt it was also important to elicit the experiences of healthcare professionals to give a fuller understanding of the use of individualised music in a specialist mental health setting.

Interview/focus group/written questioning took place with five healthcare professionals. The questioning process invited healthcare professionals to describe their personal experience of the use of individualised music with people with dementia that they were caring for. The researcher sought to understand the personal meanings that healthcare professionals attributed to their experience. Although there were many shared experiences described by healthcare professionals, every effort was made to consider each separate account and draw meaning from this.

The analysis of the focus group and interview transcripts and the two written responses from the healthcare professionals elicited two main themes. The themes were deduced from the transcripts and were not actually described verbatim by the participants. A range of thematic statements taken from the transcripts are presented to convey aspects of the thematic analysis to promote understanding and recognition of the distinct themes. The thematic statements from all the interviews are included in Appendix 25.

The two main themes identified were:

- Theme 1: Therapeutic effect
- Theme 2: Clinical complications

### 4.8.1 Theme 1 – Therapeutic effect

The theme of therapeutic effect refers to the experiences described by healthcare professionals of when the individualised music intervention had a positive effect in terms of the delivery of care to the person with dementia. The therapeutic effect may be in relation to the impact on levels of agitation, the nurse-patient relationship, or the clinical impact of using such an intervention. This theme has strong similarities with the same theme identified for family carers.

The healthcare professionals described how administering the intervention allowed them to get to know the person with dementia better, and also their family carer. One participant shared the benefits of using the music in this way:

> *"It definitely does help to connect with the patient because you are involved in this process with them, so you sit for half an hour with them or however long they want, and you speak with them, you sing with them, you dance and you speak to them, and you ask them questions about a certain song, say 'what does that remind you of', sometimes it's a wedding or things that you can go back and you can have a conversation with them, that does help with the therapeutic relationship which is really good."*
>
> *HCP[3]1*

Knowing the meaningful musical choices of the participants allowed the healthcare professionals to know another side of the person with dementia that otherwise would be unrecognised. It helped healthcare professionals to build a relationship with the person with dementia. One participant recalled:

> *"It would trigger memories with her. And also like, it was good for her…it was really good for erm… to open up conversation about her that we never knew about. I think that's a big thing that I like about it."*
>
> *HCP3*

[3] Healthcare professional

Knowing their personal preferences in music, and connecting with the person with dementia through this, supported the healthcare professionals to build a therapeutic relationship with the person with dementia and carer. It facilitated a connection between them that enabled them to see the person with dementia as a person, and not a diagnosis. One participant stated:

> *"By understanding someone's tastes in music you get a little more insight in them as a person. It also provided an opportunity to talk about specific pieces of music and the memories and emotions it evoked. I found this opened communication between staff and relatives/carers about this also."*
>
> *HCP5*

The healthcare professionals reported the therapeutic effectiveness in relation to levels of agitation or anxiety experienced by some people with dementia when listening to the individualised music. One participated shared the following illustration of how the music helped:

> *"There was one lady in the ward who experienced evident enjoyment from the music. She was often confused and disorientated in the ward environment which would cause her anxiety, however, when her music was played she transformed to a different person. She would sing and dance with staff and wanted to share her music with fellow patients in the ward. As a healthcare professional I found this to be a very positive experience."*
>
> *HCP5*

Another participant recalled:

> *"The music does help her to actually calm down a little bit and settle, as she does remember and she smiles and she erm… and I have definitely noticed that she is more settled. I'm not sure for a period of time but certainly for the shortly afterwards she will seem more calm."*
>
> *HCP1*

And another noted:

> *"One patient who often became highly agitated and accelerated would appear much more settled after listening to her personalised music."*
>
> *HCP4*

A participant also shared how the music could be used to good therapeutic effect in a preventative way to thwart the escalation of agitated behaviour:

> *"However there was times where you could see her starting to change, and that sort of sun downing behaviour would start, and if you got in there quickly with it some of the sadder music helped to slow her down, so it sort of stopped her going…stopped her behaviour escalating. So she was a success with it, she really enjoyed it."*
>
> *HCP3*

This therapeutic effect also improved sleep patterns in one person with dementia as this participant shared:

> *"Listening to the music with the patient was a good distraction and therapeutic activity. After around five minutes the patient would sit or lie down and relax, smiling and singing along. The patient would often fall asleep listening to their music and achieve a better sleep. Without the music the patient would wake up and get out of their bed several times a night."*
>
> *HCP4*

Healthcare professionals expressed delight in seeing a person with dementia respond in such an encouraging way to the music. Similarly to the family carers, they reported instances of singing, dancing, improvement in mood and agitation levels, as well as gaining personal enjoyment themselves from listening to the music and seeing the response from the person with dementia. One participant remembered:

> *"There has been benefit with it, from it, and that is evident through emotion, erm…tears, giggles, singing, dancing, patients are more settled. So you can see how the research is quite good, how the music is effective with the patients, and how we also as professionals can be involved in that, and get that therapeutic relationship, and going back to the family, involving the family is so important if they are willing to be part of it."*
>
> *HCP1*

One participant also reported the beneficial impact it had for a family carer that had been involved in delivering the music:

*"But one thing I did notice is that I think it gave [carer 2] something to focus on because he was obviously….he comes in, his wife doesn't speak to him…he will participate in personal care because he had done a lot at home…but he wasn't really doing much here. He really didn't have anything to do with her, and this was a good way to actually…although she didn't tolerate it…it gave him a purpose, it gave him a role, he was coming in and helping us give the music. So I think from….it was nice to see him reconnect with his wife, although she didn't tolerate it unfortunately, but it was nice to see that kind of thing."*

*HCP2*

Common to participant accounts was the desire to use individualised music rather than sedative medication to manage agitated behaviour. Utilising music, rather than medication, was deemed as a therapeutically better option by healthcare professionals to help to reduce levels of agitation. One participant stated:

*"If everyone was on this [individualised music], and it was benefiting them, and reducing as required medication use, it would be absolutely fantastic."*

*HCP2*

One participant had used the individualised music for a person with dementia instead of using sedative medication, and held firm beliefs in the therapeutic effect of doing so:

*"It was better than giving prn medication."*

*HCP2*

Reduction in the use of PRN (as needed) medication for agitation is something that the healthcare professionals reported that they aim to achieve. However, one participant felt quite strongly that they were restricted by the medical model and needed to move away from this if they were to use individualised music in a truly therapeutic manner. The participant stated:

*"I think we should be more holistic in our approach…rather than this medical model and relying on the medication model."*

*HCP3*

The experience of using individualised music helped one participant to see that there are other options to sedative medication. They went on to say:

> *"I still feel that we are in this medical model, and I don't think that comes from use as nurses. I think we are very much the ones that are actually… 'let's get away from this'; we don't want to give PRN, we don't want to be medication focussed, I don't always feel that goes right up to the medical team."*
>
> *HCP3*

All healthcare professionals believed in the therapeutic benefit of the individualised music intervention. They unanimously voiced that they wanted to continue to use individualised music in the care of people with dementia experiencing agitation. One participant shared:

> *"I think it's amazing to have another tool in the bag that we can pull out when we need it."*
>
> *HCP2*

Even though they saw varying levels of success in the effectiveness of the intervention, all healthcare professionals were keen to continue to use individualised music in their practice.

> *"I think this is something we should definitely pursue. It might not be for everyone – but I think it is important to take a person centred approach to this. If music has played an important part in someone's life we should ensure it continues to be. I believe this will ensure they are able to lead a fulfilling life despite the limitation caused by their illness."*
>
> *HCP5*

Healthcare professionals were keen to see the use of individualised music expand to more people in their care, and for it to become a routine part of care delivery.

> *"I think it would be good for more of the patients to have their own music and would definitely continue to use it if it had a positive effect."*
>
> *HCP4*

> *"I would advocate strongly for this to become part of our ward routine."*
>
> *HCP5*

### 4.8.2 Theme 2 – Clinical complications

The theme of clinical complications refers to the experiences described by healthcare professionals of difficulty or obstacles or negative outcomes they experienced when using the individualised music intervention. The complications arose as a result of the clinical implementation of the music intervention, meaning in relation to the treatment and observation of the person with dementia.

Healthcare professionals suggested that they thought the individualised music often triggered memories for people with dementia that had the effect of causing agitation rather than reducing it. Clinically, this was not the desired effect from the music intervention. One participant recollected an episode where the music caused a person with dementia to disengage:

> *"The carols maybe triggered those memories. And in the same way the playlist music has maybe triggered memories for her which might have been hard for her to deal with. Perhaps that's why she walked away? Who knows?"*
>
> *HCP2*

A number of healthcare professionals voiced that they thought some people with dementia had insight into their condition, and that this impeded the clinical success of the music. They felt that their insight into their condition, and the memories evoked by the music, reminded them of lost ability, lost times, lost experiences. One participant described an example of this situation:

> *"So I don't think it worked too well with her and then again I think that is because of her…. I think she's got a bit of insight….to obviously she knows, she remembers the music. I feel that she….it's quite negative for her because she's thinking back to that music and thinking that's a memory for me and now I can't….those memories are gone. And she knows, I think she's able, she knows that she's… I think that she's got insight, got insight…and she gets really distressed by knowing that she's in hospital and that she's not with her family."*
>
> *HCP 1*

Having insight, and memory recollection, became a barrier to the individualised music being effective and resulted in anxiety rather than the desired effect of relaxation. This was voiced as being more significant due to the person's hospitalisation:

> *"I think this is because as much as she does not communicate verbally, she has retained some insight into her current presentation and situation. I think the music evokes strong memories for her which reminded her of where she was [in hospital] and why."*
>
> *HCP5*

The medical condition of the person with dementia was a clinical complication that was felt to limit the effectiveness of the individualised music according to the healthcare professionals. Participants reported that some people with dementia were too unwell to get benefit from the music intervention.

> *"I think he would tolerate it more now. Whereas I think he was too unwell at the time we were doing the music. A lot of it was lack of pain relief which we didn't know about back then."*
>
> *HCP2*

> *"He has better times and worse times, and he gets on with certain staff better than other staff, how he interacts with others and that….but he was, he was too unwell when we did the music. He really was."*
>
> *HCP3*

A further complexity that healthcare professionals reported in relation to using the music intervention as part of their clinical practice was feeling limited by the nature of the research protocol. Instruction was given to administer the intervention at the same time each day. This was found to be not always feasible or in the best interest of the person.

Healthcare professionals described being restricted, feeling the necessity to give the intervention when stated by the research protocol, as opposed to when the participant would best benefit from the music.

> *"What we struggled with the most was trying to administer the music at the same time every day. This was just not feasible at times due to the unpredictability of the ward environment and the patient group. I think more flexibility on the approach would have been more beneficial."*
>
> *HCP5*

The rigidity of the research protocol complicated the clinical effectiveness of using the music for people with dementia as this participant described:

> *"But it was a pain because it was very restrictive. Say if we could have had playlists for each and every one of them, and we as staff could choose when we were able to do it, then I think it would have been better. It's not something that needs to be done every day, it's not something that needs to be done at this certain time, it's oh I've got 10 minutes free, and so and so is nice and relaxed, I'm going to go and play them some of their music, and then I'm certain they would have got more benefit from it. We were too restricted by having to give it at the same time each day."*
>
> *HCP 3*

This was further explained by this participant:

> *"I can see you wanted to keep everything the same so you could see whether the music was having an effect….but it wasn't focussed on the needs of the patient."*
>
> *HCP2*

The final clinical problem experienced by healthcare professionals was a negative response exhibited by some people with dementia when listening to their individualised music intervention. For some, listening to the music had no effect:

> *"There didn't seem to be much reaction from it, he would keep the headphones on and listen to the music, but there was nothing visual, or anything verbal, kind of indicating if he was getting any pleasure out of it."*
>
> *HCP2*

Whereas in others the lack of therapeutic effect of listening to their music was more significant and precipitated distressed behaviour, as this participant described:

> *"One patient appeared to find their music upsetting and would become tearful every time it was played."*
>
> *HCP4*

Another participant shared an experience of a person's clinical response to the music:

> *"Another lady in the ward did not appear to experience a therapeutic effect from the music and became quite tearful when this was played. Initially I did not see this as a particularly negative thing as she was expressing a different type of emotion than she usually does, however this continued and she appeared more distressed over the course of the research."*
>
> *HCP5*

The clinical outcome that occurred in these situations was not the desired outcome in relation to what was expected by healthcare professionals, but the impact of this was the realisation that music might not work for everyone.

### 4.8.3 Summary

The main themes elicited from the experiences of healthcare professionals were the therapeutic effect gained from using individualised music with people with dementia, and the clinical complications they encountered whilst implementing it. The therapeutic effectiveness of individualised music was evidenced in the narration of experiences from healthcare professionals and was much greater than the expected impact on reducing agitation in people with dementia. The wider benefits of using individualised music included the nurturing of therapeutic relationships, the recognition of music as an alternative to sedative medication, seeing the person with dementia as a person and not a diagnosis, the recognition of music as a therapeutic tool, and the desire to continue its use. But in gaining these therapeutic

experiences, healthcare professionals also faced several clinical challenges that tested their belief in the use of individualised music. In some instances, some people with dementia became more agitated by the music, or underlying medical conditions or cognitive level diminished its success. What became apparent for healthcare professionals was the recognition of the individual nature of caring for people with dementia, and that individualised music might not work for every person. But it is another tool in their bag of therapeutic interventions they can use to improve the care of people with dementia in the hospital setting.

## Chapter 5: Discussion

This study sought to explore the effect of individualised music on levels of agitation in people with moderate to severe dementia being cared for in a specialist mental health setting. It also explored the experiences of family carers and healthcare professionals in delivering this individualised music intervention. A single case experimental reversal design was employed to explore the effect of the music. This allowed each participant to serve as their own control and to ascertain whether the intervention in question had any replicable effect. The other elements of the study were investigated by exploring the family carer and healthcare professional's perceptions, perspectives and understandings of the experience of individualised music. The data was collected by individual or group interview. Overall, findings from the quantitative and qualitative data aspects of the study suggest a mixed response to the therapeutic value of the individualised music. Some participants did display a positive behavioural reaction to the music in terms of agitation levels, engagement and enjoyment of the music. However this was not consistent across the repeated administrations of the intervention. A neutral or even negative effect was noted in some participants whereby the music intervention appeared to have no impact or actually increased levels of agitation. Again this was not a consistently observed phenomenon. A number of possible reasons may explain these findings, some of which highlight important methodological considerations for future studies. Primarily, it might be that individualised music does not have any effect on levels of agitation in people with moderate to severe dementia being cared for in hospital. But previous research has shown that listening to individualised music can have a therapeutic effect on levels of agitation (Gerdner 2000, Gerdner 2005, Guétin et al. 2009, Sung, Chang and Lee 2010), as well other behaviours such as the need for restraint (Janelli, Kanski and Yow-Wu 2002), and behaviour at bath time (Thomas, Heitman and Alexander 1997). The findings from the experimental part of this current study are triangulated with the findings from the qualitative aspects – interviews with family carers and healthcare professionals – to give an overall perspective on the use of individualised music in dementia care in

specialist mental health settings. This chapter aims to draw together the findings of the study and to consider them in context of previous research and current knowledge on the use of individualised music. The effect of the individualised music on agitation levels in participants with dementia, and the main themes identified from the interviews with healthcare professionals and family carers, will underpin the following discussion.

## 5.1 Effect of individualised music on agitation levels

The present study was designed to determine the effect of individualised music on levels of agitation in people with moderate to severe dementia being cared for in a specialist mental health setting. Agitation levels were measured using the Agitated Behaviour Scale and the Cohen-Mansfield Agitation Inventory. The results of this study indicated a mixed response to the music. In some instances there was a positive response, in terms of reduced agitation and clear engagement and enjoyment of the music. On other occasions there was a negative reaction to the music. This varied across all participants, except for one participant who, on the whole, experienced a negative response to the music. This finding is contrary to previous studies outlined in Chapter 2 which have suggested that individualised music does help to reduced agitated behaviour in people with dementia on a more consistent basis. It also does not fully support Gerdner's mid-range theory of individualised music intervention whereby using individualised music just prior to peak times of agitation helped to decrease agitated behaviours. It is difficult to explain the results in this study, but a number of possible explanations can be suggested. Does the severity of the disease have significance on the response to the music? Does the hospital setting cause a difference? Does the delivery of the music by a healthcare professional rather than a family carer play a part? Did methodological issues in the study affect the results? Was there weakness in the use of the assessment tool for measuring levels of agitation? Or can it be concluded that individualised music does not have an effect on levels of agitation in people with moderate to severe dementia being cared for in hospital? Baird

and Samson (2015) suggest that music activities can improve behaviour, but go on to claim “that recent large-scale randomised control studies have questioned the specificity of the effect of music and found that it is no more beneficial than other pleasant activities” (Baird and Samson 2015 p207). None of these questions can be answered with certainty, but an exploration of some of the issues will give some insight.

### 5.1.1 Positive response to individualised music

All five participants responded to the music in some way. The positive effects of individualised music on levels of agitation were apparent during a portion of the music sessions for two participants in this study. The effects appeared marginal for other participants. Interestingly, for some participants the agitation scores were not always reflective of the positive engagement and enjoyment they gained from listening to the individualised music. When triangulated with the qualitative data, the latter was more enlightening than the actual agitation scores as to the effect of the music for the participant. Healthcare professionals reported that participants would sing, dance, tap their feet, interact about the artists, as well as appear more relaxed and improved mood. This demonstrates that using individualised music in people with moderate to severe dementia in hospital is a useful intervention to manage levels of agitation. But reasons why this might not have occurred on a more consistent basis and for all participants warrants further exploration.

### 5.1.2 Severity of the disease

The two participants in the current study that arguably had the better response to the music were both at the moderate stage of the disease. The three other participants, who were identified as being at the severe stage of their illness, had less beneficial effect from the music. This corresponds to the findings of Ragneskog et al. (2001) who also found that people most affected by dementia reacted least to the music. Similarly Thornley, Hirjee

and Vasudev (2015) in their study on the use of music therapy in an inpatient psychiatry unit found limited benefit of music therapy and related this to the severity of the disease in the participants, hypothesizing they were unable to meaningfully engage in the intervention. This discovery raises the possibility that in the more advanced stages of the dementia, you are less likely to get a therapeutic effect from listening to individualised music. It is impossible from the current study to extrapolate much significance from this suggestion as there was such a small sample, but further exploration of stage of disease and use of individualised music is possibly warranted. To rival this theory though, neuroscientists assert that an individual's ability to respond to music is potentially preserved, even in the late or severe stages of dementia when verbal communication may have ceased (Baird and Samson 2015). If this is the case, severity of the disease would have no bearing on the effect of individualised music. It could be argued that the participants with severe dementia did respond to the music, but not always in the desired way. The music did trigger a response, showing that their ability to respond to music was preserved, but the response it triggered was to increase levels of agitation rather than reduce them. The reason for this is not clear, but when analysed with data from the qualitative element of the study, family carers and healthcare professionals both suggested that the music triggered memories to which the participant had insight, and caused them distress rather than comfort. They also reported that participants were unwell, the very fact they required to be in hospital, which they believed impacted on the effect of the individualised music. This will be further explored later in the discussion.

### 5.1.3 Hospital setting

All participants involved in this study had recently been hospitalised due to their dementia and decline in mental health. So the environment and people (healthcare staff and other patients and relatives) were all new. Three of the participants were also moved between hospital wards during the study which meant another new environment to orientate to as well as a new team of

staff. It is well documented that unfamiliar environments, such as hospital wards, combined with memory problems, can be distressing and disorientating for people with dementia and lead to agitated behaviour (Bray et al. 2015, Cooke et al. 2010, Cunningham 2006, McCloskey 2004). Therefore researching the effect of individualised music on people with dementia in a hospital setting experiencing a decline in their mental health, who are exposed to an increased number of stressors, was perhaps less likely to have a positive effect on levels of agitation than found in other studies where the intervention has been researched on individuals living at home (Park and Specht 2009, Park 2013) or in long term care facilities (Gerdner 2005, Guétin et al. 2009, Ragneskog et al. 2001), where the care providers are either family members or care staff who are familiar and with whom relationships will have been formed. Nonetheless, the purpose of this study was to explore whether an individualised music intervention had any effect on levels of agitation in people with dementia, specifically in hospital, therefore the impact of the setting may have had some bearing on the mixed response to the music intervention, and should be considered when drawing conclusions from the results.

### 5.1.4 Delivery of the music intervention by healthcare professionals and memory recollection

The music intervention in the study was mainly administered by healthcare professionals rather than family carers. Only two participants had occasional involvement of family carers: a spouse, who was involved in facilitating music listening with his wife; and two siblings who assisted their brother. All other participants received their music via nursing staff on the ward. A significant element of the individualised music intervention is proposed as the triggering of meaningful memories associated with the piece of music. As nursing staff, rather than the family carer, mainly oversaw playing the music, they almost certainly would be unaware of the memory associated with that piece of music, making it difficult to interact with the participant around the associated memories. This is undoubtedly a methodological weakness in the study and

may have had an impact on the results found in the experiment. Gerdner's mid-range theory of individualised music for agitation (2012) promotes the essence of individualised music is stimulation of remote memories which changes the focus of attention from meaningless or confusing stimuli, to positive feelings associated with the memory which have a soothing effect on the person with dementia. This in turn alleviates or prevents agitation. This process in the study would have been enhanced by verbal prompts connected to the memory to assist the participant in recalling the memories associated with that music. As these memories were, at least initially, mostly unknown by healthcare professionals, this did not take place. Had family carers been more involved with the music administration, and more able to facilitate a discussion about the relevant memories, a greater therapeutic effect may have been achieved. This is supported by data elicited from the qualitative part of the study. The issue was raised by a healthcare professional participant when interviewed. She reported a more sustained engagement with the music when administered with family as opposed to healthcare professionals. This also supports the findings of Sakamoto, Ando and Tsutou (2013) who found interactive individualised music was more effective than passive individualised music – listening to music with family members is likely to be more interactive, and potentially a more passive experience when with healthcare professionals.

Involvement of family carers was a significant finding in the study and will be examined in more detail later in this discussion. Healthcare professionals are reliant on family carers sharing memories associated with their loved one's individualised music to allow therapeutic discussion to take place between the nurse and the participant. However this is sometimes hard to achieve as family carers are not always aware of the memory associated to a piece of music, and often identify music because they knew their loved one 'liked it' rather than it triggering a specific memory. The researcher had responsibility for meeting with the participant and family carer to identify the meaningful music and more effort should have been made to elicit and document the associated memories of the music to facilitate this process. This is another methodological weakness to the study. A greater beneficial effect is probably

more likely to occur if the memory can be identified and shared with healthcare professionals, or if family carers can be present to prompt that memory recollection.

### 5.1.5 Assessment tools for agitation

The Agitated Behaviour Scale was used to measure levels of agitation as documented in Section 3.7.1. High levels of inter-rater reliability are documented in relation to this tool; however this was not evident in the healthcare professional participants involved in this study. When asked to score a scenario case developed and scored by the Ohio State University the range of scores varied from underscoring by 32% to over scoring by 10%, a difference of 42% between the lowest score measured and the highest score measured. Therefore it could be argued that the daily agitation scores recorded for the music sessions and non music sessions during the study are only somewhat reliable. This reduces the potential generalisability of study findings. The Agitated Behaviour Scale was a new tool for the nursing team to administer as they had not previously used anything to measure levels of agitation experienced by their patients. The researcher spent time with individual staff explaining the tool and how to use it. Although this appeared to the researcher to have been done successfully, the nursing staff perhaps were lacking in confidence in using the tool. Shuttleworth (2017) recommends that inter-rater reliability is strengthened by establishing clear guidelines and thorough experience using the rating tool, both of which were perhaps lacking in this study. This might have been improved by introducing the tool for a few months prior to the start of the study so the nursing team could become familiar with and gain confidence in making assessments. This might have led to greater inter-rater reliability between the nurse raters and ultimately more confidence in the results.

Brett et al (2017) reported issues with the use of the Cohen-Mansfield Agitation Inventory in their study exploring the use of exercise on agitation levels. They reported the Hawthorne effect whereby staff potentially over

exaggerated the frequency of agitated behaviours because they knew the measurement was being used for research. Similarly they also suggested the increased alertness and interactivity of participants because of the intervention was possibly misunderstood as agitated behaviour by staff and reported as such through the Cohen-Mansfield Agitation Inventory. They also reported inaccurate recall and observation may have impacted on their findings. As the Cohen-Mansfield Agitation Inventory is recorded over a one week or two week period it relies on healthcare professionals recalling this information. This potentially gives rise to inaccuracy when relying on the memory of staff that are caring for several patients at a time and are not there every day to observe the behaviour of the participant. All these factors may have influenced the current study, and the latter point could explain why there was such poor completion of the Cohen-Mansfield Agitation Inventory.

### 5.1.6 Variability of agitation scores

There was several outlier agitation scores recorded as part of the data collection across participants. For some participants in the study the agitation scores were highly variable. (Todd 2017) suggests that constant variability in baselines and treatment conditions is an indicator of lack of experimental control. Continuing the baseline condition until there is stability or no visible trend-line gives more confidence that changes in trend-line in treatment conditions are a result of the intervention (Dallery, Cassidy and Raiff 2013). Likewise the same should be applied in treatment conditions. On this basis the study probably did lack experimental control as baseline and treatment conditions were set by specific number of days rather than acquiring stability in agitation scores. To achieve stability in scores would have been the ideal scenario, but restrictions on the scope of the study and time limitations negated this possibility. The results gained in this study are lacking in exact causal effect, and greater experimental control as described above would possibly have given more credible results.

## 5.2 Experiences and opinions of healthcare professionals and family carers

Including the exploration of the experiences and opinions of healthcare professionals and family carers was a useful addition to the study as the triangulation of quantitative and qualitative data on the use of individualised music provided convergent validity. Interestingly, one of the themes arising from the analysis of the transcripts overlapped between the two groups of interviewees. It could be argued that this is not surprising as they were both reflecting on the same situation, but at the same time they were experiencing the phenomenon from two different perspectives. Regardless of this, the findings provide some useful insights in the understanding of the use of individualised of music in mental health settings.

A significant theme to arise from the interviews with the family carers was around their involvement with the music intervention. This was evident from two opposing views – one being that they felt involved by being able to contribute to the creation of the playlist, and the other from feeling uninvolved by not being present when the participants were listening to the music intervention. The feeling of being involved through music identification was a hugely positive experience for the family carers and one that some reported to be cathartic. Caring for someone with dementia is known to be stressful and care-giver burden is often high (Lewis et al. 2014). Something such as creating a playlist can give evident enjoyment to family carers and allow them to feel they are doing something to help their loved one. When someone is admitted to care, whether that be a nursing home or hospital ward, family carers often feel a loss of role and purpose, guilt, conflict and uncertainty (Bauer and Hay 2003). Giving family carers something constructive to do, such as identifying meaningful music, allows them to feel involved and gives them a focus that they know will help their loved one. This was evident in the current study. This idea is in line with the work of de Vries, Drury-Ruddlesden and Gaul (2016) who found that the desire to help and support the person with dementia when admitted to hospital was at the forefront and a primary focus of all family members. This almost certainly

explains the sense of disappointment shared by family carers in this current study, many of whom did not have the opportunity to be involved when their loved one was listening to the individualised music. Unfortunately most family carers did not get the chance to 'help' or 'support' their loved one with the individualised music. This was not a purposeful action of the nursing staff but a coincidental occurrence due to the timing of the intervention as part of the research protocol, and timing of visits by family. The family carers desire to be part of the delivery of the intervention, either on a practical level or from an observational perspective, was something that was important to all family carers and something that they all hoped would happen in the future. As discussed earlier, family members being present when listening to music could facilitate memory recall in relation to the music which is an important aspect of Gerdner's mid-range theory individualised music for agitation (Gerdner 1997). Gerdner (2005) also reported the involvement of family members in the delivery of individualised music facilitated a collaborative relationship between staff and family. Therefore the lack of family carer involvement found in this study has important implications for future use. It is essential that use of individualised music should incorporate family members to a level and degree that they are comfortable to be involved (Bauer et al. 2014).

Benefits of individualised music were highlighted as being important by both family carers and healthcare professionals. There was noteworthy overlap in several aspects in this area, such positive effects on levels of agitation for participants resulting from the music; music being better than using medication to manage agitation; and a unanimous desire by both groups to continue to use individualised music. However, for healthcare professionals an additional benefit was reported in that the music intervention helped them to build a therapeutic relationship with their patient. Using personally meaningful music as part of nursing care allowed nursing staff to get to know another side of their patient. This finding is consistent with that of Gerdner (2005) who advocates the use of individualised music serves as a catalyst for meaningful interaction. As the ultimate aim of nursing staff is to achieve person-centred care, facilitating the use of individualised music allows them

to move towards this by getting to know the individual, their musical likes and preferences, their life history through the memories recalled via the music, and really seeing the person with dementia as a person, at the centre of their care, and their diagnosis of dementia in the background. The joint listening to the music, when it was a positive experience for the participant, allowed the nurse to connect with the person with dementia and created valuable interactions that were built on a mutual enjoyment of the music, person to person rather than patient to nurse.

Family carers and healthcare professionals in the study both advocated that they would prefer to use individualised music to manage levels of agitation in participants rather than sedative medication. There was common understanding that pharmaceutical management of agitation has side-effects and that music is a favourable alternative. This view supports the current approach of non-pharmacological management of agitation (Banerjee 2009) and the view that music is indeed a 'behavioural medication'. Banning (2017), in his recent paper *Music: The Ultimate Nonpharmacotherapeutic* suggests that we should see music as something that is 'prescribable'. He proposes that we should consider music as medicine, and we should teach medical students that the prescription of personally meaningful music is an option rather than using sedating and addictive anxiolytic drugs. This idea would support the beliefs of the family carers, and healthcare professionals, as they both articulated that they would always chose non-pharmacological approaches to manage agitation over medication. Reduction in the use of sedative medication is commonly favoured by family carers as a project in a UK nursing home demonstrated. A family carer shared the following view: "reducing medication can make life easier for carers: someone who is drugged up has no quality of life, and will be asleep for much of the time. When medication is reduced, the resident has more control and so the carer has a happier relationship with them" (Davis 2009 p23). It is evident from this current study that family carers also find music a preferred option to medication. Music cannot cause side-effects in the same way as drugs, music cannot become addictive, and music can give pleasure not only to the participant but to the wider audience able to listen to it too. This is something

that medication cannot do. Therefore offering individualised music to people with dementia is seen by family carers and healthcare professionals as a beneficial and desired alternative to drugs.

The positive effects that healthcare professionals witnessed when participants listened to their individualised music demonstrated the therapeutic effect that such an intervention can have. This finding supports Gerdner's mid-range theory of individualised music for agitation (Gerdner 1997). The possible triggering of memories by the individualised music elicited positive emotions and behaviours that had a soothing effect on participants reducing levels of agitation. In this study this was triangulated with evidence recorded by the healthcare professionals on levels of engagement and enjoyment of the music, and recounting stories of participants singing to the music, dancing, tapping their feet and hands and asking questions about the music and the artists. They also reported that some participants were more relaxed, calmer and had improved mood. Additionally, the positive effect of the individualised music can also be explained by the progressively lowered stress threshold model. Having a diagnosis of dementia results in a progressive decline in an individual's stress threshold causing a decreased ability to receive and process sensory stimuli (Hall and Buckwalter 1987). Individualised music perhaps increased this lowered stress threshold in participants by altering the perception of the stressors in the hospital setting such as the environment, new people, and new routines. The personally meaningful music may have overridden their distress reaction leading to less anxiety and, ultimately, agitation. Provision of familiar stimuli may facilitate a sense of calm in times of stress. In hospital care, people with dementia are encouraged to bring a familiar blanket, a photograph of family, or other personal mementos with them. This research has shown that we should consider meaningful music similarly and encourage patients to bring a playlist of individualised music with them if hospitalised.

Although family carers did not witness any immediate positive reactions of participants to the music themselves, they still described the success of the

intervention with their loved one as related by nursing staff. They frequently described their vicarious delight in hearing about these occurrences. That family carers praised the music intervention may be slightly surprising, since they had not actually witnessed it. However, it does reflect the confidence that family carers had in the music intervention and their belief that using music was a valuable thing to do with their loved one.

The current study also found the music intervention to have apparently counterproductive outcomes on occasions for some participants. Negative responses were exhibited such as agitated and distressed behaviour, or trying to remove the music, showing disinterest. Interestingly, although this was not the desired response from using the individualised music, healthcare professionals surprisingly reported usefulness in seeing this reaction in participants. It helped them to understand that individual and understand the meaning from their behaviour, especially in participants who could not verbalise. Healthcare professionals and family carers referred to the participants having insight into the memories that were triggered by the music. They felt this insight could explain the negative response, rather than the positive response which was hoped for, because it caused a realisation and understanding for the participant of their lost ability and function. Interestingly this was reported for the two participants with severe cognitive decline. But is this possible? Is it possible for participants to recall memories through listening to music and interpret them in such a manner? Especially when they have progressed disease aetiology? Clare (2010) reported that a degree of complex awareness can be retained even when cognitive impairments are severe, which supports that insight may well be possible. Research into face recognition has shown that photographs from the remote past were recognised more easily than recent photographs in people with late-stage Alzheimer's Disease (Kurth et al. 2015). Perhaps this is the same with memories from music? This supports the work of Cuddy and Duffin (2005) who believe that musical memory is spared in dementia. The music that triggered memories from the remote past were perhaps more vivid, and if awareness is still present, this served as a reminder of lost times? This in turn caused distress rather than comfort. The participant who had the most

marked reaction in this manner from the music also had the most active involvement from a family carer. Walmsley and McCormack (2016) found that awareness was retained in people with severe dementia and that unique interpersonal levels of awareness and social interaction were retained during family visits, and were inconsistent with expectations set by stage of the disease. Therefore having a family member present during the music intervention perhaps facilitated greater awareness of the elicited memory? This is obviously beneficial if the memory results in a positive response, but not so much if a negative response.

The underlying medical condition of the participant was also deemed to be a factor in the effectiveness of the music intervention. Other co-morbid conditions such as pain, or anxiety, were described as influencing the effectiveness. This represents a significant divergence in findings between this study and previous research in residential homes and individuals own homes. In these studies, the participants would be medically stable, in contrast to this current study where participants were in hospital due to deterioration in their mental health, and possibly their physical health. It is therefore important to identify and treat any underlying acute mental health or physical conditions and liaise with the multi-disciplinary team before commencing an individualised music intervention.

Personnel factors also had a bearing on the study. Family carers reported some healthcare professionals were not fully engaged with the philosophy of the music intervention and felt that they did not believe in the usefulness of the individualised music. This is probably a fair perception as the music was a new intervention in the clinical settings, and healthcare professionals may have been sceptical of its value. Plus it was an addition to their usual busy workload that may have fostered some resistance. Healthcare professionals themselves reported that the restrictive nature of the intervention as guided by the research protocol was unsatisfactory. Similar to the study by Tuckett et al. (2014) who explored the use of music therapy, healthcare professionals in the current study felt tied to delivering the music as per instruction given to them and this often had consequences with the routine of the ward. Or it was

deemed in their professional judgement to not be the best time to give the music to the participant. Consistency in administration of the intervention was requested from a scientific point of view, but in reality this lost something of the person-centred nature of the intervention, and perhaps the effectiveness of the individualised music. As Dewing (2010) proposes, non-pharmacological interventions for agitation should sit in a broader holistic and person-centred assessment and care plan, rather than a regimented procedure as dictated in this study.

Despite the varied response to the individualised music, all family carers and all healthcare professionals were unequivocal in their view that the individualised music should continue to be offered to all current participants, and be offered future patients in the wards. The wider effects of using the music, more than just the impact on levels of agitation, appear to outweigh any negative aspects.

This pilot study has provided initial support for the use of individualised music for people with moderate to severe dementia in specialist mental health settings. The individualised music intervention has served as a catalyst for meaningful interactions between people with dementia, family carers and healthcare professionals. Individualised music is seen as a preferred intervention for the management of agitation as opposed to pharmaceutical management, and has been shown to be an excellent way to work in partnership with family carers to promote humanistic, person-centred care to enhance the quality of life for a person with dementia whilst in hospital.

## 5.3 Limitations

Although this study has demonstrated that individualised music has had a partly beneficial effect for participants, family carers and healthcare professionals involved in the study, these findings should be considered in the context of several limitations. Firstly, generalisation of any findings is limited due to the small sample size. A larger sample would offer greater

generalisability. A degree of sampling bias may have occurred in healthcare professionals as those with a positive attitude perhaps offered themselves to be interviewed, whilst those with a negative perspective declined. Similarly, one of the participants with dementia identified by the medical team as meeting the inclusion criteria, in fact was displaying very low levels of agitation prior to starting the intervention. Therefore any effect from the individualised music would have been difficult to demonstrate. A longer pre-study phase of agitation measurement would have been beneficial to ensure participants were selected who were experiencing high levels of agitation. Adherence to the research protocol in terms of delivering the intervention at the stated times, and recording the agitation measurements as requested, was not fully achieved. Analysis of the results is more difficult when data is missing and gives a more limited perspective. The lack of inter-rater reliability in using the agitation measurement tools was an issue in this study and could have been improved by ensuring that healthcare professionals had better knowledge, skill and experience in using these tools prior to starting the research. And finally, as there was a restricted timescale to complete the study, specific time periods were set for intervention and non-intervention weeks. This limited the study as it did not allow for stability of data measurements to be achieved in baseline and intervention weeks which ideally should be the case in experimental single case reversal design studies.

## 5.4 Implications for future practice

This research study has shown that individualised music is an acceptable, feasible and practical non-pharmacological intervention to deliver in a specialist mental health setting for people with moderate to severe dementia experiencing agitation. The decision to introduce this type of music intervention into routine care requires consideration of the risks against the benefits – this study has shown there were many benefits, but if an individual were to experience a negative response to the music it can be stopped. The research has shown that the intervention can be delivered in this setting, and

delivered by nursing staff. But future use of individualised music should ensure more active involvement of family members to support music listening, and their help and involvement to recollect and document the memories associated with the music to allow further reminiscence between people with dementia and healthcare professionals when family carers are not present. To support this whole process the use of individualised music should be underpinned with more formal education and preparation of the multi-disciplinary team to ensure understanding of the intervention and commitment to the approach.

## 5.5 Future research

It is recommended that this study is repeated with a larger sample and with data collection over a longer period. This will allow more stable measurements to be achieved in baseline periods and intervention periods so that more conclusive comparisons can be made between the two. It would be interesting to investigate the effect of individualised music with active family involvement against individualised music listening without family present. Family involvement was sadly lacking in this current study so it is recommended that further research is carried out to see if a greater therapeutic effect is achieved when family are present to interact with the individual . Finally, research is needed to better understand the possible association between the stage of the disease and the effectiveness of music on levels of agitation to see if there is less impact when the disease is more severe.

## 5.6 Conclusion

The purpose of this study was to explore the effects of individualised music on levels of agitation in people with moderate to severe dementia being treated and cared for in a specialist mental health hospital setting. It also explored the feasibility and practicability of a music intervention being

delivered by nursing and allied health professionals as part of routine care, and explored the acceptability of such as perceived by healthcare professionals and family carers. Reported in this study are the quantitative and qualitative data from five people with dementia, five healthcare professionals and four family carers. Individualised music was found to have a mixed response in relation to reducing levels of agitation in people with dementia. The intervention was found to be feasible and practical to administer, although healthcare professionals felt restricted by the research protocol. They felt a more positive experience would have been achieved if they had been allowed to use their professional judgement and administer the intervention at a time more suitable to the needs of the person with dementia. The individualised music intervention was found to be an acceptable intervention to use in the specialist mental health hospital setting and healthcare professionals and family carers reported many positive examples of participants enjoying and engaging with the music, resulting in reduced levels of agitation. Although the current study is based on a small sample of participants, these findings add to the growing body of literature on the beneficial use of individualised music in the care of people with dementia. Overall, this study has brought an important contribution to the knowledge and understanding of using individualised music in a hospital setting, and the findings will be of interest to the wider National Health Service across the United Kingdom and further afield.

## Appendix 1: Background Music Questionnaire

Version 1 - 28 June 2016

**Individualised music for agitation in people with dementia**

**Background Music Questionnaire**

Completed by the CI with the person with dementia and informal carer

**Participant ID:**
**Date:**
**Time:**

Q1. How important is music in your life? TICK **ONE** BOX

1. Very important ❑
2. Important ❑
3. Neither important or unimportant ❑
4. Unimportant ❑
5. Very unimportant ❑

Q2. How often do you listen to music? TICK **ONE** BOX

1. As often as I can
2. Once or twice per day
3. Most days
4. Some days
5. Not very often

Q3. On average, how many hours per day do you spend listening to music?

_____

Q4.

a) Which technology do you use to listen to music? TICK ALL THAT APPLY

| | | | |
|---|---|---|---|
| Mp3 (e.g. iPod | ❑ | Radio | ❑ |
| Cassette player | ❑ | CD player | ❑ |
| Turntable/record player | ❑ | Laptop/Computer | ❑ |
| Other | ❑ | | |

Please specify _____

b) Which do you use most often?

_____

c) Do you require any assistance when using this device? Please TICK **ONE** BOX

Yes ❑ No ❑

d) If you answered 'Yes' to the previous question, please explain:

Q5. With whom do you normally listen to music? Please TICK **ONE** BOX

On my own ❑ With family ❑

With friend ❑ Other ❑

Please specify _____

Q6. What is your main reason for listening to music? TICK **ONE** BOX

To enjoy the music ❑ To help get through difficult times ❑

To be creative/use my imagination ❑ To relieve tension/stress ❑

To relieve boredom ❑ To express my feelings/emotions ❑

To reduce loneliness ❑ To get me in a mood I want to be in ❑

To get me in a mood I want to be in (with others) ❑

To perform activities I would normally find boring ❑

Other ❑

Please specify _____

Q7. Do you currently play a musical instrument? PLEASE **TICK** BOX

Yes ❑ No ❑

Q8. Have you ever played a musical instrument? PLEASE **TICK** BOX

Yes ❑ No ❑

Q9. How long have/did you play this instrument for?

_____ years

Q10. How many years of formal music training have you received

Yes ❑ No ❑

Q11. Please indicate the **3 types of music** you most often listen to (in order of preference)?

1.
2.
3.

Q12. Do you participate in any musical activities such as singing, playing instruments or dancing (e.g. church choir, community dance groups)?
Please provide details**:**

Any other comments:

## Appendix 2: Music Selection Form

Version 1 – 28 June 2016

**Individualised music for agitation in people with dementia**

**Music Selections Form**

Completed by the CI with the person with dementia and informal carer

**Participant ID:**
**Date of interview:**
**Time:**
**Persons present during interview**
**No. of musical selections identified:**
**Date uploaded to Mp3 device:**
**Duration of musical selections:**

| Song | Title | Artist/Band | Reason for selection | Duration | Uploaded to Mp3 device? | Confirmed via Spotify? | Order on playlist |
|---|---|---|---|---|---|---|---|
| **e.g. 1** | **Memories are made of this** | **Dean Martin** | **Love song / first song danced to with spouse** | **2.18** | **Yes** | **Yes** | **3rd** |
| | | | | | | | |
| | | | | | | | |

| Song | Title | Artist/Band | Reason for selection | Duration | Uploaded to Mp3 device? | Confirmed via Spotify? | Order on playlist |
|---|---|---|---|---|---|---|---|
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| Song | Title | Artist/Band | Reason for selection | Duration | Uploaded to Mp3 device? | Confirmed via Spotify? | Order on playlist |
|---|---|---|---|---|---|---|---|
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**Prompting questions:**

- **Musical memories from mid-teens to early twenties?**
- **Did you go dancing?**
- **Did you go to the cinema – particular films, memorable theme tunes?**
- **Particular radio or television programmes?**
- **Hymns?**
- **Music at your wedding?**
- **Did you go to Sunday school?**
- **Church choir?**
- **School songs?**
- **War time songs?**
- **Did you play an instrument?**
- **Did you plan in a band?**
- **Records/CDs in the attic, sheet music from playing an instrument?**
- **Lullabies, nursery rhymes, traditional songs?**
- **Music sung or played at family parties?**
- **Music from family holidays?**
- **Old concert tickets?**

| **Researcher notes:** |
| --- |
| |

## Appendix 3: Healthcare professional interview

Version 2 – 24 September 2016

**Individualised music for agitation in people with dementia**

Post Experiment Interview Schedule

Conducted by the CI with the Healthcare Professional

**Interview topics**

- *Experience of facilitating the individualised music intervention*: identification of positive and negative outcomes of participation for persons with dementia and healthcare professionals.
- *Development of individualised music in dementia care:* identification of potential factors that might shape and constrain implementation, recommendations to enhance efficacy of an individualised music intervention for persons with dementia.

**Semi-structured interview schedule**

Introduction

- Thank the participant for agreeing to take part.
- Explain the purpose of the interview.
- Interview will last no longer than 45 minutes.
- Format of discussion (confidentiality, no right or wrong answers, liberty to discuss anything deemed personally relevant to project).
- Participants to be reminded that discussions of the focus group must not be reiterated out with the focus group room
- Reminder: interview will be recorded using a digital voice recorder for purposes of analysis and right to ask questions/pause for a break/discontinue and withdraw from participation at any time.

Example questions

Questions will centre upon the two specified topics in no specific order, some topics may be revisited and it is likely that there will be overlap between these dependent on the nature of the responses from the participant. In addition, there will be room to expand upon answers provided and space to discuss anything deemed personally relevant to the project. Questions detailed below will be rephrased and/or further explanation will be provided to clarify each question if required.

*Can you tell me a bit about your experience of participating in delivering the individualised music programme? What did you think of it?*

*Imagine I was another healthcare professional or colleague on the ward who had not taken part in this programme, how would you describe it to them? Can you describe one of the sessions in detail to me? What happened? What were the outcomes of this, if any?*

*In reflecting upon each of the sessions you delivered, can you tell me a bit about your perception of the person's involvement in the programme?*

*Can you tell me a bit about the person's behaviour before, during and after each session?*

*Having participated in this programme, can you tell me a bit about your thoughts on the use of music for people with dementia?*

*Can you tell me a bit about your thoughts about using such a programme in mental health care?*

*Can you tell me a bit about your thoughts on the treatment and care of people with dementia in mental health care? How would you describe it? Is there anything you feel can be done to improve this?*

*Before participating in the programme, how would you describe your experience and knowledge of caring for people with dementia? How would you describe this now? How did you feel about participating in this programme at the outset? How do you feel about participating in the programme now?*

*Can you talk to me a bit about the nature of implementing this programme alongside routine care? Do you feel you were able to do so effectively? How did this compare to a typical week at work?*

*Did you experience and problems when delivering the programme? If so, what? How did you overcome these?*

*Is there anything you would change about the way in which the programme is delivered? Why/why not?*

*Is there anything you would add to the programme to improve the way in which it is delivered? Why/why not?*

*Is there anything you would change/add to the programme to improve outcomes for healthcare providers? Why/why not?*

*Is there anything you would change/add to the programme to improve outcomes for people with dementia? Why/why not?*

*Is there anything you would change/add to the programme to improve outcomes for family carers? Why/why not?*

*Would you participate in a programme like this again? Why/why not?*

*Would you recommend this to other healthcare professionals? Why/why not?*

*What advice would you give to other healthcare professionals regarding this?*

*Do you think this programme should be used in mental health care?*

*Is there anything you think would help facilitate this?*

*If you were to do this again, is there anything you would do differently?*

Conclusion

- Is there anything else anyone would like to add that you think is relevant to the project?
- Do you have any questions about anything that has been discussed?
- If you would like to discuss anything further out-with the interview, the researcher will be available.
- Everything discussed within the interview will be completely confidential, no comments or information will be linked to any real names or information.
- Participants to be reminded that discussions of the focus group must not be reiterated out with the focus group room
- If there is anything else you would like to discuss at any time, please feel free to contact me.
- Thank participant for their time.

## Appendix 4: Family carer interview

Version 1 – 28 June 2016

**Individualised music for agitation in people with dementia**

Post Experiment Interview Schedule

Conducted by the CI with the Family Carer

**Interview topics**

- *Experience of participating in the individualised music intervention*: identification of positive and negative outcomes of participation for persons with dementia and family carers.
- *Development of individualised music in dementia care:* identification of potential factors that might shape and constrain implementation, recommendations to enhance efficacy of an individualised music intervention for persons with dementia

**Semi-structured interview schedule**

Introduction

- Thank the participant for agreeing to take part.
- Explain the purpose of the interview.
- Interview will last no longer than 45 minutes.
- Format of discussion (confidentiality, no right or wrong answers, liberty to discuss anything deemed personally relevant to project).
- Reminder: interview will be recorded using a digital voice recorder for purposes of analysis and right to ask questions/pause for a break/discontinue and withdraw from participation at any time.

Example questions

Questions will centre upon the two specified topics in no specific order, some topics may be revisited and it is likely that there will be overlap between these dependent on the nature of the responses from the participant. In addition, there will be room to expand upon answers provided and space to discuss anything deemed personally relevant to the project. Questions detailed below will be rephrased and/or further explanation will be provided to clarify each question if required.

*Can you tell me a bit about your visits to the hospital over the last 4 weeks? In your opinion, how do you think [insert person's name] has been feeling?*

*How would you describe [insert person's name] mood in general over the past 4 weeks? Is there anything you feel has contributed to this?*

*Can you tell me a bit about your opinion of the care and treatment that [insert perosn's name] has received over the last 4 weeks?*

*Can you tell me a bit about your experience of participating in the individualised music programme from your own perspective? How do you feel about your role in this?*

*Imagine I was another carer who had not taken part in this programme, how would you describe it to them? Can you describe one of the sessions in detail to me? What happened? What were the outcomes of this, if any?*

*Is there anything you would change about your role in this? Is there anything you would add to this role? Why/why not?*

*In thinking about [insert person's name], can you talk to me a bit about [insert person's name] experience of taking part in the programme, from your own perspective? How do you think he/she felt about taking part?*

*Did you notice anything different about [insert person's name] before, during and after the music session? If so, what?*

*Having participated in this programme, can you tell me a bit about your thoughts on the use of music for persons with dementia?*

*Can you tell me a bit about your thoughts about using such a programme in mental health care?*

*Can you tell me a bit about your thoughts on the treatment and care of individuals with dementia in mental health care? How would you describe it? Is there anything you feel can be done to improve this?*

*How did you feel about participating in this programme at the outset? How do you feel about participating in the programme now?*

*Is there anything you would change about the way in which the programme is delivered? Why/why not?*

*Is there anything you would add to the programme to improve the way in which it is delivered? Why/why not?*

*Is there anything you would change add to the programme to improve the outcomes for family carers? Why/why not?*

*Is there anything you would change add to the programme to improve the outcomes for people with dementia ? Why/why not?*

*Would you participate in a programme like this again? Why/why not?*
*Would you consider using this with [insert person's name] at home/in future visits?*

*Would you recommend this to other family carers? Why/why not?*
*What advice would you give to other family carers regarding this?*
*Do you think this programme should be used in mental health care?*

*Is there anything you think would help facilitate this?*

*If you were to do this again, is there anything you would do differently?*

Conclusion

- Is there anything else you would like to add that you think is relevant to the project?
- Do you have any questions about anything that has been discussed?
- If you would like to discuss anything further out-with the interview, the researcher will be available.
- Everything discussed within the interview will be completely confidential, no comments or information will be linked to any real names or information.
- If there is anything else you would like to discuss at any time, please feel free to contact me.
- Thank participant for their time.

**Appendix 5: Invitation letter for nearest relative/guardian/welfare power of attorney of the person with dementia**

Version 2 – 24 September 2016

LETTER OF INVITATION FOR NEAREST RELATIVE / GUARDIAN / WELFARE ATTORNEY OF THE PERSON WITH DEMENTIA

Date:

Dear Sir / Madam,

I am writing to you as the nearest relative, guardian, welfare attorney of [insert name].

| I would like to invite you to take part in the following study: |
| --- |
| Individualised music for agitation in people with dementia |

I am a Dementia Nurse Consultant at NHS Fife and studying for a Masters by Research at Abertay University investigating the effect of listening to individualised musical preference for patients with dementia in mental health care settings.

At the moment, very little is known about the use of individualised music listening in hospital settings.

I would therefore like to invite you to take part in the study, to help us to investigate the effect of listening to individualised music.

You have been identified as a carer of a potential participant who has been admitted to a mental health ward and has been diagnosed with dementia.

As [insert name] is currently unable to make his/her own decisions I would like to ask your permission for [insert name] to be involved. Before you decide if you would like [insert name] to take part or not, you need to understand why this study is needed and what will be required from him/her.

I have attached an information sheet for you. Please take the time to read the following information carefully, and discuss it with others if you wish.

If you decide you are willing for [insert name] to participate or have any further questions about the study, please contact me. The contact details are provided on the information sheet.

Thank you for your consideration and time.

Kind regards,

Helen Skinner
Alzheimer Scotland Dementia Nurse Consultant / Study Lead
NHS Fife

## Appendix 6: Participant information sheet for nearest relative/ guardian/ welfare power of attorney of the person with dementia

Version 2 – 24 September 2016

**PARTICIPANT INFORMATION SHEET FOR NEAREST RELATIVE/GUARDIAN/WELFARE ATTORNEY OF THE PERSON WITH DEMENTIA**

**Individualised music for agitation in people with dementia**

***Individualised music*** *is music that has been integrated into the individual's life and is based on personal preferences.*

Part 1 of this information sheet tells you about the purpose of this study. It also tells you what will happen to [insert name], should you consent of their behalf to participate in the study.

Part 2 gives you more detailed information about the conduct of the study.

You are being invited to consider giving your permission for [insert name] to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and discuss it with others if you wish. Please ask me if there is anything that is not clear or if you would like more information. Thank you for reading this.

**Part 1**

What is the purpose of the study?

At present listening to individualised music is encouraged and recommended for people with dementia. However, these recommendations are based on studies where music is delivered either in residential care or in the community. There are currently no studies looking at individualised music listening for people with dementia in mental health settings and very little research regarding the use of individualised music in the latter stages of the disease. With regards to the latter, we feel this is a very important group of people that are currently being overlooked, which is why we wish to include [insert name] in the study.

We would like to find out what effect individualised music might have for people with dementia that experience agitation.

Why has the patient been chosen?

[insert name] has been invited to take part in the study as they have been diagnosed with dementia and admitted to Stratheden Hospital, NHS Fife.
However, they currently lack the capacity to make an informed decision about whether they can take part in a research study. We are therefore asking you as their nearest relative, welfare power of attorney or guardian if you give consent on their behalf to join this study. This is permissible under the Adults with Incapacity (Scotland) Act 2000.

Do they have to take part?

NO, it is up to you to decide whether they take part in the research or not. If you decide that [insert name] should take part, you are free to change your mind at any time, without giving a reason. This will not alter their care in any way, now or at any stage in the future.
Irrespective of participation, usual care will be provided for [insert name]. This will be decided by the healthcare team based on current guidelines and standards.

What will happen to [insert name] if they take part in the research?

The researcher, Helen Skinner, will meet with you to discuss the study. Helen can answer any more questions you have about the study and discuss any concerns you might have.
If you are happy for [insert name] to take part, Helen will ask for written consent for them to participate.

What next?

[insert name] will firstly be asked to take part in a conversation led by Helen, with yourself. This discussion will focus upon [insert name] music listening habits, experience of music across the lifespan and music tastes and preferences.
Following completion of this interview, Helen will load the individual's personal music choices (identified during the initial interview) on to a music playing device. One of the clinical healthcare team within the ward will then provide [insert name] with this music every day for 7 days and will monitor their response throughout. [insert name] will listen to the music for 30 minutes each session.
[insert name] will then have 7 days without listening to their individual music. After this, we will re-introduce the individualised music for [insert name] to listen to for a further 7 days.

How will we know if this works?

The nursing staff will collect information about how agitated [insert name] is feeling and what medications they are taking for this. We will do this:

- Every day for 7 days before the music is introduced
- Every day for 7 days whilst they are listening to the individualised music (14 days in total)

- Every day for 7 days when you are not listening to the music.

With your permission, the researcher Helen may also video-record [insert name] during the music sessions. This recording will be stored securely and will only be used for teaching health care staff. We will pixelate [insert name] face so they are not recognised and their name will not be used.

*Please note, Helen will not have direct access to any of [insert name] medical records or notes and will only collect information that you agree to provide.*

During the study
Helen will be available to discuss any part of the study with you and answer any questions that you may have.
All of the nursing staff will make sure that the study does not disrupt usual care and will also be available to answer any questions or concerns.
You are free to withdraw [insert name] from the study at any point and you do not have to provide a reason for doing so.

Will you or [insert name] receive payment for taking part in the study?
No. The study will take place during [insert name] hospital stay so that you are not out of pocket.
When the study is complete, should you and [insert name] wish to keep the music playing device, you will be free to do so.

What are the possible disadvantages and risks of taking part?
As this study involves a discussion about musical preferences and experiences of music from the past with the researcher who is a trained nurse, we believe that [insert name] will not be put in any situation that will lead to any uncomfortable or adverse events. On occasion, conversation regarding one's music background and preferences can often lead to discussion of life history which can be an emotional experience. However, if [insert name] appears upset or distressed at any point, the researcher will pause proceedings to check that [insert name] wishes to continue participating in the research and the opportunity to take a break from the session should he/she wish to do so.
[insert name] will be free to refrain from discussing anything that they do not wish to disclose and free to withdraw at any point of the study, without having to provide a reason to do so.
If you feel that [insert name] may have experienced any emotional distress or are upset owing to participation in the research study, please alert Helen or a member of the ward team as soon as possible. Please see Part 2: What if there is a problem?

What are the possible benefits of taking part?
There may be no direct benefit to [insert name] from participating in this research but the information you provide will help us become more informed about the use of individualised music in the care of people with dementia in mental health settings that may have benefits for individuals with dementia – like [insert name] – and their carers in the future.

What is there is a problem?
Any complaint about the way [insert name] has been treated during the study, or any harm you feel [insert name] may have suffered from taking part will be fully addressed in Part 2 of this information sheet. If you have any concerns please contact the researcher (contact details at the end of the information sheet).

Will my taking part in the study be kept confidential?
Yes. All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard the privacy of [insert name] at every stage, as explained in Part 2.

What should I do if I am interested in [insert name] taking part?
Please feel free to discuss the study with your relatives, friends or healthcare professionals.
The nursing staff will seek permission for Helen to contact you to discuss the study further.
Helen will meet with you at a suitable date and time to do so.
If you are happy for [insert name] to take part, written permission (consent) for them to participate in the study will be obtained.
If you are thinking about taking part, please read PART 2.

**Part 2**

What happens if I don't want to carry on with the study?
You/ [insert name] can withdraw from the study and you do not have to give a reason. If you withdraw because of anything to do with the study itself, the researcher, Helen, would be grateful if you would tell her. This is so she can improve her research in the future. However, whether you tell Helen or not is entirely up to you. Should you withdraw, you can choose to:

- Withdraw from the whole study. We would like to keep the information we have collected up to that point, if you agree. Or:
- Withdraw from the research evaluation, but continue with the music sessions.

Involvement of family doctor / General Practitioner (GP)
With your consent, we will let [insert name] GP know that [insert name] is taking part in the study, if you chose to do so.

What happens to the information after the study?
Helen will collect all of the information and store this securely on a password protected computer. She will analyse what this data tells us about using individualised music in mental health hospitals.

Will taking part in this study be kept confidential?
Yes. Ethical and legal practice will be followed at all times and all information will be handled in confidence. Confidentiality will be maintained by:

- No name will be used when using any of the data gained from the questionnaires or interviews

- All personal information and information from the recordings and transcripts will be saved on a password protected computer. Once the data is transcribed it will be deleted from all recording devices.
- Only the researcher, Helen Skinner and her research supervisors (see details below) will have direct access to this information.
- According to regulations, all data will be retained for five years and will then be disposed of carefully.

Helen will follow NHS and Abertay University regulations.
It is possible that a person from regulatory authority or Research and Governance may want to check that Helen is carrying out the study in an ethical way and to monitor study quality and to access data collected during the study, where it is relevant to them taking part in this research. The sponsor is responsible for overall management of the study and providing insurance and indemnity.

What will happen to the results of the study?
The results of the study will be a Masters by Research dissertation and will be published in scientific journals, and dementia charity magazines. We will also present our findings at conferences. The results will also help to inform the use of individualised music in people with dementia in mental health settings, and feed in to the work of the charity Playlist for Life©. Direct quotes may be used in these publications, however [insert name] name will not be used and [insert name] will not be identifiable in any published results.

Will I be informed about the results of the study?
Helen will send you a summary of the study findings should you wish to find out the results.

Who is organising and funding this research?

Helen Skinner is carrying out the research as part of her work for a Masters by Research qualification at Abertay University, Dundee.
The project is funded by the university and supervised by Professor Geoff Dickens and Mrs Suzanne Croy.
The music listening equipment has been provided by 'Healthy Harmonies' NHS Fife Staff Choir.
Helen's role is a nurse and researcher.

Who has reviewed the study?
All research in the NHS is looked at by an independent group of people called a Research Ethics Committee, to protect your interests. A favourable ethical opinion has been obtained from NHS Scotland A REC. NHS management approval has also been obtained.
This study has also been approved by Abertay University Ethics Committee.

What if there is a problem?

If you have a concern about any aspect of this study please contact the researcher who will do her best to answer your questions (contact details at the end of the information sheet). If [insert name] is harmed by taking part in this research project, there are no special compensation arrangements. If [insert name] is harmed due to researcher negligence, then you may have grounds for a legal action for compensation but you may have to pay your legal costs. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way [insert name] has been approached or treated during the course of the study, the normal NHS complaints mechanisms will be available to you (see contact details below).

If you need more information or help that Helen cannot provide, please speak with any member of the ward staff.

**Thank you for reading this information and for thinking about [insert name] taking part in this study.**

**For any further questions please contact Helen Skinner.**

Contact details

If you have any questions or concerns about the research, please contact the researcher Helen. You can speak to Helen in person (at the hospital) or via email or telephone.

Helen Skinner
Alzheimer Scotland Dementia Nurse Consultant
[redacted]
Email: [redacted]
Telephone: [redacted]

Complaints

If you have any questions or concerns that Helen cannot answer, or if you want to make a formal complaint, you can do so through NHS Fife Patient Relations Department or by contacting Helen's research supervisors Prof Geoff Dickens or Mrs Suzanne Croy. Please see contact details below:

Patient Relations Department
[redacted]
Email: [redacted]
Telephone: [redacted]

Research supervisors:
Prof Geoff Dickens:
Phone: [redacted]
Email: [redacted]

Suzanne Croy:
Phone: [redacted]
Email: [redacted]

Independent advice regarding research

The Research Sub-Group of the Scottish Dementia Working Group has produced guidelines regarding research participation.
Please see 'Core principles for involving people with dementia in research'.
http://dementiavoices.org.uk/wp-content/uploads/2014/06/involving-people-with-dementia-in-research1.pdf

In addition, further advice can be sought directly from the following:

Alzheimer Scotland
Telephone: 0808 808 3000
Open 24 hours a day, 7 days a week

Alzheimer's Research UK
Telephone: 0300 111 5111
Open Monday – Friday, 9am-5pm

INVOLVE (National Institute for Health Research)
Telephone: 023 8065 1088

**Appendix 7: Consent form for nearest relative/ guardian/ welfare power of attorney of the person with dementia**

Version 2 – 24 September 2016

Participant Identification Number:

## CONSENT FORM FOR NEAREST RELATIVE/GUARDIAN/WELFARE ATTORNEY FOR PERSON WITH DEMENTIA

## Individualised music for agitation in people with dementia

**Name of the researcher:**
Helen Skinner
[redacted]
Telephone: [redacted]
Email: [redacted]

| | | Please initial all boxes |
|---|---|---|
| 1. | I confirm that I have read and understand the information sheet dated 24th September 2016 (Version 2) for the above study.<br>I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction. | |
| 2. | I understand that [insert name] participation is voluntary and that I am free to withdraw [insert name] at any time without giving any reason, without [insert name] medical care or legal rights being affected. | |
| 3. | If I withdraw [insert name] at any point, I give the researcher permission to use the study information up to that point. | |

| | | |
|---|---|---|
| 4. | I give the researcher permission to use my contact details to contact me about this study only. | |
| 5. | I give permission to the clinical team of [insert name] to pass on anonymous relevant clinical information to the researcher (e.g. about [insert name] dementia diagnosis). | |
| 6. | I understand that relevant sections of [insert name] medical notes and data collected during the study may be looked at by individuals from regulatory authorities or the NHS Board, where it is relevant to [insert name] taking part in this research.<br>I give permission for these individuals to access [insert name] records. | |
| 7. | I understand that [insert name] may be video-recorded during the music sessions only. I understand that all these recordings will be stored securely and their face will be pixelated and their name will not be used to identify them. | |
| 8. | I give permission to use [insert name] video recordings for educational purposes to teach healthcare staff (e.g. in face to face lectures and conferences. | |
| 9. | I understand that [insert name] views of individualised music listening in hospitals will be audio-recorded, should they be given this intervention. I understand that all the study information will be stored anonymously and securely. I give permission for their views to be recorded and written down, and for direct quotes to be used anonymously. | |
| 10. | I agree to [insert name] GP being informed of their participation in the study. | |
| 11. | I agree to [insert name] taking part in the above study. | |

I confirm that I am the nearest relative for _____ and that no other nearest relative or welfare power of attorney or guardian exists.

Relationship to patient _____

I confirm that I am the welfare power of attorney or guardian for _____

| _____ | _____ | _____ |
|---|---|---|
| Name of participant | Date | Signature |
| _____ | _____ | _____ |
| Name of person taking consent | Date | Signature |

When completed: 1 copy for the participant, 1 copy for the researcher site file, 1 copy (original) to be kept in medical notes.

## Appendix 8: Invitation letter for healthcare professional

Version 2 – 24 September 2016

# LETTER OF INVITATION FOR HEALTHCARE PROFESSIONALS

Date:

Dear Sir / Madam,

I would like to invite you to take part in the following study:

**Individualised music for agitation in people with dementia**

I am a Dementia Nurse Consultant at NHS Fife and studying for a Masters by Research at Abertay University investigating the effect of listening to individualised musical preferences for patients with dementia in mental health care settings.

At the moment, very little is known about the use of individualised music listening in hospital settings.

As you will know, I have been undertaking the above study in your ward with people with dementia experiencing agitation. I now want to move on to explore the thoughts and feelings towards the use of individualised music for people with dementia from the personal viewpoint of healthcare professionals based in mental health settings.

I would therefore like to invite you to take part in the next part of the study, exploring the experience of healthcare professionals.

You have been identified as a potential participant as you are employed by NHS Fife, within the mental health wards at Stratheden Hospital, and are responsible for providing care for people diagnosed with dementia. You may also have been involved in administering individualised music to patients with moderate to severe dementia on your ward as part of the research study

Before you decide if you wish to take part or not, you need to understand why research is needed in this area and what will be required from you. Therefore, we have attached an information sheet for you to read.

Please take the time to read the following information carefully, and discuss it with others if you wish.

If you decide you are willing to participate or have any further questions about the study or what you would need to do, please contact me. The contact details are provided on the information sheet.

Thank you for your consideration and time.

Kind regards,

Helen Skinner
Study Lead
NHS Fife

## Appendix 9: Participant information sheet for healthcare professional

Version 2 – 24 September 2016

**PARTICIPANT INFORMATION SHEET FOR HEALTHCARE PROFESSIONAL**

**Individualised music for agitation in people with dementia**

***Individualised music*** *is music that has been integrated into the individual's life and is based on personal preferences.*

Part 1 of this information sheet tells you about the purpose of this study.

Part 2 gives you more detailed information about the conduct of the study.

**Part 1**

What is the purpose of the study?

At present listening to individualised music is encouraged and recommended for people with dementia. However, these recommendations are based on studies where music is delivered either in residential care or in the community. There are currently no studies looking at individualised music listening for people with dementia in mental health settings and very little research regarding the use of individualised music in the latter stages of the disease. In addition, there are no studies to date looking at the thoughts and feelings towards the use of individualised music for persons with dementia from the personal viewpoint of healthcare professionals based in mental health settings. We feel this is a very important group of people that are currently being overlooked and, potentially the group that may be responsible for delivering this programme in the future. For this reason, we want to hear your opinions.

Why have I been invited?

You have been invited to take part in the study because you are part of the existing healthcare team responsible for the care of persons diagnosed with dementia and admitted to Stratheden Hospital, NHS Fife. You may also have been involved in administering individualised music to patients with moderate to severe dementia on your ward as part of the research study exploring the

effect of individualised music on agitation; therefore we are keen to learn about your experience and thoughts on this.

Do I have to take part?
NO, it is up to you to decide whether you take part in the research or not. If you decide to take part we will ask you to sign a consent form prior to taking part in the study. You are free to withdraw from this study at any time, without giving a reason.
You decision to participate in this study will not have an effect on your employment in the hospital.

What will happen if I take part in the research?
The researcher, Helen Skinner, will meet with you to discuss the study. Helen can answer any questions you have about the study and discuss any concerns you might have.
If you are happy to take part, Helen will ask for written consent prior to your participation.
You will be invited to take part in a focus group or one to one interview. We will discuss topics such as:

- Your experience of facilitating and aiding the implementation of the individualised music intervention
- Your perception of the outcomes of this intervention
- Your recommendations for using individualised music for persons with dementia

What will I have to do?
You will be asked to provide your own opinions of individualised music in dementia care. In doing this we will ask you to respect the confidentiality of other participants (e.g. other participating healthcare professionals and participating patients and informal carers) and do not discuss individuals' thoughts outside of the focus group/interview.
The focus group or interview will be recorded using a digital voice recorder. The audio recording of the conversations will then be used to write down all the comments made and will then be analysed by the researcher.
The focus group or one to one interview will not last any longer than 45 minutes.

During the study
Helen will be available to discuss any part of the study with you and answer any questions that you may have.
You are free to withdraw from the study at any point and you do not have to provide a reason for doing so.

Will you receive payment for taking part in the study?
No. You will not be required to participate (attend the hospital) out-with your normal working hours, therefore we do not expect you to incur any additional travel expenses.

What are the possible disadvantages and risks of taking part?
As your involvement includes participating in a focus group or interview we believe you will not be put in any situation that will lead to uncomfortable or adverse events. Nonetheless, conversation regarding your experiences caring for people with dementia can often be an emotional experience. If you appear upset or distressed at any point, the researcher will pause proceedings to check that you wish to continue participating in the research and offer you the opportunity to take a break from the session should you wish to do so.
You are free to refrain from discussing anything you do not wish to disclose and free to withdraw at any point of the study, without having to provide a reason for doing so.
The focus group/interview may contain sensitive questions/discussion regarding your attitudes and approach to people with dementia at work. You will be reminded that you do not have to answer any questions you do not wish to do so.
If you do experience any emotional distress or are upset owing to participation in the research study, please alert Helen as soon as possible and inform the Senior Charge Nurse (on duty). Please see 'Part 2: What if there is a problem?'

What are the possible benefits of taking part?
There may be no direct benefit to you from participating in this research but the information you provide will help us become more informed about the use of individualised music in the care of people with dementia in mental health settings that may have benefits for individuals with dementia and other healthcare professionals in the future.

What is there is a problem?
Any complaint about the way you have been treated during the study, or any harm you feel you may have suffered from taking part will be fully addressed in Part 2 of this information sheet. If you have any concerns please contact the researcher (contact details at the end of the information sheet).

Will my taking part in the study be kept confidential?
Yes. Ethical and legal practice will be followed at all times and al information will be handled in confidence, as explained in Part 2. Any direct quotes used will be completely anonymous.

What should I do if I am interested in taking part?
Please feel free to discuss the study with your relatives, friends or other healthcare professionals.
If you would like to take part please contact Helen who will arrange to meet with you at a suitable date and time to discuss the study further. If you are happy to take part, written permission (consent) for you to participate in the study will be obtained.
If you are thinking about taking part, please read PART 2.

**Part 2**

What if there is a problem?

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to the researcher's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal NHS complaints mechanisms will be available to you (see contact details below).

Will my taking part in this study be kept confidential?

Yes. Ethical and legal practice will be followed at all times and all information will be handled in confidence. Confidentiality will be maintained by:

- No name will be used when using any of the data gained from the focus groups or interviews.
- All personal information and information from the recordings and transcripts will be saved on a password protected computer. Once the data is transcribed it will be deleted from all recording devices.
- Only the researcher, Helen Skinner and her research supervisors (see details below) will have direct access to this information.
- According to regulations, all data will be retained for five years and will then be disposed of carefully.

What will happen to the results of the study?

The results of the study will be a Masters by Research dissertation and will be published in scientific journals, and dementia charity magazines. We will also present our findings at conferences. The results will also help to inform the use of individualised music in people with dementia in mental health settings, and feed in to the work of the charity Playlist for Life©. Direct quotes may be used in these publications, however your name will not be used and you will not be identifiable in any published results.

Will I be informed about the results of the study?

Helen will send you a summary of the study findings should you wish to find out the results.

Who is organising and funding this research?

NHS Fife

UNIVERSITY of ABERTAY DUNDEE

Helen Skinner is carrying out the research as part of her work for a Masters by Research qualification at Abertay University, Dundee.
The project is funded by the university and supervised by Professor Geoff Dickens and Mrs Suzanne Croy.
Helen's role is a nurse and researcher.

Who has reviewed the study?
All research in the NHS is looked at by an independent group of people called a Research Ethics Committee, to protect your interests. A favourable ethical opinion has been obtained from NHS Scotland A REC. NHS management approval has also been obtained.
This study has also been approved by Abertay University Ethics Committee.

**Thank you for reading this information and for thinking about taking part in this study.**
**For any further questions please contact Helen Skinner.**

Contact details
If you have any questions or concerns about the research, please contact the researcher Helen. You can speak to Helen in person (at the hospital) or via email or telephone.
Helen Skinner
[redacted]
Email: [redacted]
Telephone: [redacted]

Complaints
If you have any questions or concerns that Helen cannot answer, or if you want to make a formal complaint, you can do so through NHS Fife Patient Relations Department or by contacting Helen's research supervisors Prof Geoff Dickens or Mrs Suzanne Croy. Please see contact details below:
Patient Relations Department
Fife NHS Board
[redacted]
Email: [redacted]

Research supervisors:
Prof Geoff Dickens:
Phone: 01382 [redacted]
Email: [redacted]

Suzanne Croy:
Phone: 01382 [redacted]
Email: [redacted]

Independent advice regarding research

The Research Sub-Group of the Scottish Dementia Working Group has produced guidelines regarding research participation.
Please see 'Core principles for involving people with dementia in research'.
http://dementiavoices.org.uk/wp-content/uploads/2014/06/involving-people-with-dementia-in-research1.pdf

In addition, further advice can be sought directly from the following:
Alzheimer Scotland
Telephone: 0808 808 3000
Open 24 hours a day, 7 days a week
Alzheimer's Research UK
Telephone: 0300 111 5111
Open Monday – Friday, 9am-5pm

INVOLVE (National Institute for Health Research) Telephone: 023 8065 1088

**Appendix 10: Consent form for healthcare professional**

Version 2 – 24 September 2016

Participant Identification Number:

## CONSENT FORM FOR HEALTHCARE PROFESSIONALS

# Individualised music for agitation in people with dementia

**Name of the researcher:**
Helen Skinner
Alzheimer Scotland Dementia Nurse Consultant
[redacted]
Telephone: [redacted]
Email: [redacted]

| | | Please initial all boxes |
|---|---|---|
| 1. | I confirm that I have read and understand the information sheet dated 24th September 2016 (Version 2) for the above study.<br>I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction. | |
| 2. | I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without legal rights being affected. | |
| 3. | I understand that the topics discussed during the interviews/focus groups will be recorded using a digital voice recorder and that the audio recordings will be transcribed, with the possibility of verbatim quotations being used. I understand that all these recordings will be stored securely and will be anonymised. I give permission for my thoughts and opinions to be recorded and transcribed, and verbatim quotations to be anonymously used. | |

| | | |
|---|---|---|
| 4. | I understand that some of the questions may address sensitive issues regarding my attitudes and approach to caring for people with dementia at work. I understand I do not have to answer any questions I do not wish to. | |
| 5. | I agree to my taking part in the above study. | |

| _____ | _____ | _____ |
|---|---|---|
| Name of participant | Date | Signature |

| _____ | _____ | _____ |
|---|---|---|
| Name of person taking consent | Date | Signature |

When completed: 1 copy for the participant, 1 copy for the researcher site file.

## Appendix 11: Invitation letter for family carer

Version 2 – 24 September 2016

# LETTER OF INVITATION FOR A CARER

Date:

Dear Sir / Madam,

I would like to invite you to take part in the following study:

**Individualised music for agitation in people with dementia**

I am a Dementia Nurse Consultant at NHS Fife and studying for a Masters by Research at Abertay University investigating the effect of listening to individualised musical preferences for patients with dementia in mental health care settings.

At the moment, very little is known about the use of individualised music listening in hospital settings.

I would therefore like to invite you to take part in the study, to help us to investigate the effect of listening to individualised music.

You have been identified as a potential participant as you currently care for an individual diagnosed with dementia who has been admitted to a mental health ward at Stratheden Hospital (NHS Fife).

Before you decide if you wish to take part or not, you need to understand why research is needed in this area and what will be required from you. Therefore, we have attached an information sheet for you to read.

Please take the time to read the following information carefully, and discuss it with others if you wish.

If you decide you are willing to participate or have any further questions about the study or what you would need to do, please contact me. The contact details are provided on the information sheet.

Thank you for your consideration and time.

Kind regards,

Helen Skinner
Study Lead
NHS Fife

## Appendix 12: Participant information sheet for family carer

Version 2 – 24 September 2016

**PARTICIPANT INFORMATION SHEET**
**FOR CARER**

**Individualised music for agitation in people with dementia**

***Individualised music*** *is music that has been integrated into the individual's life and is based on personal preferences.*

Part 1 of this information sheet tells you about the purpose of this study.

Part 2 gives you more detailed information about the conduct of the study.

**Part 1**

What is the purpose of the study?
At present listening to individualised music is encouraged and recommended for people with dementia. However, these recommendations are based on studies where music is delivered either in residential care or in the community. There are currently no studies looking at individualised music listening for people with dementia in mental health settings and very little research regarding the use of individualised music in the latter stages of the disease. In addition, there are no studies to date looking at the thoughts and feelings towards the use of individualised music for persons with dementia, from the personal viewpoint of the carer. We feel this is a very important group of people that are currently being overlooked, which is why we want to hear your opinions and have your input into the development of an individualised music programme for people with dementia.

Why have I been invited?
You have been invited to take part in the study because you are a carer for someone who has dementia and has been admitted to one of the mental health wards at Stratheden Hospital, NHS Fife.

Do I have to take part?
NO, it is entirely up to you to decide whether you take part in the research or not. If you decide to take part we will ask you to sign a consent form prior to taking part in the study. You are free to withdraw from this study at any time, without giving a reason.
Irrespective of your participation in the research study, usual care will be provided for the individual you care for.

Who is doing the research?
Helen Skinner is the Alzheimer Scotland Dementia Nurse Consultant for NHS Fife and is conducting this study in fulfilment of her Masters in Research dissertation.

What will happen if I take part in the research?
The researcher, Helen, will meet with you to discuss the study. Helen can answer any more questions you have about the study and discuss any concerns you might have.
If you are happy to take part, Helen will ask for written consent prior to your participation.

What next?
You will take part on two occasions.
Firstly, in a conversation with the person you care for, at the beginning of the project. This conversation will be led by Helen. We will discuss topics such as their musical background and experiences, current use of and attitudes to music, and identify familiar music preferences for the person you care for that are considered to be personally meaningful to them and the reasons for these choices. This will allow us to build a playlist of individualised music.
The second conversation, again with Helen, will take place at the end of the study, either with or without the person you care for. This is to discuss topics such as your experience of the individualised music programme, your perceptions of the outcomes of the music intervention, and your recommendations for an individualised music programme for people with dementia. This conversation will not last any longer than 45 minutes.
These conversations will be recorded using a digital voice recorder. The audio recording of the conversations will then be used to write down all the comments made and will then be analysed by Helen.

What else will happen?
Between the first and second conversation, the person you care for will be involved in the 'experiment' part of the study. This will comprise of:

- 7 days of no individualised music and a daily and weekly measurement of agitation
- 7 days of individualised music for 30 minutes per day and a daily and weekly measurement of agitation
- 7 days of no individualised music and a daily and weekly measurement of agitation
- 7 days of individualised music for 30 minutes per day and a daily and weekly measurement of agitation

The alternation between no music and music will help us decide if the music makes any difference to the person you care for. After the last 7 days of music the experiment part of the study will finish, and the person you care for will be able to continue to listen to the music if desired.
The music sessions will be delivered by the healthcare team who will monitor the individual's response to these. You do not have to be present during these sessions.

What will I have to do?
All you have to do is come to the hospital at a suitable date and time to discuss the development of an individualised music programme from your perspective and to support the person you care for in a conversation regarding his or her musical background, experience and preferences, as well as his or her views of the programme.

During the study
Helen will be available to discuss any part of the study with you and answer any questions that you may have.
You are free to withdraw from the study at any point and you do not have to provide a reason for doing so.

Will you receive payment for taking part in the study?
Any additional travel expenses will be reimbursed. If you wish, we are happy to organise a taxi for you and we will pay for this.

What are the possible disadvantages and risks of taking part?
As your involvement includes two interviews, with Helen who is a trained nurse, we believe that you will not be put in any situation that will lead to uncomfortable or adverse events.
On occasion, conversation regarding one's musical background and preferences can often lead to discussion of life history which can often by an emotional experience for both you and the person you care for.
If you, or the person you care for, appear upset or distressed at any point, the researcher will pause proceedings to check that you and/or the individual you care for wish to continue participating in the research. She will offer you the opportunity to take a break from the session should you wish to do so. Both you and the individual you care for are free to refrain from discussing anything you do not wish to disclose and free to withdraw at any point of the study, without having to provide a reason for doing so.
If you do experience any emotional distress or are upset owing to participation in the research study, please alert Helen as soon as possible and inform the Senior Charge Nurse (on duty). Please see 'Part 2: What if there is a problem?'

What are the possible benefits of taking part?
There may be no direct benefit to you from participating in this research but the information you provide will help us become more informed about the use of individualised music in the care of people with dementia in mental health settings, that may have benefits for individuals with dementia – like the person you care for – and their carers in the future.

What is there is a problem?
Any complaint about the way you have been treated during the study, or any harm you feel you may have suffered from taking part will be fully addressed in Part 2 of this information sheet. If you have any concerns please contact any of the researchers (contact details at the end of the information sheet).

Will my taking part in the study be kept confidential?
Yes. Ethical and legal practice will be followed at all times and al information will be handled in confidence, as explained in Part 2. Any direct quotes used will be completely anonymous.

What should I do if I am interested in taking part?
Please feel free to discuss the study with your relatives, friends or other healthcare professionals.
If you would like to take part please contact Helen who will arrange to meet with you at a suitable date and time to discuss the study further. If you are happy to take part, written permission (consent) for you to participate in the study will be obtained.
If you are thinking about taking part, please read PART 2.

**Part 2**

What if there is a problem?
If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to the researcher's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal NHS complaints mechanisms will be available to you (see contact details below).

Will my taking part in this study be kept confidential?
Yes. Ethical and legal practice will be followed at all times and all information will be handled in confidence. Confidentiality will be maintained by:

- No name will be used when using any of the data gained from the interviews.
- All personal information and information from the recordings and transcripts will be saved on a password protected computer. Once the data is transcribed it will be deleted from all recording devices.
- Only the researcher, Helen Skinner, and her research supervisors (see details below) will have direct access to this information.
- According to regulations, all data will be retained for five years and will then be disposed of carefully.

What will happen to the results of the study?
The results of the study will be a Masters by Research dissertation and will be published in scientific journals, and dementia charity magazines. We will also present our findings at conferences. Direct quotes may be used in these publications, however your name will not be used and you will not be identifiable in any published results. The results will also help to inform the use of individualised music for people with dementia in mental health settings, and feed in to the work of the charity Playlist for Life©.

Will I be informed about the results of the study?
Helen will send you a summary of the study findings should you wish to find out the results.

Who is organising and funding this research?

Helen Skinner is carrying out the research as part of her work for a Masters by Research qualification at Abertay University, Dundee.
The project is funded by the university and supervised by Professor Geoff Dickens and Mrs Suzanne Croy.
The music listening equipment has been provided by 'Healthy Harmonies' NHS Fife Staff Choir.
Helen's role is a nurse and researcher.

Who has reviewed the study?
All research in the NHS is looked at by an independent group of people called a Research Ethics Committee, to protect your interests. A favourable ethical opinion has been obtained from NHS Scotland A REC. NHS management approval has also been obtained.
This study has also been approved by Abertay University Ethics Committee.

**Thank you for reading this information and for thinking about taking part in this study.**
**For any further questions please contact Helen Skinner.**

Contact details
If you have any questions or concerns about the research, please contact the researcher Helen. You can speak to Helen in person (at the hospital) or via email or telephone.
Helen Skinner
Alzheimer Scotland Dementia Nurse Consultant
[redacted]
Email: [redacted]
Telephone: [redacted]

Complaints

If you have any questions or concerns that Helen cannot answer, or if you want to make a formal complaint, you can do so through NHS Fife Patient Relations Department or by contacting Helen's research supervisors Prof Geoff Dickens or Mrs Suzanne Croy. Please see contact details below:

Patient Relations Department
Fife NHS Board
[redacted]
Email: [redacted]

Research supervisors:
Prof Geoff Dickens:
Phone: 01382 [redacted]
Email: [redacted]

Suzanne Croy:
Phone: 01382 [redacted]
Email: [redacted]

Independent advice regarding research

The Research Sub-Group of the Scottish Dementia Working Group has produced guidelines regarding research participation.
Please see 'Core principles for involving people with dementia in research'.
http://dementiavoices.org.uk/wp-content/uploads/2014/06/involving-people-with-dementia-in-research1.pdf

In addition, further advice can be sought directly from the following:
Alzheimer Scotland
Telephone: 0808 808 3000
Open 24 hours a day, 7 days a week
Alzheimer's Research UK
Telephone: 0300 111 5111
Open Monday – Friday, 9am-5pm

INVOLVE (National Institute for Health Research)
Telephone: 023 8065 1088

**Appendix 13: Consent form for family carer**

Version 2 – 24 September 2017

Participant Identification Number:

## CONSENT FORM FOR CARER

# Individualised music for agitation in people with dementia

**Name of the researcher:**
Helen Skinner
Alzheimer Scotland Dementia Nurse Consultant
[redacted]
Telephone: [redacted]
Email: [redacted]

| | | Please initial all boxes |
|---|---|---|
| 1. | I confirm that I have read and understand the information sheet dated 24th September 2016 (Version 2) for the above study.<br>I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction. | |
| 2. | I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without legal rights being affected. | |
| 3. | I understand that the topics discussed during the interviews will be recorded using a digital voice recorder and that the audio recordings will be transcribed, with the possibility of verbatim quotations being used. I understand that all these recordings will be stored securely and will be anonymised. I give permission for my thoughts and opinions to be recorded and transcribed, and verbatim quotations to be anonymously used. | |

| | | |
|---|---|---|
| 4. | I understand that some of the questions may address sensitive issues regarding my attitudes and approach to caring for people with dementia. I understand I do not have to answer any questions I do not wish to. | |
| 5. | I agree to my taking part in the above study. | |

| _____ | _____ | _____ |
|---|---|---|
| Name of participant | Date | Signature |

| _____ | _____ | _____ |
|---|---|---|
| Name of person taking consent | Date | Signature |

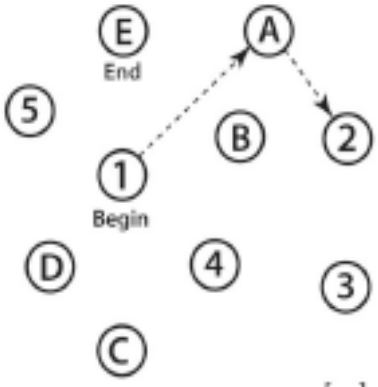
When completed: 1 copy for the participant, 1 copy for the researcher site file.

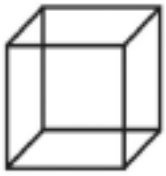
## Appendix 14: Montreal Cognitive Assessment

MONTREAL COGNITIVE ASSESSMENT (MOCA)
Version 7.1 Original Version

NAME :
Education : Date of birth :
Sex : DATE :

**VISUOSPATIAL / EXECUTIVE**



Copy cube

[ ] [ ]

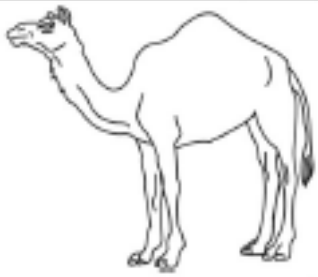
Draw CLOCK (Ten past eleven) [ 3 points ]

[ ] Contour [ ] Numbers [ ] Hands

POINTS

__/5

**NAMING**



[ ] [ ] [ ]

__/3

**MEMORY** Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.

| | FACE | VELVET | CHURCH | DAISY | RED |
|---|---|---|---|---|---|
| 1st trial | | | | | |
| 2nd trial | | | | | |

No points

**ATTENTION** Read list of digits (1 digit/ sec.).

Subject has to repeat them in the forward order [ ] 2 1 8 5 4

Subject has to repeat them in the backward order [ ] 7 4 2

__/2

Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors

[ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B

__/1

Serial 7 subtraction starting at 100 [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65

4 or 5 correct subtractions: **3 pts**, 2 or 3 correct: **2 pts**, 1 correct: **1 pt**, 0 correct: **0 pt**

__/3

**LANGUAGE** Repeat : I only know that John is the one to help today. [ ]

The cat always hid under the couch when dogs were in the room. [ ]

__/2

Fluency / Name maximum number of words in one minute that begin with the letter F [ ] _____ (N ≥ 11 words)

__/1

**ABSTRACTION** Similarity between e.g. banana - orange = fruit [ ] train – bicycle [ ] watch - ruler

__/2

**DELAYED RECALL**

| | Has to recall words WITH NO CUE | FACE | VELVET | CHURCH | DAISY | RED | Points for UNCUED recall only |
|---|---|---|---|---|---|---|---|
| | | [ ] | [ ] | [ ] | [ ] | [ ] | |
| **Optional** | Category cue | | | | | | |
| | Multiple choice cue | | | | | | |

__/5

**ORIENTATION** [ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City

__/6

© Z.Nasreddine MD www.mocatest.org Normal ≥ 26 / 30

TOTAL __/30

Add 1 point if ≤ 12 yr edu

Administered by: _____

## Appendix 15: Participant Background Questionnaire

Version 1 – 28 June 2016

**Individualised music for agitation in people with dementia**

**Participant Background Questionnaire**

Completed by the CI via consultation with the Consultant in Old Age Psychiatry

**Participant ID:**
**Date:**
**Time:**

Age:
Sex:
Educational Attainment:
Ethnic Origin:
Religion:
Marital Status:
Living Arrangements:

Dementia Subtype:
MoCA Score:
Severity of Cognitive Decline:
Date of Diagnosis (if available):

Current treatment
Medical:
Non-medical:

Date of Admission:
Reason for Admission:
Expected duration of stay:

Researcher notes:

## Appendix 16: Agitated Behaviour Scale

**AGITATED BEHAVIOUR SCALE**

| | | | |
|---|---|---|---|
| **Patient Name** | | **Period of observation** | |
| | | **Date:** | |
| **Observation environment** | | **Time from:** | **am/pm** |
| **Rater: (staff name)** | | **Time to:** | **am/pm** |
| | | | |
| **With music** ❒ | **Without music** ❒ | **(*Please tick)*** | |

At the end of the observation period indicate whether the behaviour described in each item was present and, if so, to what degree: slight, moderate or extreme.

Use the following numerical values and criteria for your ratings:
**1** = absent: the behaviour was not present

**2** = present to a slight degree: the behaviour is present but does not prevent the conduct of other, contextually appropriate behaviour (the individual may redirect spontaneously, or the continuation of the agitated behaviour does not disrupt appropriate behaviour)

**3** = present to a moderate degree: the individual needs to be redirected from an agitated to an appropriate behaviour, but benefits from such cueing

**4** = present to an extreme degree: the individual is not able to engage in appropriate behaviour due to the interference of the agitated behaviour, even when external cueing or redirection is provided

DO NOT LEAVE BLANKS

| | | |
|---|---|---|
| 1 | Short attention span, easy distractibility, inability to concentrate | |
| 2 | Impulsive, inpatient, low tolerance for pain or frustration | |
| 3 | Uncooperative, resistant to care, demanding | |
| 4 | Violent and or threatening violence toward people or property | |
| 5 | Explosive and / or unpredictable anger | |
| 6 | Rocking, rubbing, moaning or other self stimulating behaviour | |
| 7 | Pulling at tubes, restraints etc | |
| 8 | Wandering from treatment areas | |
| 9 | Restlessness, pacing , excessive movement | |
| 10 | Repetitive behaviours, motor and / or verbal | |
| 11 | Rapid, loud or excessive talking | |
| 12 | Sudden changes of mood | |
| 13 | Easily irritated or excessive crying and / or laughter | |
| 14 | Self abusiveness, physical and / or verbal | |
| **TOTAL SCORE** | | |

## Appendix 17: Cohen Mansfield Agitation Inventory

**Patient:**

**Period of Observation**

**From:_____/_____/_____ to _____/_____/_____**

Please read each of the 29 agitated behaviours, and circle how often (from 1 to 7) each was manifested by the resident during the last 7 days.

| | Never<br>1 | Less than once a week<br>2 | Once or twice a week<br>3 | Several times a week<br>4 | Once or twice a day<br>5 | Several times a day<br>6 | Several times an hour<br>7 | Would occur if not prevented<br>8 |
|---|---|---|---|---|---|---|---|---|
| 1. Pace, aimless wandering | | | | | | | | |
| 2. Inappropriate dress or disrobing | | | | | | | | |
| 3. Spitting (including at meals) | | | | | | | | |
| 4. Cursing or verbal aggression | | | | | | | | |
| 5. Constant unwarranted request for attention or help | | | | | | | | |
| 6. Repetitive sentences of questions | | | | | | | | |
| 7. Hitting (including self) | | | | | | | | |

| | Never<br>1 | Less than once a week<br>2 | Once or twice a week<br>3 | Several times a week<br>4 | Once or twice a day<br>5 | Several times a day<br>6 | Several times an hour<br>7 | Would occur if not prevented<br>8 |
|---|---|---|---|---|---|---|---|---|
| 8. Kicking | | | | | | | | |
| 9. Grabbing onto people | | | | | | | | |
| 10. Pushing | | | | | | | | |
| 11. Throwing things | | | | | | | | |
| 12. Strange noises (weird laughter or crying) | | | | | | | | |
| 13. Screaming | | | | | | | | |
| 14. Biting | | | | | | | | |
| 15. Scratching | | | | | | | | |
| 16. Trying to get to different place eg out of room, building | | | | | | | | |
| 17. Intentional falling | | | | | | | | |
| 18. Complaining | | | | | | | | |
| 19. Negativism | | | | | | | | |

| | Never<br><br>1 | Less than once a week<br><br>2 | Once or twice a week<br>3 | Several times a week<br>4 | Once or twice a day<br><br>5 | Several times a day<br><br>6 | Several times an hour<br>7 | Would occur if not prevented<br>8 |
|---|---|---|---|---|---|---|---|---|
| 20. Eating/drinking inappropriate substances | | | | | | | | |
| 21. Hurt self or other (cigarette, hot water etc) | | | | | | | | |
| 22. Handling things inappropriately | | | | | | | | |
| 23. Hiding things | | | | | | | | |
| 24. Hoarding things | | | | | | | | |
| 25. Tearing thing or destroying things | | | | | | | | |
| 26. Performing repetitious mannerisms | | | | | | | | |
| 27. Making verbal sexual advances | | | | | | | | |
| 28. Making physical sexual advances | | | | | | | | |
| 29. General restlessness | | | | | | | | |

## Appendix 18: Medication Form

Version 1 – 28 June 2016

**Individualised music for agitation in people with dementia**

**PRN Medication Form**

Completed by healthcare professionals and CI

**Participant ID:**
**Date:**
**Time:**

| Day of study | PRN Medication administered? | Date and Time | Name, strength, form and dosage (Number/times per day/interval between dose) | Reason for administration | Music session administered? | Additional notes |
|---|---|---|---|---|---|---|
| **E.g. Day 1** | | | | | | |
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| **Day of study** | **PRN Medication administered?** | **Date and Time** | **Name, strength, form and dosage** (Number/times per day/interval between dose) | **Reason for administration** | **Music session administered?** | **Additional notes** |
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| **Day of study** | **PRN Medication administered?** | **Date and Time** | **Name, strength, form and dosage** (Number/times per day/interval between dose) | **Reason for administration** | **Music session administered?** | **Additional notes** |
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| **Day of study** | **PRN Medication administered?** | **Date and Time** | **Name, strength, form and dosage** (Number/times per day/interval between dose) | **Reason for administration** | **Music session administered?** | **Additional notes** |
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| Day of study | PRN Medication administered? | Date and Time | Name, strength, form and dosage (Number/times per day/interval between dose) | Reason for administration | Music session administered? | Additional notes |
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| Researcher notes: |
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## Appendix 19: Music Session Documentation

Version 1 – 28 June 2016

# Individualised music for agitation in people with dementia

**Music Session Documentation**

Completed by the Healthcare Professional

**Person with Dementia Participant ID:**
**Healthcare Professional Participant ID:**
**Date:**
**Time:**

**Session number:**

*Please use this space to record any additional information regarding the session to include, the patient's responsiveness to and, engagement in, the session, and other activities/events taking place before and during the session, and any non-verbal behaviours, verbal interactions/utterances throughout. Please also record any other information you feel is relevant to the research project.*

**Please rate the extent to which you feel the participant was engaged in the session?**

| Not at all engaged | | Somewhat engaged | | Very engaged |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

**Please rate the extent to which you feel the participant enjoyed the session?**

| Not at all enjoyable | | Somewhat enjoyable | | Very enjoyable |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

**Additional comments/observations**

## Appendix 20: Scenario for Agitated Behaviour Scale

Agitated Behaviour Scale: Scenario

Sally is a 15-year-old female who sustained a traumatic brain injury secondary to a moving vehicle accident three weeks ago. Following medical stabilization, she was admitted to the rehabilitation unit one week ago.

This evening, Sally is eating her dinner in the dining hall. She is generally able to feed herself independently, but requires occasional cueing to finish the meal because she becomes distracted by other patients in the room. She'll work on her meal for a short time, then go over to another table to talk to another patient. Without cueing, she would move from table to table, never resuming her meal. With cueing, she usually returns to her meal, but sometimes has a brief outburst of irritation before doing so. She is not violent, but does express anger briefly.

After dinner, Sally wants to participate in a simple card game with two other patients and a nurse. However, she is having trouble following the sequence of the game. She doesn't wait for her turn, even after several cues to do so. When she sees another player pick a card she needs, she immediately says she needs that card and tries to grab it. Cues are not successful in inhibiting this behavior. She tries to move her wheelchair away from the table during the game, and the nurse must physically hold her chair to prevent her from leaving the room. Verbal cues are not successful. The nurse must eventually leave the game with Sally so that she can move herself up and down the hall. It is not possible to keep her in one area continuously, so the nurse must supervise her constantly.

It is time to get ready for bed, and the nurse guides Sally into her room to change into her bedclothes. Sally is initially resistant to getting undressed, so the nurse lets her sit in her chair for a minute while she prepares the bed. When she returns, Sally is cooperative with changing her clothes and getting into bed.

Once in bed, Sally moves about excessively to the point that she is in danger of rolling off the bed. Some of the movement involves rubbing her ear against the pillow, while other movement appears to be random fidgeting. The bedrails and a bed belt are utilized to keep her in bed safely, however they do not significantly inhibit her movements. She frequently goes through extended periods of repeated a sequence of sitting up, then laying down, then pulling at the bed belt. Her movements result in slipping underneath the belt, requiring repositioning by the nurse supervising her. Redirection and cueing are not effective in inhibiting any of the behavior observed. The nurse must provide constant supervision with physical restraint, medicate, or allow Sally to get out of bed and move up and down the hall with constant supervision and intervention.

## Appendix 21: NHS Scotland: Scotland A Research Ethics Committee Ethical Approval

**Scotland A Research Ethics Committee**

Research Ethics Service
2nd Floor Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone: 0131 465 5680
www.hra.nhs.uk

NHS SCOTLAND

Scotland A REC
2nd Floor Waverley Gate
2 - 4 Waterloo Place
Edinburgh
EH1 3EG
Tel: 0131-465-5679

26 October 2016

[redacted]

Dear Mrs Skinner

| | |
|---|---|
| **Study title:** | **A pilot study to explore the effect of individualised music on agitation in patients with moderate to severe dementia in a specialist mental health hospital setting: a single case experimental reversal design study** |
| **REC reference:** | **16/SS/0140** |
| **IRAS project ID:** | **203846** |

Thank you for your letter of 17th October 2016, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Miss [redacted]

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

[redacted]

**Adults with Incapacity (Scotland) Act 2000**

I confirm that the Committee did approve this research project for the purposes of the Adults with Incapacity (Scotland) Act 2000. The Committee was satisfied that the requirements of section 51 of the Act would be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

**Conditions of the favourable opinion**

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).*
*Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.*

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of management permissions from host organisations*

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact [redacted] the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

**Ethical review of research sites**

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

The Committee has not yet completed any site-specific assessment (SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon as an SSA application(s) has been reviewed. In the meantime no study procedures should be initiated at non-NHS sites.

**Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

| *Document* | *Version* | *Date* |
|---|---|---|
| Covering letter on headed paper [Cover Letter] | 1 | 13 July 2016 |
| Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnity Cover Letter Abertay University] | 1 | 10 July 2016 |
| GP/consultant information sheets or letters [GP Letter] | 1 | 28 June 2016 |
| Interview schedules or topic guides for participants [Post experiment interview schedule with Healthcare Professional] | 1 | 28 June 2016 |
| Interview schedules or topic guides for participants [Post experiment interview schedule with carer] | 1 | 28 June 2016 |
| Interview schedules or topic guides for participants [Post experiment interview schedule with Healthcare Professional] | 2 | 24 September 2016 |
| Letters of invitation to participant [Letter of invitation to Person with Dementia with Capacity] | 1 | 28 June 2016 |
| Letters of invitation to participant [Letter of invitation to Healthcare Professional] | 1 | 28 June 2016 |
| Letters of invitation to participant [Letter of invitation to Carer] | 1 | 28 June 2016 |
| Letters of invitation to participant [Participant Invitation Letter for Carer for Person with Dementia without Capacity] | 1 | 28 June 2016 |
| Other [NHS Fife Capacity Documentation] | | 11 July 2016 |
| Other [Participant Background Questionnaire] | 1 | 28 June 2016 |
| Other [Montreal Cognitive Assessment (MoCA)] | | 11 July 2016 |
| Other [Agitated Behaviour Scale] | | 11 July 2016 |

| | | |
|---|---|---|
| Other [Cohen Mansfield Agitation Inventory (CMAI)] | | 11 July 2016 |
| Other [Background Music Questionnaire] | 1 | 28 June 2016 |
| Other [Music Selections Form] | 1 | 28 June 2016 |
| Other [PRN Medications Form] | 1 | 28 June 2016 |
| Other [Music Session Documentation] | 1 | 28 June 2016 |
| Other [Response letter to Provisional Opinion Letter] | 1 | 24 September 2016 |
| Other [Response letter to Further Information Letter] | 1 | 17 October 2016 |
| Participant consent form [Consent form Healthcare Professional] | 1 | 28 June 2016 |
| Participant consent form [Consent form for Carer] | 1 | 28 June 2016 |
| Participant consent form [Consent form for Carer of Person with Dementia without Capacity] | 2 | 24 September 2016 |
| Participant information sheet (PIS) [PIS for Carer for People with Dementia without Capacity] | 2 | 24 September 2016 |
| Participant information sheet (PIS) [PIS for Healthcare Professional] | 2 | 24 September 2016 |
| Participant information sheet (PIS) [PIS for Carer] | 2 | 24 September 2016 |
| REC Application Form [REC_Form_25072016] | | 25 July 2016 |
| Research protocol or project proposal [Research Protocol] | Version 8 | 17 October 2016 |
| Summary CV for Chief Investigator (CI) [Helen Skinner CV] | | 10 July 2016 |
| Summary CV for supervisor (student research) [CV Geoff Dickens] | 1 | 12 July 2016 |
| Summary, synopsis or diagram (flowchart) of protocol in non technical language [Protocol Summary] | 3 | 23 June 2016 |

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

**After ethical review**

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

NHS SCOTLAND

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

**User Feedback**

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

**HRA Training**

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

| 16/SS/0140 | Please quote this number on all correspondence |
|---|---|

With the Committee's best wishes for the success of this project.

Yours sincerely

[redacted]

Dr [redacted]
Chair

Email: [redacted]

Tel: [redacted]

*Enclosures:* "After ethical review – guidance for researchers" *[SL-AR2]*

*Copy to:* [redacted]

## Appendix 22 NHS Fife: Research and Development Department Permission

Medical Director

Hayfield House
Hayfield Road
KIRKCALDY
KY2 5AH

NHS Fife

[redacted]

17 November 2016

Our Ref [redacted]

Enquiries to
E-mail
Telephone [redacted]

Website www.nhsfife.org

Dear Mrs Skinner

**Project Title: A pilot study to explore the effect of individualised music on agitation in patients with moderate to severe dementia in a specialist mental health hospital setting: a single case experimental reversal design study**

Thank you for your application to carry out the above project. Your project documentation (detailed below) has been reviewed for resource and financial implications for NHS Fife and I am happy to inform you that NHS permission for the above research has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed were:

| Document | Version | Date |
|---|---|---|
| Documents referred to within REC letters | | |
| Protocol | 8 | 17 October 2016 |
| REC provisional favourable opinion letters | | 2 September 2016<br>13 October 2016 |
| REC final favourable opinion letter | | 26 October 2016 |
| IRAS SSI Form | 5.3.1 | 28 October 2016 |
| IRAS R&D Form | 5.3.1 | 11 November 2016 |
| University Ethics approval | | 16 November 2016 |

The terms of the approval state that you are the Principal Investigator authorised to undertake this study within NHS Fife, with assistance from Dr [redacted]

I note that the favourable ethical opinion applies to all NHS sites taking part in the study therefore no separate Site Specific Review is required in this case. The sponsors for this study are University of Abertay.

Details of our participation in studies will be included in annual returns we are expected to complete as part of our agreement with the Chief Scientist Office. Regular reports of the study require to be submitted. Your first report should be submitted to Dr [redacted] R&D Manager, R&D Department, [redacted] 12 months time and subsequently at yearly intervals until the work is completed. A Lay Summary will also be required upon completion of the project.

In addition, approval is granted subject to the following conditions:-

[1] NHS Fife was awarded the Carbon Trust Standard in February 2010 and is the first Scottish NHS Board to achieve this accolade.

NHS
Fife

All research activity must comply with the standards detailed in the Research Governance Framework for Health & Community Care (http://www.cso.scot.nhs.uk/publications/resgov/resgov.htm), health & safety regulations, data protection principles, other appropriate statutory legislation and in accordance with Good Clinical Practice (GCP).

Any amendments which may subsequently be made to the study should also be notified to [redacted] R&D Research Coordinator ([redacted], as well as the appropriate regulatory authorities. Notification should also be given of any new research team members post approval and/or any changes to the status of the project.

This organisation is required to monitor research to ensure compliance with the Research Governance Framework and other legal and regulatory requirements. This is achieved by random audit of research. You will be required to assist with and provide information in regard to monitoring and study outcomes (including providing recruitment figures to the R&D office as and when required).

As custodian of the information collated during this research project you are responsible for ensuring the security of all personal information collected in line with NHS Scotland IT Security Policies, until the destruction of this data. Permission is only granted for the activities for which a favourable opinion has been given by the REC (and which have been authorised by the MHRA where appropriate).

The research sponsor or the Chief Investigator or local Principal Investigator at a research site may take appropriate urgent safety measures in order to protect research participants against any immediate hazard to their health or safety. The R&D office [redacted] should be notified that such measures have been taken. The notification should also include the reasons why the measures were taken and the plan for further action. The R&D office should be notified within the same time frame of notifying the REC and any other regulatory bodies.

I would like to wish you every success with your study and look forward to receiving a summary of the findings for dissemination once the project is complete.

Yours sincerely

[redacted]

Cc. [redacted]

## Appendix 23 Abertay University: Ethics Committee Approval

**From:** [redacted] [redacted]>
**Date:** 16 November 2016 at 16:24:20 GMT
**To:** HELEN SKINNER <[redacted]>
**Cc:** Geoff Dickens <[redacted]>
**Subject: Decision on your Research Ethics Application**

Abertay University

Project Reference Number: SHS_R_2015-16_15
Project Title: **A pilot study to explore the effect of individualised music on agitation in patients with moderate to severe dementia in a specialist mental health setting: a single case experimental reversal design study**

Proposer: **Helen Skinner**
Matriculation number: [redacted]
Programme: MSc/MBA/MTech/LLM By Research (SHS), Stage 1
Supervisor: Geoff Dickens

The above Project has been granted **Full ethical approval**.

**Additional Conditions**:
*NB: you are not required to resubmit your application if you have been given Additional Conditions.*

**Standard Conditions**:
*These apply to all Research Ethics applications*

i The Proposer must remain in regular contact with the project supervisor.

ii The Supervisor must see a copy of all materials and procedures prior to commencing data collection.

iii If any substantive changes to the proposed project are made, a new ethical approval application must be submitted to the Committee. Completed forms should be resubmitted through the Research Ethics Blackboard course.

iv Any changes to the agreed procedures must be negotiated with the project supervisor.

Failure to comply with these conditions will result in ethical approval being revoked by the Ethics Committee.

**SHS Research Ethics Committee**
**16.11.16**

## Appendix 24: Thematic statements from all transcripts from family carers

### THEME 1: UNREALISED ENGAGEMENT

**Supporting thematic statements:**

*Carer 1 Well I'm sorry to say I've not actually been here when [participant 1] has had the music*

*Carer 1 I tend to visit in the afternoon, about this time usually, but the nurses were giving her the music in the evening, as this is when she usually becomes more unsettled. So I missed it sadly. I would've really liked to have been here.*

*Carer 1 I maybe should have come at a different time so I could see [participant 1] having the music*

*Carer 1 I think that they should have involved me more*

*Carer 1 I'm not saying it should only be done when I am here. I don't think that's right at all, but I would have liked to have been more involved in some way*

*Carer 1 I would have really liked to see it happen, and see the effect*

*Carer 2 And what seems to happen is that things are happening within her, triggering memories….. And it just leads to a certain amount of frustration*

*Carer 2: Well I'll have to admit that the music would have triggered memories. There was a resistance to it*

*Carer 2 In the past she would have enjoyed all that music. But at the moment she didn't enjoy it. As simple as that*

*Carer 2 [participant 2] is a roman catholic….was a very staunch member of the catholic church…err… her religion meant a lot to her. Christmas is a festival and in our family [participant 2] was pivotal in Christmas. Christmas was very important to her and her children. Now I think that the memory of that must have made her feel very unsettled……. She was no longer involved in the preparation for Christmas, whether it be decorations, making the cakes, or going to church and enjoying the Christmas service, erm… that seems to… well….it has been taken away from her. She may have been thinking 'why have I not been involved in this'?*

*Carer 2 Could I say it might have been looked on as just something you did, no interest really*

*Carer 2 You are dependent on staff being rigorous in what they do, you are not making things up, it's what you see. And you've got to…. It's like a lab test, you've got to sit down and do things in the correct order, otherwise you're not going to get results*

*Carer 2 You really need people who are committed, believe in what they are doing in a way that you would do, to make sure that the results that you get are credible results*

*Carer 3 I think it would have been difficult, and it's not a criticism in any way… but staff are busy, and sometimes I can't be there at certain times and it would be difficult to try and tally when we were both…when it was mutually agreeable for the staff and the ward and for me to be in here. But yes I would have liked to have been here*

*Carer 3 I just wonder whether the music is a reminder to him of past times… that he's realising what he can't do anymore. Would that explain why he only seems interested in the music for a short time? I think it might be bringing back memories for him that he would much rather not recall.*

*Carer 3 I just think at the moment its making him remember things which might be causing him to be upset rather than bringing him enjoyment? But I just think it's the stage he's at rather than anything else…*

*Carer 3 Those weeks was when his behaviour became really unsettled (weeks 3 and 4 of the study). He became more restless and was pacing a lot more round the ward, and was really angry at times. He hadn't been like that for a while. Eventually they realised he was in pain, from his back. They have just changed his pain killers and he is more settled.*

*Carer 5 I think [participant 5] might have responded better if I was there when he was having the music. I would love to chat to him about the music when he is listening to it and recall the memories*

*Carer 5 I'd really love to be there when he has it as it helps me remember happy times as well*

*Carer 5 I just wish I could have seen some of this*

*Carer 5 I just wonder whether [participant 5] is really too unwell for the music at this time. He was admitted to hospital because of his nerves….and I don't think they've really got them sorted yet. I just think that when he is a bit more settled he might get more benefit from the music. At the moment he is just so distracted by everything I really don't think he can focus on the music properly*

*Carer 5 And he really likes music, he gets a lot of enjoyment from the music, so I'm sure at the right time, in the right environment, it will probably be so much more beneficial. Right now, I just think he is too unwell*

*Carer 5 We asked that one of the male nurses didn't deliver care, or the music to [participant 5]. We had witnessed a few times how he was with [participant 5], not the music but other times…and we could see that he was making [participant 5] even more agitated. [participant 5] just didn't connect with him….just like we all do at times I suppose….so we asked for him not to give the music to [participant 5]. I know there was times when the male nurse had given the music to [participant 5] and he always told us when we visited that [participant 5] hadn't enjoyed the music. That doesn't surprise me because I don't think the male nurse really wanted to do the music with [participant 5], and he probably made [participant 5] agitated anyway, whether he was having the music or not*

*Carer 5 But I don't think he really believed in…or erm…saw any benefit in the music*

**THEME 1: THERAPEUTIC EFFECT**

*Carer 1 Delighted to help. And the family helped as well*

*Carer 1 It's let me feel like I'm doing something to help her too. Even though I've not had chance to be part of the music yet, just meeting with you, with [participant 1], to identify the music was enjoyable in itself. Reminiscing about old times and talking about fond memories was so enjoyable. It was a lovely afternoon we all had together identifying the songs. I've felt like I've done something to help [participant 1] and I'm just looking forward to listening to the music with [participant 1]*

*Carer 1 But the staff have told me how much [participant1 1] has enjoyed it. They've said she has loved the music*

*Carer 1 She said that [participant 1] really enjoyed it. She'd been singing along to the words, and moving about, trying to dance*

*Carer 1 Yes my daughter said it was lovely to see mum smiling again*

*Carer 1 Yes she said [participant 1] was definitely more relaxed, erm…more contented I think were the words she used*

*Carer 1: Definitely…. Dancing down the ward*
(in response to being asked if he felt the music has been helpful)

*Carer 1 And the effect on [participant 1] that I haven't seen, but the nurses have described as wonderful*

*Carer 1 I rang in after the first time she'd had the music they said its great… they said 'last night as soon as we put it on [participant 1] was singing and she was wanting other patients to sing along' and their description was that it was a delightful reaction.*

*Carer 1 They said she was much calmer, and less agitated, and interacting in a meaningful way with other patients*

*Carer 1 Our second eldest daughter was there in the evening and immediately when she got home she said wonderful. Erm, that it was great, that it was lovely. She had [daughter's name] up dancing*

*Carer 1 Without a doubt, from what everyone has told me, the nurses, my daughter, when [participant 1] has been listening to the music she has been calmer, more relaxed, engaged with the music, interacting with others. This has only been beneficial. What negatives are there to identify? It's just amazing that something so simple…such a simple idea…can have such a positive impact.*

*Carer 1 I know you nurses talk about person centred care….whatever you mean by that….but this is [participant 1] centred care, you've put what's important to [participant 1] at the centre, and that important to her and it's important to me*

*Carer 1 It might not work for everyone but it's better than pumping them full of drugs*
*Carer 1 I think it's a great idea. I think it should go on and on. Erm…I mean if every ward, not just people with [participant 1] complaint, but anybody, people in surgical wards, cancer wards, perhaps even pregnant ladies or ladies who've just had babies, people anywhere, I think it will work. But I realise it's a specific think for dementia. And I think it's great for that.*

*Carer 1 I think it will be great if she can take this with her to the care home*

*Carer 1 I will certainly be encouraging her to use it when she goes to the care home*

*Carer 1 I definitely want her to use it in the care home, and more often too*

*Carer 1 I know it was a trial here, and you were doing it under research conditions, but I'd like her to have it more frequently, whenever she wants to listen to it…..whenever she starts to become a little agitated I'd like the nurses to try it to see if it calms her down. So use it as much as we can.*
*Carer 2 And I would be quite happy for the music research to be continued*

*Carer 2 Oh definitely, definitely. I mean there's nothing… how would I put it….music involves probably the deepest senses. It can make you emotional, make you sad, happy etcetera etcetera and obviously it has made [participant 2] sad but surely we can link it to make [participant 2] happy? And if that's the case then music will be successful. And it's not that it's not successful, it's just not successful in one particular case. But there are many cases where it has been successful. It's worth trying, definitely worth trying*

*Carer 2 It's worth trying. If it fails, it fails, If it's successful, who cares, as long as some people benefit from it*

*Carer 2 I think it's a great thing to try*

*Carer 2 But what I'm thinking is that if she has improved on the other drug it might be interesting to see what her reaction is to the music now*

*Carer 3 It was quite easy….erm…it wasn't difficult at all, I thought of songs that we had listened to together, obviously there was lots, but particular ones from certain times that I can picture memories to.*

*Carer 3 [participant 3] does like listening to music and I think as long as he was relatively calm at the time he was listening to it, I think it would have benefited him*

*Carer 3 There is one thing that I remember…it wasn't when [participant 3] was having the music but it was when another patient had their music playing…[participant 3] was walking about the ward, pacing quite a lot, backwards and forwards around the ward….the other patient had their music playing through the little speaker and [participant 3] went over to her and became interested in her music….the lady was up on her feet…dancing a bit… and [participant 3] joined in with her…not exactly dancing but listening along to her music. It only lasted a couple of minutes but it was nice to see him do that.*

*Carer 3 If music can help someone become less agitated then that has to be better than pumping them full of drugs to dampen their behaviour. I would guess just about everybody has some music that triggers a memory. Surely this has to be better than medication. Music lightens the soul…brightens the day. I would much rather [participant 3] gets to listen to his favourite music than giving him prn medication – any day*

*Carer 3 I know it's had a mixed effect on [participant 3] but I really do think it's a great thing*

*Carer 3 Yes… oh yes…. Definitely. I really think that [participant 3] might get more from it as he becomes more advanced*

*Carer 5 I found it quite nostalgic going through our CDs and indentifying songs that were significant*

*Carer 5 They told me about a time that he had sung along to the music, and had asked questions about who was singing….I think it was Max Bygraves the nurse said….that was really nice for me to know as it shows that he can recall some memories. That nurse also told me that he seemed to enjoy the more upbeat songs, the faster ones. The nurses often said that if he managed to focus on the music he was often more relaxed afterwards.*

*Carer 5 If it means that the doctors don't need to give as many drugs to calm people down, to relax them more, then that has to be good. I would much rather [participant 5] listened to music to relax him than be given drugs.*

*Carer 5 I guess it might not work for everyone, but it's a great thing to try.*

*Carer 5 I really hope that the nurses continue using it with [participant 5] and I really hope I get chance to be involved with it more. I want to give it a fair chance to see if it is going to work.*

## Appendix 25: Thematic statements from all transcripts from healthcare professionals (HCP)

### THEME 1: THERAPEUTIC EFFECTS

*HCP1 You get to know your patients and you can see how they react to it, and how they enjoy it, erm…how different songs, when you do get to know them, how they feel about it, they love it, they start dancing, singing, and it really does make them happy*

*HCP1 It definitely does help to connect with the patient because you are involved in this process with them, so you sit for half and hour with them or however long they want, and you speak with them, you song with them, you dance and you speak to them, and you ask them questions about a certain song, say 'what does that remind you of', sometimes it's a wedding or things that you can go back and you can have a conversation with them, that does help with the therapeutic relationship which is really good.*

*HCP1 It gave us that opportunity to get that bond with the patient, get to know the patient, have a therapeutic relationship, and keep it as well. It was good in that way.*

*HCP1 I think it's great. I've not actually heard of it before, but I think it's great…so I've never really come across the music before which is really good. I think that you forget that music plays a really big part in people's lives. When you think about it really for these patients with dementia it's really great that you can, with their family or whoever knows them really well, can identify the music that they've enjoyed throughout their life and I think it's a great thing to do and to research. It's gone really well here. The majority of patients absolutely love it.*

*HCP1 I did it with [participant 1]. She absolutely…she loved it! I did it with her and other members of staff did it with her as well, with the speaker on she really enjoys it, she sings along.*

*HCP1 [participant 1] who erm…she isn't really agitated but she becomes quite fixated on cleaning, erm...she kind of roams the ward, explores the ward, so that's been a real distraction when she's sat down and listened to the music, it's got her more settled*

*HCP1 He likes to explore the ward as well, likes to go wandering, and actually at one time [participant 1] was listening to her music and he was exploring the ward and he actually stopped to sing and dance in the sitting room to [participant 1] music.*

*HCP1 She loves the music, I've noticed in the morning when we are getting her up after she's had a long lie, that she has the music playing in her room. Because actually the other day there, when we were getting her up and changed and she was getting really quite emotional about a song. But she*

*never wanted it off, but she was just so emotional but in a good way, it was happy tears, that's what she told us.*

*HCP1 I think the music is really effective…erm… and it is good for them because they communicate, they think, they interact and it's really good.*

*HCP1 With the experience I've had here, the majority of the patients absolutely love it.*

*HCP1 And actually the music that has been on for him [participant 4], he actually sings along to. He absolutely loves it and out of the blue at random he will just start singing one of the songs that he can remember from his playlist. Erm… and that's meaningful for him, he has that purpose, he obviously…his dementia is progressed that much that he might not know any of the songs that are playing at the moment that are current, so it means a lot to him. And because he has got that memory, he knows the words to the songs, which tells me a lot.*

*HCP1 His communication is quite reduced. He knows the words of the songs. He will sing them. Erm…which just tells you…just shows you. And he does, and he'll just do it out of the blue. There will be no music playing and he will start singing.*

*HCP1 Well before I couldn't tell what he was talking about, what he was saying, but now I can actually hear what he's saying, you can hear the songs. So I think for him [participant 4] that playlist has been really beneficial.*

*HCP1 With [participant 1] she is more settled, she sits there, and she smiles, she is more happy, and even when the music is off, she will giggle and she will laugh, and I suppose you can say she is more settled*

*HCP1 The music does help her to actually calm down a little bit and settle, as she does remember and she smiles and she erm… and I have definitely noticed that she is more settled. I'm not sure for a period of time but certainly for the shortly afterwards she will seem more calm.*

*HCP1 There has been benefit with it, from it, and that is evident through emotion, erm…tears, giggles, singing, dancing, patients are more settled. So you can see how the research is quite good, how the music is effective with the patients, and how we also as professionals can be involved in that, and get that therapeutic relationship and going back to the family, involving the family is so important if they are willing to be part of it.*

*HCP1 So obviously as individuals, as human beings, to remember what their life, their experience, what they've been through…and to do that through music is so important, it's really good.*

*HCP2 Well, [participant 1]….absolutely fantastic! She was absolutely fantastic on it.*

*HCP2 I think that was the thing, you seen her instantly smile. And then she would start singing along, sometimes she would have a wee dance in her seat, or if she was standing she would have a wee dance as well.*

*HCP2 But one thing I did notice is that I think it gave [carer 2] something to focus on because he was obviously….he comes in, his wife doesn't speak to him…he will participate in personal care because he had done a lot at home…but he wasn't really doing much here. He really didn't have anything to do with her, and this was a good way to actually…although she didn't tolerate it…it gave him a purpose, it gave him a role, he was coming in and helping us give the music. So I think from….it was nice to see him reconnect with his wife, although she didn't tolerate it unfortunately, but it was nice to see that kind of thing.*

*HCP2 It was better than giving prn medication.*

*HCP2 I think it would have to get looked at that if everyone was on this, and it was benefiting them, and reducing as required medication use, it would be absolutely fantastic*

*HCP2 I love it, I think it's fantastic and I would love to see it come in.*

*HCP2 I think it's amazing to have another tool in the bag that we can pull out when we need it*

*HCP3 It would trigger memories with her. And also like, it was good for her…it was really good for erm… to open up conversation about her that we never knew about. I think that's a big thing that I like about it*

*HCP3 However there was times where you could see her starting to change, and that sort of sun downing behaviour would start, and if you got in there quickly with it some of the sadder music helped to slow her down, so it sort of stopped her going…stopped her behaviour escalating. So she was a success with it, she really enjoyed it.*

*HCP3 I definitely remember with [participant 1] one night doing it. I was so impressed by how well engaged, and how well she done at it, she loved singing and laughing and you could see it, you could totally see it in her face. And I really enjoyed, really enjoyed 'her' at that point. I thought this is lovely, this is so rewarding.*

*HCP3 I still feel that we are in this medical model, and I don't think that comes from us as nurses. I think we are very much the ones that are actually 'let's get away from this', we don't want to give prn, we don't want to be medication focussed, I don't always feel that goes right up to the medical team.*

*HCP3 I think we should be more holistic in our approach…rather than this medical model and relying on the medication model.*

*HCP4 Listening to the music which had been chosen for the patient helped me to get to know them better and I enjoyed being able to listen to music which was personal to each patient.*

*HCP 4 Overall a positive experience for the patients involved and with two out of three patients I used it with it helped to decrease levels of agitated behaviour.*

*HCP4 One patient who often became highly agitated and accelerated would appear much more settled after listening to her personalised music.*

*HCP4 Listening to the music with the patient was a good distraction and therapeutic activity. After around five minutes the patient would sit or lie down and relax, smiling and singing along. The patient would often fall asleep listening to their music and achieve a better sleep. Without the music the patient would wake up and get out of their bed several times a night.*

*HCP4 I think that the patient had previously enjoyed music when they were younger and found it relaxing to listen to personalised music which they were able to remember and sing along to.*

*HCP4 I think that the personalised music was a good tool to be able to have and often provided a good therapeutic activity for the patients.*

*HCP4 With personalised iPods I was able to use the music when I felt it was needed and would benefit the patient most.*

*HCP4 Definitely helpful having the music personalised and has a more positive effect compared with music on the radio.*

*HCP4 I think it would be good for more of the patients to have their own music and would definitely continue to use it if it had a positive effect.*

*HCP5 By understanding someone's tastes in music you get a little more insight in them as a person. It also provided an opportunity to talk about specific pieces of music and the memories and emotions it evoked. I found this opened communication between staff and relatives/carers about this also.*

*HCP5 It allows staff to gain insight into the person and further enhances relative and carer involvement. It also promotes person centred care.*

*HCP5 I enjoyed spending 1:1 time with the patients. I enjoyed the music and I enjoyed seeing the recognition on people's faces when a certain song was played.*

*HCP5 There was one lady in the ward who experienced evident enjoyment from the music. She was often confused and disorientation in the ward environment which would cause her anxiety, however, when her music was played she transformed to a different person. She would sing and dance with*

*staff and wanted to share her music with fellow patients in the ward. As a healthcare professional I found this to be a very positive experience.*

*HCP5 Hopefully, when we are staffed to our establishment we will be able to factor in playlist for life/music therapy as part of our daily routine.*

*HCP5 I think it is something that definitely has a place within our ward.*

*HCP5 I would definitely continue to use it with patients who appear to enjoy and benefit from it.*

*HCP5 I would advocate strongly for this to become part of our ward routine.*

*HCP5 I think this is something we should definitely pursue. It might not be for everyone – but I think it is important to take a person centred approach to this. If music has played an important part in someone's life we should ensure it continues to be. I believe this will ensure they are able to lead a fulfilling life despite the limitation caused by their illness.*

**THEME 2: CLINICAL COMPLICATIONS**

*HCP1 I think that one of our patients [participant 2] it didn't really work well for her. I think her dementia….she's quite early on, quite early on in her dementia. I think that [participant 2] has got quite a bit of insight. Erm…she's a lot younger.*

*HCP1 So I don't think it worked too well with her and then again I think that is because of her…. I think she's got a bit of insight….to obviously she knows, she remembers the music. I feel that she….it's quite negative for her because she's thinking back to that music and thinking that's a memory for me and now I can't….those memories are gone. And she knows, I think she's able, she knows that she's… I think that she's got insight, got insight…and she gets really distressed by knowing that she's in hospital and that she's not with her family.*

*HCP1 I do really think, and I could be wrong, but I think it is because she has a lot more insight that say [participant 1] would have. It's just levels of dementia and how long they have been diagnosed with it and if it's early onset or if it's progressed.*
*HCP1 I think it just varies with different patients, how they present at the time, what time of day it is….what their presentation is really like, if they have slept, it really does depend on a lot of factors that really do influence whether they want to go through with it, enjoy it, or don't enjoy it*

*HCP1 Sometimes it brings her happy tears, I've seen her in the morning when it has been on she cries, but she doesn't want it off, obviously reminiscing. She's going back to that time, and it means a lot to them.*

*HCP1 It made her quite tearful, when…quite tearful, and she did begin to slam doors and get quite upset at it.*

*HCP1 I think it's a great intervention. It's just a case of working out which patients benefit …will respond to the music… as we've found it works for some but not for others*

*HCP2 [participant 2] does have insight, so she still does have that bit of insight, so I think she knows it was Christmas which are quite difficult times for lots of people anyway, isn't it?*

*HCP2 The carols maybe triggered those memories. And in the same way the playlist music has maybe triggered memories for her which might have been hard for her to deal with. Perhaps that's why she walked way? Who knows?*
*HCP2 I think he would tolerate it more now. Whereas I think he was too unwell at the time we were doing the music. A lot of it was lack of pain relief which we didn't know about back then.*

*HCP2 But I think part of that became very task orientated because we were trying to stick to the research study by doing it at the same time every day, so it was like two o clock it must be done then, or eight o clock like [participant 1] it had to be done then…*

*HCP2 I can see you wanted to keep everything the same so you could see whether the music was having an effect….but it wasn't focussed on the needs of the patient*

*HCP2 No two days are the same in here and no two patient's presentation is the same. So to say they are always going to be agitated at that particular time, it's never going to work. And as [HCP3] was saying, it's maybe not something that gets done every day, but when someone…when we notice that someone is starting to become agitated.*

*HCP2 I know we could have done it out with that, but we knew then we still had to do it at the set time as well….so it just…I think the restriction, but also the staffing.*

*HCP2 I think it was very much a mixed bad….we've definitely seen patients thrive on it….it seemed to work fantastic for them…and then on the other side, not. Really not have any benefit whatsoever.*

*HCP2 I totally agree about what HCP3 was saying….because there was songs on her playlist that would make her cry, but it was a good thing…a good way to make her reflect…get her to talk about why she was crying, a good way to get conversation going with her, but I think you knew then to move it on to happier songs, because you didn't want her to stay in that kind of sad way.*

*HCP2 There didn't seem to be much reaction from it, he would keep the headphones on and listen to the music, but there was nothing visual, or anything verbal, kind of indicating if he was getting any pleasure out of it.*

*HCP2 I don't think it…err…you can say that it's an outright conclusion that it never worked. With everybody at some point when it was done there was some reaction to the music….except for [participant 4], but with other people, whether it be singing, dancing or throwing something or walking away from it…because walking away from something is still a reaction…erm…I think there's always…I know the fact that [participant 2] never engages well with it, that is still a reaction. So it worked as it gave us…it gave us…it let us know it didn't work.*

*HCP2 He threw it on a couple of occasions actually, so I didn't see a good side to it with him*

*HCP3 So whether it has taken her back to 'yes it was sad', but because she doesn't vocalise anything, it's hard to say whether its tears of sadness, tears of understanding, is it tears because its triggering a memory, is it because she's frustrated?*

*HCP3 He has better times and worse times, and he gets on with certain staff better than other staff, how he interacts with others and that….but he was, he was too unwell when we did the music. He really was.*

*HCP3 At that point his mood fluctuated so much that it could be put down to coincidence if you got a smile out of him or if he threw something, it could be related to pain rather than…erm….so I think he was just too unwell.*

*HCP3 Although I think it did become to us a very task orientated thing for us. For me it did become more of a task, this has got to be done because it's for the study rather than…..*

*HCP 3 But it was a pain because it was very restrictive. Say if we could have had playlists for each and every one of them, and we as staff could choose when we were able to do it, then I think it would have been better. It's not something that needs to be done every day, it's not something that needs to be done at this certain time, it's oh I've got 10 minutes free, and so and so is nice and relaxed, I'm going to go and play them some of their music, and then I'm certain they would have got more benefit from it. We were too restricted by having to give it at the same time each day.*

*HCP3 So to have something that's good, but to be regimented to this is the time you are going to enjoy it, or this is the time you are going to get anything from it, didn't work for us.*

*HCP3 The biggest thing with that was because it was research based it was just so restrictive for us, with staffing numbers, so it was mainly getting done at night time which is our busiest time….so it's sort of that time and throughout the afternoon when we get our admissions in, a change of shift,*

*so you've constantly got catching up on yourself and chasing things up, phone calls, people getting back to you, so it was always like…the late shift can be really really on the go, and its finding the time to stop….but I think it's a really good thing.*

*HCP3 Yes she didn't like it and she made that clear to us. Normally [participant 2] walks from one end of the corridor to the opposite end, all day, every day. And she doesn't verbalise anything to us, she rarely shows emotion. Now and again after personal care, she will thump and bang a door. But that really is her only methods of communication. Other than that she can be very difficult to read, and she doesn't give a lot away facially. So for us to be able to say [participant 2] didn't like it, I think it sort of lets us…it let us figure out how [participant 2] presents when she doesn't like something.*

*HCP3 There was odd times when I used the music with [participant 1] and she went too far past the point of engagement with it, you had to time it right with her.*

*HCP3 He would listen to the music happy enough, but there was no real acknowledgement of it, even when I was sitting with him and I sang along with it, to see if I can engage him with that but there was nothing there. But saying that he didn't try to remove it or try to stop the music so maybe he was enjoying it?*

*HCP3 I would go further and say that it was more than not engaging with the music. She was distressed at times by the music.*

*HCP3 And then I remember doing it another night with her when her presentation was just the same and I just missed that window with her and she just wasn't interested. I tried to get her to sit down and engage with it, but she was too preoccupied with leaving to pick up her kids, or get the shopping, and I tried the headphones and I tried the speakers….in fact one of those nights I remember trying to skip through songs to get to the next one to see if it had an effect. I think it is lucky if you can get it before they start to get agitated. It's luck. But I think it's more of a ….or from what I've seen you get more of a positive reaction from it when someone is settled first of all and it's more enjoyable.*

*HCP3 I remember the time I done it he responded to the music, appeared to engage, sing or hum along a bit, but it was only for a short time, just a few minutes really….not long at all.*

*HCP4 Generally a positive outcome although appears to trigger upsetting memories for one patient.*

*HCP5 I think this because as much as she does not communicate verbally, she has retained some insight into her current presentation and situation. I think the music evokes strong memories for her which reminded her of where she was and why.*

*HCP4 I think that as long as it is used as required and not seen as a chore that has to be done every day whether the patient is agitated for not.*

*HCP4 One patient appeared to find their music upsetting and would become tearful every time it was played.*

*HCP4 I think it is important to recognise when it may have a negative and upsetting effect for a patient and only used for those which it can benefit.*

*HCP5 What we struggled with the most was trying to administer the music at the same time every day. This was just not feasible at times due to the unpredictability of the ward environment and the patient group. I think more flexibility on the approach would have been more beneficial.*

*HCP5 Another lady in the ward did not appear to experience a therapeutic effect from the music and became quite tearful when this was played. Initially I did not see this as a particularly negative thing as she was expressing a different type of emotion than she usually does, however this continued and she appeared more distressed over the course of the research.*

*HCP5 Sometimes a lasting effect was noted, sometimes they were unable to tolerate the music for any length of time. I think as long as some therapeutic effect was noted, regardless of how long this was for, it was of benefit.*

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