A series of research projects about health and social care for older people

Final report 2013

Is music the best medicine?: Using prescribed music to enhance quality of life for people with dementia and their carer

Janice Caine
Service Manager - Alzheimer Scotland

P·R·O·P
PRACTITIONER RESEARCH: OLDER PEOPLE

crfr
centre for research on families and relationships

iriss
Institute for Research and Innovation in Social Services

An Overview of the Practitioner-Research: Older People Project

Project overview

The PROP practitioner-research programme is a partnership between the Centre for Research on Families and Relationships (CRFR) at the University of Edinburgh and the Institute for Research and Innovation in Social Services (IRISS). It was funded through the Economic and Social Research Council. This programme also received support from the Scottish Government's Joint Improvement Team.

CRFR and IRISS partnered with a group of Scottish Local Authorities, NHS, third and independent sector organisations to produce this practitioner-research programme. The partners include NHS Lothian, West Lothian Council, Glasgow City Council, Alzheimer Scotland, and Scottish Care and VOCAL Midlothian and Midlothian Council.

This project is underpinned by two key premises. The first recognises that to improve care for older people there is a need for an improved evidence base that relates directly to the needs of those providing services and those developing policy. The second premise is the need to better share this evidence base through greater use of this resource by key audiences and users. One way to achieve both objectives is through the co-production of knowledge between academic researchers and those involved in delivering care.

The PROP project brings together a team of practitioners in health and social care provision, academics and specialists in evidence-use and knowledge media from IRISS and CRFR. Collectively we have synthesized existing evidence, generated new evidence and improved the use of this evidence with the partner organisations. Our aim is to promote a culture of evidence-informed inquiry with the hope that this supports improvements in the lives of older people across Scotland.

Project Aims

Through the delivery of a practitioner-research programme, we aim to achieve the following:

- Improve the volume and quality of research produced by those delivering health and social care for older people
- Increase awareness of, and improve access to, research created by those involved in providing care for older people
- Support greater engagement and collaboration between researchers and practitioners involved in researching and delivering care for older people across health and social care contexts
- Extend theoretical and practical understandings of the knowledge translation, brokerage and exchange processes that are effective between academics, users, policymakers and practitioners when sharing good practice in the production and utilisation of findings relating to the health and social care of older people

About Practitioner Research

Practitioners undertake a considerable amount of research, in fact Mitchell and colleagues estimate that 'practitioner research in social work probably occupies a major part of the total volume of research activity in this field' (Mitchell et al, 2010: 8).

There is evidence to suggest that practitioner research can be a valuable approach for strengthening the use of research not just for the individual practitioner undertaking research but potentially for the organisation and perhaps even the sector in which they are based. These benefits vary depending on the support available for the practitioner and how the research endeavour is structured; which can for instance involve support being provided by other practitioners, academics or research colleagues based in-house or in external organisations. Some of the benefits of practitioner research for the practitioner and their organisation can include:

- Delivers research of direct relevance to practice concerns
- Improves research capacity of individual practitioners and organisations

- Strengthens the active role of the practitioner in the research process
- Brings the worlds of policy, practice and research closer together
- Helps an organisation develop the capacity for critical inquiry and a "learning orientation"
- Supports the desire for and the use of research done by "outsiders"
- Reduces the distance knowledge has to travel from research to practice
- Provides a starting point for further research-practice collaboration

(Armstrong and Alsop, 2010; Roper, 2002; Anderson and Jones, 2000: 430)

However, we are not necessarily maximising the impact of research undertaken by practitioners in social services and health for three main reasons:

1) Practitioner researchers often lack professional support and training related to the use and application of research methods and theory.

2) Practitioners struggle to access existing evidence related to their work, thus potentially affecting the quality of what they are able to produce.

3) Practitioners engaged in conducting research into their own team, service or organisation do not usually have the time or capacity to disseminate their research findings or to support its use in other services or organisations.

The PROP Practitioner-Research Programme

This Practitioner-Research Programme (PRP) was delivered between May 2012 and August 2014. Over this period, the nine practitioners involved in the PROP project designed and carried out an empirical research project directly related to their practice and the theme of care for older people.

The partner organisations (Alzheimer Scotland, Glasgow City Council, Midlothian Council, NHS Lothian, West Lothian Council, and VOCAL) made a commitment to support selected members of staff to participate in the PRP. Practitioners were allocated ½ day/week for research, six days for research training and two days for knowledge exchange seminars.

Each practitioner-researcher was allocated a mentor from the University of Edinburgh, NHS Lothian or IRISS. This mentor supported the research design and analysis in the project and provided guidance on how best to use research findings to develop policy and practice.

A series of six training sessions was delivered between July 2012 and February 2013. These full-day events focused on six areas of research practice: (1) resources for research, (2) project management and research planning, (3) research design, (4) generating evidence, (5) analysing evidence, and (6) knowledge exchange.

Knowledge exchange events were held in October 2012 and May 2013 to facilitate learning from these research projects within and across the stakeholder organisations. These events supported practitioners to share and disseminate research findings and provide evidence to partners and stakeholders about best practice.

Project Outputs

The project outputs focus on two areas: (1) improving the care of older people and (2) improving the use and usefulness of research for those involved in providing care. These include:

- 8 completed practitioner-research projects, including final reports and summary postcards
- 1 summary booklet of the PROP programme of practitioner-research
- 2 knowledge exchange events
- 2 peer-reviewed journal articles about improving the use and usefulness of research for those involved in delivering services
- An evaluation briefing paper about the practitioner research project

For more details, please see our website: http://blogs.iriss.org.uk/prop/

How to Reference this Report

When making use of this material, use the following reference for this report:

Caine, J. (2013) ‘Is Music the Best Medicine?’ Scotland: CRFR/IRISS.

References

Anderson, G. and Jones, F (2000) Knowledge Generation in Educational Administration From the Inside Out: The Promise and Perils of Site-Based, Administrator Research in Educational Administration Quarterly (Vol. 36, No. 3 (August 2000) 428-464

Armstrong, F. and Alsop, A. (2010) ‘Debate: co-production can contribute to research impact in the social sciences’, Public Money & Management, 30 (4): 208-10

Mitchell, F., Lunt, N. and Shaw, I. (2010) Practitioner research in social work: A knowledge review. Evidence and Policy, 6 (1): 7 -31

Roper, L. (2002) ‘Achieving successful academic-practitioner research collaborations’, Development in Practice, 12 (3-4): 338-345

Contents

Executive summary

The purpose of this practitioner research was to test: if (preferred) music was prescribed daily to a person with dementia using an MP3 player and headphones could this impact positively on their mood/ well being and would this have a positive impact on the carer?

Five couples were recruited to take part in this small scale study and all completed it. The participants with dementia were in the early-moderate stages of their illness. The results of feedback from people with dementia showed the music had affected their mood positively in 33 out of 35 occasions. The participants who listened all reported they were more relaxed and the music brightened their mood. The carer diaries revealed that the effect during and after was positive and the person's mood had improved. How long the positive effect lasted was different for each person. Follow up 2 months later showed that only 1 person was still regularly listening to the music. Further work needs to be done on how the use of music can be supported for longer

Findings

For the five participants with dementia:

- Each stated that listening to the music had made them more relaxed and happier. In 33 out of 35 occasions it had a positive impact on their mood making them feel better than a 'normal' day (Appendix 1)
- Using an MP3 player and headphones allowed people to focus on the music and cut out any distraction
- In one case the participant with dementia was depressed but music still had a positive impact

For the five participants who were carers:

- The five carers observed and agreed that on 33 occasions out of 35, individuals with dementia had enjoyed listening to the music
- While the person with dementia listened to the music, the carer got a break and didn't have to worry about them
- In three of the cases where a positive impact was stated, the effects lasted for a few hours. One carer reported 30-40 minutes. Another carer reported difficulties in ascertaining length of effect as the person she cared for settled and relaxed and went to bed
- There was an expectation from carers that the person with dementia would ask to listen to their player during the washout period if they enjoyed it. This was despite the fact that they recognised the cognitive impairment to memory caused by dementia. Carers need support and encouragement to prompt the person they care for to use music.

For all participants:

- All carers and participants with dementia found it a positive experience
- Listening to music for participants with dementia relies on their carer reminding them and often in assisting them with the player and headphones
- Using music in the home per se doesn't constitute a therapeutic intervention. Using music with a personal player and headphones cuts out distractions and appears to concentrate its effect for the person with dementia
- All carers felt the person with dementia would have listened longer if they had not been reminded to stop. Out of 35 occasions of listening only twice did people ask to stop listening

Introduction

As a practitioner working in the field of dementia for many years, I am interested in researching how music can benefit the lives of people with dementia and their carers. I have read about the benefits of music to people with dementia. Sacks writes in his article, 'Wired for Sound';

> 'Humans are uniquely able to produce and enjoy music – very few other animals can do so. But not only is music one of the fundamental ways we bond with each other, it literally shapes our brains. Perhaps this is so because musical activity involves many parts of the brain (emotional, motor, and cognitive areas), even more than we use for our other great human achievement, language. This is why it can be such an effective way to remember or to learn. It is no accident that we teach our youngest children with rhymes and songs. As anyone who can't get an advertising jingle or a popular song out of their head knows, music burrows its way deep into the nervous system, so deep, in fact, that even when people suffer devastating neurological disease or injury, music is usually the last thing they lose. He further states, perhaps most remarkably, people with Alzheimer's disease and other dementias can respond to music when nothing else reaches them. Alzheimer's can totally destroy the ability to remember family members or events from one's own life – but musical memory somehow survives the ravages of disease, and even in people with advanced dementia, music can often reawaken personal memories and associations that are otherwise lost' (2008)

I have seen music overcome the communication challenges that dementia brings with it and also reduce agitation and some of the behavioural aspects it brings. People with dementia who enjoy music often benefit from its use within our day care groups, however little of this is offered in the home as a therapeutic intervention. Often the carer is not privy to the positive effects on the person with dementia and fails to witness the change in the person's mood as well as how it impacts on their wellbeing.

If the person is feeling agitated or stressed they are more likely to be prescribed medication than music! I have seen the effects music can have in lightening the mood on a person improving communication and acting as a catalyst for reminiscence.

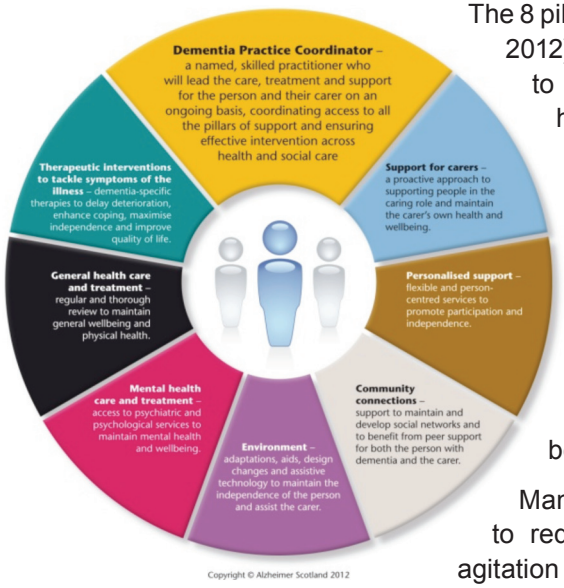
Music can be a non-threatening activity that doesn't place the same demands on people that other complex activities do and appears to have a positive impact on people who enjoy it; relaxation and mood is improved.

My research is grounded in the belief that music can offer huge benefits to people with dementia who respond to it. However, like every other activity I believe it needs to be person centred. Sacks writes about music, "It seeks to address the emotions, cognitive powers, thoughts and memories, the surviving "self" of the patient, to stimulate these and bring them to the fore. It aims to enrich and enlarge existence, to give freedom, stability, organisation and focus". (p336, 2011).

It is the capacity of music in maintaining a person's identity; reminding them of their life history and maintaining personhood that is important (Kitwood, 1997)

There are 84,000 people diagnosed with dementia in Scotland. 60% diagnosed with dementia live in their own homes either alone or with a carer (Alzheimer Scotland, 2013). This means approximately 50,400 people will be living in the community. In my experience, care provision for the family is often provided either by putting support into the home for the individuals with dementia or the person attends a day setting to give the carer a break. However there are long periods when the individuals with dementia and carer spend time together.

Family caregivers are critical to the quality of life of people with dementia (Brodaty & Donkin, 2009) yet often interventions focus solely on the person with dementia.



The 8 pillars Model of Community Support (Alzheimer Scotland, 2012) is a comprehensive and evidence based approach to supporting people with dementia and their carers. It highlights the need for a fully integrated approach from health and social care in maintaining people with dementia and supporting them at home (p5,2012).

Background

I undertook a literature review using Cinahl, Medline and Embase databases with key words: dementia, older people, music, music therapy, quality of life, well being, and iPod therapy. Range: from 2000 onwards.

Many studies focus on the use of music in long term care to reduce behaviours associated with dementia such as agitation (Lou, 2001; Ragneskog et al, 2001; Cooke et al, 2010, Raglio et al, 2010;); or focused on people at the later stage of their illness and within institutional settings (Sung & Chang, 2005). Many looked at reducing professional carer stress but didn't focus on improving the well being of people with dementia or their carer in the home. It is recognised that music-based activities involving caregivers provide an important emotional bonding experience, and has positive impacts on care, social relationships and quality of life (Gotell et al, 2000). One study looked at various creative therapies including music within a hospital setting and concluded that people with dementia responded with pleasure and enjoyment (Rylatt, 2012).

Some research did focus on using music activities within the home which involved people with dementia and their carers (Brotons, 2003, Hanser et al, 2011). However, the latter study which looked at caregiver-assisted activities also recognised there was a large dropout and recommended input from music therapists.

Much is written on whether music can improve well being or quality of life. Hays and Minichiello argue that 'music can be used to promote a better quality of life for older people' (2005 p261). Foster describes music as 'is unparalleled in its capacity to connect with and give life to that spirit' (2009 p48) whilst Sixsmith and Gibson state:

> *As well as being enjoyed in its own right, music can enable people to participate in activities that are enjoyable and personally meaningful (p127)*

My study aims were to:

- Analyse if individualised music can be prescribed as a therapeutic intervention on a daily basis (similar to prescribed exercise) to the person with dementia. If it has a positive effect will this impact positively on the carer?
- If the effect is positive, is this sustained and for how long?
- Can people with dementia and carers (where appropriate) be encouraged to use this method to enhance their lives?

My study objectives were to:

- To explore if music can be used to enhance a person with dementia and their carers life
- To explore if some of the benefits of activity provided by practitioners can be extended into the home environment

My study aims to provide an intervention that would need minimal input from professionals and minimal work for the carer and person with dementia. I accessed some information on IPod therapy (Clardy, 2012) and information on the 'Music and Memory Programme' which is being established in care homes in Canada. This programme is grounded in neuroscience studies and evidence from sixty facilities

(Music & Memory, 2012) and again is for people in the later stages in care facilities. The intention with my study was to use individualised music on an MP3 player with headphones. From a personal point of view and experience, individually-selected music appears to be more meaningful and there is research that suggests this is more effective (Sherrat et al, 2004; Gerdner, L.2000).

Method

Design and sample

This was a small-scale qualitative study involving five people with dementia and their carers using a Participative Action Research (PAR) approach. Rather than just observing people, I wanted to involve my participants actively and find research methods that were meaningful. PAR puts the emphasis on people working together and also allows people to represent their own interest. The participants with dementia were actively involved through discussion groups and interviews and my understanding of what the relevant issues were increased. As Walters states: 'Research should be more than just finding out; research should also involve an action component that seeks to engender positive change and is a participatory process that requires the equal and collaborative involvement of the 'community of research interest' (p1, 2009).

The study focused on people's experiences and their narrative. I wanted participants to be involved in the design of the feedback and also input into how long they would listen to the music and what type of music they would listen to. The participants with dementia would be involved in developing a feedback form using photographs and words similar to an emotional touch point.

Sample

The participants were known to me as they used our dementia cafe where we use music as the major activity. The criteria for participation were that the person should enjoy music; and be in the early to moderate stage of their illness. I needed them to have the capacity to understand the concept of the study and be able to participate in some of its design.

Data collection

As I was using a person centred approach I did not want to use any medicalized assessment tools with participants with dementia. It would have inhibited participants if they were to undergo assessment before and after listening to music. I wanted to rely on individualised pen portraits and their responses to explain their experience.

I used a combination of discussion groups, interviews, feedback forms and diaries. Evidence from both carers and the person with dementia entailed measuring mood and identifying if music had any effect on mood; then measuring how long this lasted. I was interested in people's perceptions and experiences and used interviews and discussion groups to solicit and capture these.

Table of Methods

Method	Number of carers	Numbers of people with dementia
Semi structured interview	5	5
Discussion group	5	5
Individual discussions		2
Diaries	5	

The discussion group format is described in Fig 1. Further information on the discussion groups is available in Appendix 2. The interviews and discussion groups were audio taped and then transcribed. Semi Structured interviews were conducted with both the carer and person with dementia on an individual basis after the listening period (see Appendix 3). I wanted to explore with the people with dementia how they had found the experience and their thoughts on how it had affected them including

their experience of listening with headphones. I also wanted to find out from carers their experience and what effects they had noticed on the person they cared for and the extent of any benefit. Their diaries also noted mood before and after the listening and what the reaction to listening was. The discussion group with participants with dementia was co-facilitated. Due to two people with dementia not being able to attend the discussion group I had individual discussions with them to ascertain length of listening, period of time and format of feedback using photographs and words.

The Feedback form was designed by participants with dementia using emotional touch points. Emotional touch points are a simple method of tapping into people's emotions enabling them to express how they feel using words and in this case also photographs and allowing them to express themselves more easily (Alzheimer Scotland, 2011, Dewar et al, 2009). I used this method to devise a way of feeding back immediately after their listening experience. I needed to ascertain how the music made people feel. We devised the scale by identifying words and photos that described how they felt on a normal day which formed a baseline. We created a similar scale for a good day and a bad day. When looking at the completed scale, I would be able to see the impact based on how they describe on a daily basis. I didn't want to weight any of their responses to the research question so they were asked to tick as many as they wished. In this way I would measure their immediate response and back it up with the carer diaries. A copy of the form is in Appendix 4.

Each carer kept a daily diary during the listening week and was to note any observations during the washout period.

Individual prescription times were decided by the participants. They decided what would be the best time for the person with dementia to listen (see times in individualised portraits). Individualised music was identified and the MP3 players filled. Despite searching there was no one MP3 player that is dementia friendly and I settled on one I felt was easiest.

A discussion group was planned for the five participants with dementia covering the questions below. Two of the participants were unwell on the day so separate meetings took place using the same format.

Fig 1 Discussion group with participants with dementia

Discussion Group with participants with dementia	Results of discussion
How long they would listen to music on a daily basis?	30-45 minutes at their prescribed time
What period of time i.e. 7/10/14 would they listen?	7 days listening and 7 days washout period
Measures to prompt with research due to their cognitive impairment	Each participant would have a folder with prescription time, length and period of listening, prompt to complete feedback forms
Discuss any support needed to keep research on track	Carers would contact researcher
To design and devise a feedback form that people with dementia would complete after listening	Resulted in a baseline of mood scales that they would tick every day to identify any change in their mood
Scale of Mood designed by participants with dementia	
How people felt on a daily basis?	Pensive, Thoughtful, Bored, What's the Point
How they felt when they had a good day?	Light & Bright, Cheerful, Happy Mood, Peaceful
How they felt when they had a bad day?	Fed Up, Down in the Dumps/In a Tangle, Can't be Bothered, Feeling Left Behind

Fig 2 Discussion group was held for five carers to discuss and agree

Discussion Group for five carers	Discussions
The length of time people with dementia had agreed and how long the research would span over	Carers agreed the 30-45 minutes seemed fine but two carers felt the people they cared for may not want to stop listening. Measure built in that they would not stop the person listening but note the length of time listened. Prescription would include this
The carers role in reminding, prompting with listening, equipment and feedback form	Discussed that they would need to remind re time and when to stop and to complete feedback after. They would probably have to prompt and assist with the equipment. MP3 player would be used on shuffle to reduce overcomplicating the research
Completing and maintaining a diary of mood before, whilst listening and after during the period of listening and washout period.	Carers were happy enough to do this. I agreed I would write a cover page to remind them what observations I needed. i.e. mood before, during listening, mood benefit, effects and how long they lasted
Discuss if they needed any backup measure.	All five carers felt happy but agreed they would contact me by phone if there were any issues with research, equipment use or other difficulties

Ethics

I undertook self-audit checklist through the University of Edinburgh and applied to my organisation for ethical approval. I did not consider that my study would cause any risk or harm to its participants. I completed an ethics access form and provided my participation information form to Alzheimer Scotland. This included information about data protection and maintaining anonymity within my research text. Appendix 5. Confidentiality was maintained about the participants who took part and all names were anonymised.

As a practitioner, I was aware of my position of power as someone who not only knew the participants but was also providing them with a service. I assured my participants that if they didn't want to participate it wouldn't influence the service they received. As participants had to have capacity to consent, they were usually in the early to moderate stages of their illness.

During the discussion group with people with dementia, I had a co-facilitator. While it is important to recognise that in my dual role as practitioner and researcher, it may have been difficult for the participants to see me as a researcher. I don't feel it caused any difficulty. One carer said 'If it hadn't been you I wouldn't have taken part'. One advantage was the existing positive relationship which allowed such trust however it made me more aware of my position.

Data analysis

I drew on a grounded theory approach; which looks at the discovery of theory from data. Moreover it can provide relevant predictions, explanations and interpretations (Glaser & Strauss, 1999). I used a thematic analysis approach to categorise various themes initially. By constantly re-analysing the themes these were distilled down to eight.

Summary of Themes from Data Analysis	
1	Participant with dementia's experience of listening
2	Carer's observation of person listening
3	Carer's experience
4	Length of listening/timing
5	Using Equipment
6	Expectation of Carers
7	Preferred Music
8	Mood Benefit

This allowed me to further test my data against the research question: whether music could enhance mood for the person with dementia and if that would impact on the carer if the answer was positive.

The other method was a narrative approach when reading through the data and interpreting and generating the participant's stories in the form of vignettes and Ipoems, which are available in appendix 6. My in depth analysis is in appendix 7.

Reflections

This was a small scale study with a reliance on a small sample of people. To increase rigour I checked findings with each carer. I have included more in depth reflections on research involving people with dementia in appendix 8 including reflections on the different methods I used.

Case studies

The vignettes below describe the participants with dementia and their experiences during the research study along with observations and experiences of their carers.

Jack and Ella

Jack is an active 81-year-old man who lives with his wife, Ella. He was diagnosed with Alzheimer's three years ago. He still enjoys going to the golf club in the morning however can be quite restless in the afternoon and bored. Ella told me she had tried to get him to listen to music on a CD player when he was first diagnosed. He loves music but was so listless. She felt it would give him an activity. He felt this was patronising and refused. Jack loves music and enjoys singing. His choices were light classical: Il Divo, Catherine Jenkins, The Three Tenors, Welsh Male voice choir, The Priests, Scottish traditional/Folk, Susan Boyle and his favourite being church music. Prescription time is 2pm.

Jack managed to work the MP3 player after an initial prompt from Ella. She said "He really enjoyed the music and it made him feel relaxed and peaceful". He enjoyed listening with headphones and described it as "making it more intense as it's solely for him. And he became absorbed in listening". When asked if he felt it had any effect he said "Oh definitely – oh much more relaxed". He said he would" enjoy it as a therapy" and said he felt "much more relaxed, definitely made a difference to my mood". Jack said of the music "it's the music I like". When asked if he has anything else to feedback. He says "I'd just like to thank you for giving me the chance to listen to it. Thoroughly enjoyed it. It kept her off my back". He agrees it worked as a break for both him and Ella.

Ella said that she "never had any problems motivating Jack to listen. He was totally into it: listening and singing along and conducting to the music and really enjoyed the sessions. He would sit and conduct in the seat and was perfectly happy". She asked him how he felt after and he would say "Oh I'm happy" – he was always happy. Ella said she would "encourage him to do it; it was a routine". She also felt, prescribing it made it more acceptable to access. It had been impossible for her to get him to listen to CDs prior to the research. She felt Jack wouldn't feel he was being forced by her. She prompted him to listen for 45 minutes but was sorry when the listening was over. She described that he might be restless prior to listening but after it left him happy and contented, definitely more contented. Improved his mood and established a routine. This effect lasted the rest of the afternoon. She described how in during the week after the washout period, she observed that he became restless at 2pm which was his prescription time to listen so she felt it had established a routine. (See Ipoem in appendix 6)

Molly and John

Molly is a 79-year-old very active lady who lives in the country. She and her husband, John have farmed all their lives. Molly used to garden a lot and still likes to keep busy in the garden. She has always been a social lady and loves company. She was diagnosed with Alzheimer's a couple of years ago and it causes her to be very emotional and her mood can change quite quickly. She often looks for her husband and follows him around. Her choices were Country and Western,

Traditional Scottish/Folk, Foster & Allan, Susan Boyle; Light classical: Il Divo, The Three Tenors, Catherine Jenkins, Russell Watson. She used to love going dancing and has always enjoyed music when out socially. Prescription time is 2pm. When asked if she enjoyed it Molly said, “Oh it was alright” but “if it was a fine day, I could be out in the garden. I would say it did make me feel better - it made me relax. I was going to be doing that (listening) and that’s all that was done”. She said that “maybe your mind can be very busy planning- music made you relax”. Molly enjoyed the music: “I enjoyed it because it was music I know. I was fine pleased with it”. The music evoked memories for Molly and she talked about these again in our interview becoming quite emotional. “I’m an emotional person (crying)”. She felt even though the memories were sometimes painful: “It is still nice to remember”. Molly couldn’t manage to work the MP3 player so John did this.

John described Molly: “she cried most of the time. Said she enjoyed the music even though it made her cry”. On the first day she was so emotional he took the music away from her. After that she cried less. She was relaxed and focused on a photograph of five generations of the family. It evoked vivid memories from long ago-memories of their wedding, first house sixty years ago. He felt she enjoyed the music and found it “relaxing and restful”. There was one day she didn’t enjoy the music as the language was foreign. She became frustrated and kept taking off the headphones. Another day although she was wearing headphones she continued to talk to him so he left the room. She listened for 30 to 45 minutes daily. One day he gave her the music in bed and she was “fair delighted –thoroughly enjoyed it and didn’t want to stop listening”. John worked the player and left it on shuffle. He felt after listening: she would be a lot brighter. He felt this lasted for 30 to 45 minutes.

May and Barbara

May is a 74 year old fit and active lady who lives with her husband. Her son and daughter-in-law live in the same house in the country. She has had a diagnosis of Alzheimer’s since 2009. Her daughter-in-law, Barbara, is the main carer as the situation between May and her husband can be highly volatile and fraught with a lot of arguing. She spends a lot of time upstairs in her little room watching TV and listening to music. Often she confuses reality with what she listens to and starts accusing her husband. This leads to heated arguments. Her music preferences cover an eclectic mix including 60s, 70s, Country and Western. The music she chose included various classical albums including Bach, Mozart, Tchaikovsky to light classical including Il Divo, Catherine Jenkins, Russell Watson, The Three Tenors and Spanish Tenors. Prescription time is 7pm. May said: “she enjoyed listening and found it very calming – yes thoroughly enjoyed it. She felt it calmed her and made her relax”. She described it as a positive experience – “I thought it was going to be repetitive, but it wasn’t”. She thoroughly enjoyed using the MP3 player (Barbara worked this) and described how she “could sit upstairs with the headphones on and nobody could distract her – it shuts everything out”. When I asked her if she thought the music had had an effect on her mood: it had and she thought she wasn’t as irritable but felt others would have to say. I asked her was all the music enjoyable and she felt some was more than others. (see IPoem in Appendix 6)

Barbara described that “May was quite happy to listen to it- put the headphones on and relaxed, sitting there with her eyes shut for 45 minute – sometimes she would sing to it”. She didn’t feel there was a noticeable difference as May would tidy up a bit and then go straight to bed – she felt the timing had been wrong. As it was 7pm she felt, May would basically listen to the music and go to bed. If she had listened in the afternoon would probably have noticed more of a difference. One night her Barbara’s husband forgot to remind May to stop listening and she listened for 2 ½ hours. Barbara felt May marked the feedback form dependent on how the music made her feel. “Using shuffle was very good for her and she thoroughly enjoyed it – each bit was different – she really enjoyed this”. When filling in the feedback she felt three or four feelings and that really depended on what she was listening to. May’s mood was described in the diary as settled, relaxed, very settled.

Maria and Tony

Maria is a 73-year-old lady who lives with her husband, Tony. She loves music and was a Contralto singer in her younger days and she belonged to a light operatic society so really enjoys music. She was diagnosed with vascular dementia 2 1/2 years ago. She has great difficulties with mobility and often feels isolated and lonely due to this and living in a rural location. She was very low in mood during the research period and three days in to it was prescribed antidepressants. She loves Classical and light classical including light operatic music and chose a huge variety of mixed Classical albums, Il Divo, Catherine Jenkins, Spanish Tenors, The Three Tenors and Mario Lanza. Prescription time was 2pm (later changed to 4pm so she could concentrate solely on listening). When I first fitted the headphones on Maria she was totally enraptured: humming, conducting and swaying with her eyes closed. Of her listening experience she said "fine, I love the music so it's no hassle. I enjoyed it – I love music. You were just gone! You can't talk and listen. I sat there and spent I forget how long at it". I asked her if it would be enjoyable to be prescribed music – "Oh, of course – it's music".

Tony described Maria as being: "Away with the fairies, singing and swaying, eyes closed and fully engrossed". There was a "transition in mood from listening to the music. Was always interested in doing it". Tony described "if it had been any other music it probably wouldn't have worked" he felt "it didn't have to be the music she knew but the style of music". Tony said of the MP3 player that once he got the hang of it, it was easy. He also felt "the shuffle feature was good as once it was turned on again, it went back to where it had stopped". I asked Tony if it had had an effect on him "certainly afterwards it was easier – but before it was just the same". After listening, Tony said there was the familiar happy mood. This "familiar happy mood" usually lasted until bedtime except one night. A period of 3 to 4 hours.

Grace and Jim

Grace lives with her partner, Jim. She was diagnosed with Alzheimer's 3 1/2 years ago. She also has a lot of physical illness, including asthma and arthritis so spends a lot of time in bed and often says she is down in the dumps. She was a concert pianist and performed at various venues. She was also a piano teacher and loves listening to music. She comes from a musical family. Her music choices were mixed Classical albums, light classical including Il Divo, The Priests, The Three Tenors, Andre Rieu – violinist and Johnny Cash. Prescription time was 2pm but Grace liked to listen in the morning when in bed. She said of her experience "It does work- it was lovely thank you. Terrific. It was fine as I've been in bed quite a lot – even just lying there he could fit it up". Grace would change the music herself "It's better to use one that's light (when I'm down) – like the classical ones. If I was down I would jiggle the music so I was feeling lighter". Grace did become anxious and 'down' about having to give up the player as the weekend came. I offered to loan it to her – "It's wonderful, it's really wonderful -– I hope I'm not taking it away from anyone else".

Jim felt that Grace 'enjoys listening' to the music. He would put the headphones on, as Grace put them on the wrong way, and felt it was a positive experience "Oh it's positive as I can come down and not worry because I know she is listening to the music enjoying it. If she's upstairs I can either watch my sport or TV". I asked did it give him a break? "Oh yeah,yeah". Jim said the effect of being in a good mood after and cheerful could last a few hours. If Grace had been feeling down before, after listening to the music he felt she was in a happier mood and wanted to go out. Toward the end of the week she had been worried about returning the MP3 player. The player was used on shuffle so as Jim said she could be listening to Tchaikovsky then Johnny Cash.

Discussion on Vignettes

With Jack, his wife commented that as someone introduced the activity to her husband it made it easier. She had previously tried with little success. She felt it gave her a break however it's worth noting Jack felt this too. I would argue it is important for both the person with dementia and carer to get a break. It

is worth noting that Ella felt the music established a routine and her husband always felt happy after listening however after a month he was no longer listening.

Molly found that music evoked memories from sixty years ago and was very powerful in eliciting emotional responses. Although she cried a lot she also felt it was “nice to remember”. I feel this is an important aspect to consider. Just because someone cries when they listen to music does not mean they are not enjoying it. Molly was a very busy person so she didn’t settle as well as others except when she was given the player in bed one morning. In that event she really settled and enjoyed it. Again this would show timing was an important factor for the person.

May listened in the evening at 7pm and it the carer felt it would have been better if she had listened in the afternoon. The benefits may have been greater for the carer and more obvious. May in particular often becomes confused with reality and programmes on television or radio. She benefitted from headphones as they cut all distractions out and listening to music didn’t cause her to misinterpret any events.

Maria particularly responded well to music. The minute the headphones went on she would sway in time to the music completely lost in the music. Tony said there was a transition in mood instantly and her mood benefit lasted for three to four hours. In particular Maria was depressed during the research however her mood still improved. The shuffle aspect was good for Maria as she couldn’t work the MP3 player herself. Tony changed the time of listening to 4pm as Maria would have been busy ‘cutting up meat for the cat’ at the initial time. This would have interrupted her listening.

Grace found the music was more beneficial when she was in bed in the morning. She found it hard to get up with her physical symptoms and used the music to “lighten her mood”. She would do this by changing the music to suit. She could work the shuffle herself. Jim could relax as he knew she was settled upstairs and it allowed him some personal time. The music lightened her mood and she would want to go out.

Implications for policy and practice

My findings fit well with the recommendations in the recent Alzheimer Scotland report ‘Delivering Integrated Dementia Care: The 8 Pillars Model of Community Support’ (Alzheimer Scotland, 2012). This report seeks to address many issues about cohesive partnership working between health and social care and it serves as a blueprint to approaches that can make a difference.

In particular my findings around the use of music fit well in to Pillar Two which looks at therapeutic intervention for people with dementia. It recognises therapies will aim to delay deterioration, enhance coping maximise independence, and improve quality of life (P19).

My findings also contribute to Pillar Six that, ‘Carers require increasing support to accept and adapt to the changes to the person with dementia and the impact of this on their lives. To this end they also recognise that Carers require training in interventions that are effective for people with dementia’ (p26). However, the importance of supporting carers and the people with dementia to use the MP3 player to access music is important as evidenced by follow-up interviews which found that despite the benefits gained by carers of people with dementia only one person was still actively using the MP3 player, whilst another person uses it intermittently.

Conclusion

In conclusion for people with dementia they all felt that listening to the music had improved their mood, making them more relaxed and happier. In 33 out of 35 occasions it had raised their mood and made them feel better than they did on a normal day; their carers agreed. All ten participants found it a positive experience.

Listening to music on the radio doesn’t offer the same therapeutic benefits. Listening to music on a personal player and head phones cuts out distractions and appears to concentrate its effect for the person with dementia. It also allows the carer to be in the same room and undertake their own activity.

One person was clinically depressed yet the music was still able to ‘lighten her mood’

Using the MP3 player on shuffle allowed the person with dementia to listen and music would continue rather than turning off at the end of an album. This meant length of play was uninterrupted. It also made the operation of the player easier for the carer and person with dementia as it could be turned off and when used again would start from that point. This simplified the process of using the player which is important for some older carers. Only one person with dementia could use the player with prompting. Another could shuffle the songs independently.

Whilst the person was listening to music this gave the carer a break and they didn’t have to worry about the person with dementia. In three of the cases a positive impact on mood lasted for a few hours, one case it was difficult to ascertain as the person with dementia was settled and went to bed.

The aspect of timing of listening is important. It should be at a time when the person with dementia is not planning to undertake other tasks and they can solely concentrate on listening. It should also be at a time where the carer can benefit from the improved mood and not in the evening. Having said this, it may benefit someone who becomes unsettled in the evening and this should be identified.

It is important that the music chosen for the player is what the person with dementia likes and wants to listen to. The carer is important in supporting the person with dementia to identify this. One carer identified ‘classical’ as a genre of music his wife would like and this worked fine. However care must be taken; I put a Spanish three tenors album on Molly’s player as she liked ‘The Three Tenors’ and it made her very frustrated.

There is evidence from my research that more work has to be done to support carers to use music on MP3 players as an intervention. Despite acknowledging that it benefited both themselves and the person with dementia; there is only one person still actively using it. This probably says more about the complexity and stress of caring and is something as a practitioner I will continue to focus my efforts on. Using music as an intervention in this way would require carers to support the person they care for with using the player, reminding and encouraging them. People with dementia forgot they had listened to the music. One carer said ‘I asked her what she was listening to, yet she had already forgotten’. Obviously this is difficult for the carer, yet does not negate the fact they enjoyed it and benefited from the change in mood.

With increasing numbers of people with dementia and their carers living in the community, my research highlights its use in improving the quality of life for people with dementia and their carer within the home, the positive outcomes experienced by the person with dementia in the home, and the minimal input required from the carer to achieve a benefit from it. Music therapists are not usually employed in the home, however, I would argue aspects of their role could be taken on by social, health and other service providers who understand the relevance and aspects of using music as an intervention taking into account the needs of the person with dementia and their carer. Even if listening to music benefits the person with dementia for 1 hour and increases their mood and benefits their carer for that period; this window of opportunity could be built upon and encouraged.

We could focus on improving the life of people with dementia and their carer at a much earlier stage so it is part of daily life and an established routine the individual has accepted much earlier on in their illness rather than only trying to use music to enhance communication and reduce agitation at a much later stage of the illness. This could also easily be transferred into care homes and to others in long stay care or hospitals where people with dementia’s lives are isolated and activity is reduced. Listening to preferred music could continue to give pleasure to people in the later stages when other activity proves difficult; it could be an enhancement that care managers could purchase as part of a personalised package of care.

Knowledge exchange

The findings of this work will be shared as a report with my organisation, Alzheimer Scotland.

I will also produce a simplified booklet with ideas and thoughts on best practice and how people could set up a programme of individualised music.

I will discuss and promote my findings by presenting them at a conference. There are other practitioners in the field of dementia with whom I work and I will share the findings with them and, of course, all my participants.

I intend to continue promoting the use of personalised music on MP3 players for people with dementia and their families to improve any opportunity to enhance their lives.

Reflections

I felt I was in a privileged position as a Practitioner Researcher as it gave me access to people with dementia and carers who may want to be involved in the research. It gave me an opportunity to look more in depth at an aspect of practice I have been involved with for many years and find ways of proving this. As a practitioner, I was always aware of my position of 'power'. Although I always ensured participation was their decision, participants were keen 'not to let me down'. One carer couldn't write and I said he should pull out but he didn't want to let me down and got his daughter over every day to write up the diary. One of the benefits I think for participants was they trusted me and knew me. I knew using PAR would be more difficult with people with dementia and this was certainly true. Involving them in the concepts of time was difficult but devising the feedback form was really useful and easier for them to participate in. During the semi-structured interviews, there were limits to what they could remember as the study had been two weeks prior. They could speak about the experience of listening when prompted but some had forgotten they had listened as often as they had. That is why I needed the carer input. I thoroughly enjoyed all the process of data collection and found the writing up difficult and outside my comfort zone.

Another aspect of the process that was hugely satisfying was being involved in devising a feedback form. Our discussions prompted a spontaneous discussion between participants about how it felt having dementia and gave some fascinating insights. Molly knew she was repetitive and explained even though she knew, she still found herself constantly asking her husband the same question. Jack expressed that he often felt stupid because he couldn't remember things and needed to depend on his wife. As a practitioner this gives me valuable insights that can help improve my communication, skills and experience. Formulating the mood scale also gave me insight into how they felt. I had never wanted to use a 'stock' assessment as I always felt it was impossible for other people to describe a person with dementia's every day mood. After our discussion this was apparent and even I was surprised. Using audio recordings of our conversations also gave me opportunities to reflect on my communication. Normally during a conversation I try to listen and also read people's expressions. By transcribing the audio tapes it gave me time to really listen and hear the nuances I had missed, or reflect on the pauses I should have taken.

I did get an opportunity to see the effect of music on Maria. I was spending time with her whilst her husband was elsewhere and took the opportunity to fit the headphones and have her listen to her choice of music on the player. Immediately she was entranced, her eyes closed, swaying she conducted an imaginary orchestra and hummed along. She was completely oblivious to my presence and a nurse entered and asked "What have you given her?" "It's just music", I replied.

References

Alzheimer Scotland, (2012) Delivering Integrated Dementia Care: The 8 Pillars Model of Co Caregiver Well-Being: Community Support

Alzheimer Scotland (2013) Statistics: Number of people with dementia in Scotland living in the community (accessed from L.Kinnaird. January 2013).

Alzheimer Scotland Practice Development Team, (2011). Alzheimer Scotland Practice Guideline 'Creative Evidence Gathering' (Capturing the impact services have on individuals. accessed from Alzheimer Scotland Intranet)

Brodaty, H., & Donkin, M. (2009). Family caregivers of people with dementia. Dialogues in Clinical Neuroscience 11(2):217-28.

Brotons,M.,(2003) Music Therapy with Alzheimer's Patients and Their Family Caregivers: A pilot Project. Journal of Music Therapy,40(2), pp.138-150

Clardy, C.H (2012) iPod Music Therapy Helps People with Dementia Recover Identity (Temporarily) accessed July 2012 on http://community.sw.org/2012/06/ipod-music-therapy-helps-people-with-dementia-recover-identity/

Cooke, M.L,. Moyle, W,. Shum, D.H.K,. Harrison, S.D., and Murfield,J.E (2010) A randomized controlled trial exploring the effect of music on agitated behaviours and anxiety in older people with dementia. Aging & Mental Health 14 (8) pp. 905–916

Dewar,B., Mackay, R., Smith, S., Pullin, S., and Tocher, R., (2009) Use of emotional touchpoints as a method of tapping into the experience of receiving compassionate care in a hospital setting. Journal of Research in Nursing.15(1) 29-41.

Foster, B., (2009) Music for Life's Journey: The Capacity of Music in Dementia Care.

Alzheimer's Care Today 10(1):42-49

Glaser, B.G., and Strauss, A.L., (1999) The Discovery of Grounded Theory: Strategies for Qualitative Research. Library of Congress:USA

Gotell, E., Brown, S. and Ekman, S. L. 2000. Caregiver-assisted music events in psycho- geriatric care. Journal of Psychiatric and Mental Health Nursing, 7, 119–25.

Gerdner LA (2000) Effects of individualized versus classical "relaxation" music on the frequency of agitation in elderly persons with Alzheimer's disease and related disorders. International Psychogeriatrics 12, 49-65.

Hanser, S.B., Butterfield-Whitcomb, J., Kawata, M., (2011) Home-based Music Strategies with Individuals who have Dementia and their Family Caregivers. Journal of Music Therapy 48(1),pp 2-27

Hays,T., and Minichiello, V., (2005) The contribution of music to quality of life in older people: an Australian qualitative study. Ageing & Society 25, pp. 261-278.

Kitwood,T., (1997) Dementia Reconsidered: The person comes first. Open University Press

Lou, M.F., (2001) The use of music to decrease agitated behaviour of the demented elderly: the state of the science. Scandinavian Journal of Caring Sciences, 15,165–173.

Music & Memory, 2012 Making the Case for Personalised Music: A Guide for Elder Care Professionals accessed Febuary 12th at www.musicandmemory.org

Raglio, A., Bellelli, B., Traficante, D., Gianotti, M., Ubezio, M.C., Gentile,S., Bellandi, D., Villani, D., and Trabucchi, M., (2012) Efficacy of music therapy treatment based on cycles of sessions: A randomised controlled trial. Aging & Mental Health, 16 (2) pp 265-267

Ragneskog H, Asplund K, Kihlgren M & Norberg A (2001) Individualized music played for agitated patients with dementia: analysis of video-recorded sessions. International Journal of Nursing Practice 7, 146-155.

Rylatt, P., (2012) The benefits of creative therapy for people with dementia. Nursing Standard. 26 (33) pp.42-47

Sherratt K, Thornton A & Hatton G (2004) Music interventions for people with dementia: A review of the literature. Aging & Mental Health 8, 3-12.

Sacks, O., (2007) Musicophilia: Tales of Music and the Brain, Picardy publishing

Sacks, O., (2008) Wired for Sound. The Oprah Magazine http://www.oprah.com/health/Oliver-Sacks-Finds-the-Bond-Between-Music-and-Our-Brains#ixzz2VWIm3zPR accessed 6th June 2013

Sixsmith, S. and Gibson, G., (2007) Music and the Wellbeing of people with dementia. Ageing & Society. (27), pp 127–145

Sung, H.C and Chang, A.M (2005) Use of preferred music to decrease agitated behaviours in older people with dementia: a review of the literature. Journal of Clinical Nursing.14 pp.1133-1140

The Scottish Government (2010). Scotland's National Dementia Strategy. Edinburgh

Walter, M. (2009) Social Research Methods. 2nd ed., Oxford University Press.

Acknowledgments

The researcher would like to gratefully acknowledge all the people that have made this study possible. First and foremost, I would like to thank Alzheimer Scotland for allowing me to participate and paying for my involvement in Practitioner Research for Older People. Lindsay Kinnaird in particular for obtaining any information I required and helping me obtain equipment. Valerie Sleigh who typed all my transcribed notes; Stephen Caine who supported my involvement. My mentor Heather Wilkinson, Research director at University of Edinburgh who has helped me with all aspects of the research, all the people who gave presentations to us at Edinburgh University and were a source of information and clarity. The people involved in PROP and especially Catherine-Rose Stocks-Rankin, PhD research student who has been a continual source of positivity and support.

Finally I would like to thank the carers and people with dementia who made this study possible and also thank my team for their patience and understanding when I have been absent. The researcher most gratefully acknowledges the kind help and assistance of all these people.

Appendix 1 - Table of feedback

This table shows the length of time that each participant with dementia listens. It shows the carer comments of how the person reacted during listening and if there was a benefit afterwards and how long that lasted.

Barbara mood was enhanced on 6 out of 7 days; Maria's mood was enhanced 6 out of 7 days; Jack's mood was enhanced 6 out of 7 days; Grace 6 out of 7 days; Molly's was enhanced 6 out of 7 days and music had a negative impact on her 1 day

Explanation of coloured mood scale.

Red = mood experienced on a good day

Brown = mood experienced everyday

Blue = mood experienced on a bad day

Molly 2pm	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Amount of time listened	35 minutes	30 minutes	30 minutes	40 minutes	35 minutes	30 minutes	45 minutes
Feedback from person	Cheerful Thoughtful (tearful)	Light & Bright Cheerful Happy Mood Peaceful	Bored	Light & Bright Cheerful Peaceful	Light & Bright Cheerful Peaceful	Light & Bright Cheerful Happy Mood	Cheerful Happy Mood Thoughtful
Feedback from carer	Cried most of time. Happy memories, relaxed listening.	Cried again but not as much as yesterday	Didn't enjoy songs as they were in foreign language. Frustrated	Enjoyed, kept talking to carer, he left room. She enjoyed and listened longer.	Enjoyed, found it relaxing & restful	In bed comfortable & relaxed. Lost concentration.	Thoroughly enjoyed, didn't want to stop. Happy memories
Effect sustained	Brighter mood - 30-45minutes	Brighter mood 30-45minutes		Brighter mood 30-45minutes	Brighter mood 30-45minutes	Brighter mood 30-45minutes	Brighter mood 30-45minutes

Grace 2pm	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Amount of time listened	45mins- 1hr	45mins- 1hr	45mins- 1hr	45mins- 1hr	45mins- 1hr	45mins- 1hr	45mins- 1hr
Feedback from person	Happy Mood Thoughtful	Happy Mood Peaceful	Happy Mood Peaceful Thoughtful	Peaceful Pensive	Pensive Thoughtful	Light & Bright Happy Mood Peaceful	Light & Bright Happy Mood
Feedback from carer	Bit down before. Brighter afterwards	Not a good day. Enjoying music cheerful	Good day, enjoying music, discussing why	Felt slightly sick. Good afterwards, muddled and talkative	Felt sick before. Enjoyed listening.	Bad start. Seemed to enjoy music.	Ok today. Enjoys music.
Effect sustained	Mood improved the rest of the afternoon	Cheerful for rest of the afternoon	Mood improved the rest of the afternoon	Mood improved the rest of the afternoon	Anxious afterwards Thinks she has to return MP3 player.	Ok afterwards	Brighter mood for a while then down in dumps later, realises MP3 player will go

Jack 2pm	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Amount of time listened	45mins	45mins	45mins	45mins	45mins	45mins	45mins
Happy Mood	Peaceful	Light & Bright	Peaceful	Light & Bright	Thoughtful	Peaceful	Happy Mood
Feedback from carer	Totally absorbed. More content and bright for the rest of the afternoon	Happy listening More content and bright for the rest of the afternoon	Singing along, conducting More content and bright for the rest of the afternoon	Loves the music More content and bright for the rest of the afternoon	Loves the music More content and bright for the rest of the afternoon	Happy & relaxed. Really enjoyed	Totally into it
Effect sustained	More content and bright for the rest of the afternoon	More content and bright for the rest of the afternoon	More content and bright for the rest of the afternoon	More content and bright for the rest of the afternoon	More content and bright for the rest of the afternoon	More content and bright for the rest of the afternoon	Left him happy and contented
Maria 4pm	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Amount of time listened	30mins	30mins	30mins	30mins	30 mins	30-40mins	30-45mins
Feedback from person	Happy Mood Thoughtful	Happy Mood Peaceful	Happy Mood Peaceful Thoughtful	Peaceful Pensive	Pensive Thoughtful	Light & Bright Happy Mood Peaceful	Light & Bright Happy Mood
Feedback from carer	Has been down for some time but mood lighter and brighter after listening.	Again lighter and brighter after listening		7.15pm 30mins Happy sing along	Brighter mood today	Brighter mood today, singing along	Good mood before but tired
Effect sustained	Change of mood lasted for a couple of hours	Lasted a couple of hours but deteriorated to melancholy by bedtime	Happy mood continued to bedtime at 9pm	Brighter mood afterwards until bedtime	Brighter mood afterwards until bedtime	Familiar happy mood after lasted until bedtime- 9pm.	Familiar happy mood after lasted till 9pm

May 7pm	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Amount of time listened	40mins	40mins	1hr	45mins	40mins	2.5hrs	40mins
Feedback from person	Cheerful Happy Mood	Cheerful Thoughtful	Light & Bright Happy Mood	Peaceful Pensive	Pensive Thoughtful	Cheerful Happy Mood Peaceful	Peaceful Thoughtful
Feedback from carer & effect	Settled well and relaxed	Very relaxed	Enjoyed listening again	Moody before music but was relaxed whilst listening	Settled & relaxed. Filled form in after 10minutes.	Enjoyed listening	Very relaxed,
Effect sustained	So relaxed she went straight to bed afterwards		Again was very settled & relaxed	Moody again afterwards		Very relaxed and went to bed almost straight afterwards	Again went to bed almost straight afterwards

Appendix 2 - Discussion group for participants with dementia

Appendix 2 - Discussion group for participants with dementia

Length of time 1.5 hrs

Venue: Banff Castle small meeting room

Format of discussion i.e. discussion, break for refreshments, further discussion

Welcome participants & introduce co-facilitator.

Explain reasons : I've invited you here today is because you've agreed to participate in my research. Explain what the research is and also that I want to involve you in the design of the research as much as possible.

1. Discuss the length of time they think would be best for listening to the music. Ask them their thoughts first and prompt as necessary i.e.30-45minutes
2. Discuss the period of time the research will cover i.e. the period of time they will listen to music. Again ask their initial thoughts and prompt with 7/10/14 days. Explain there will need to be a matching period for not listening. Washout period to compare if there are any differences

Break for refreshments

After break have photos and cards placed on a table for participants to look at as prompts.

Explain: In order for you to feedback how you are feeling I want to use words that have meaning to you.

- For example on an everyday basis what words describe how you feel. Just say whatever comes to mind and we'll write them down on the flipchart. Look at the photos and see if any of the photos express how you feel.
- Now I want you to think about how you feel on a day that's not so good. One of those days that isn't turning out how you hoped. What words describe how you feel? Look at the photos and see which ones show your mood.
- Now I want you to think about a really good day. Think about a day where you've enjoyed yourself, and had a good day maybe had a good laugh. What words would describe how you feel? Look at the photos and see which ones show your mood.

So now we have all these words to describe how you feel I will make up a feedback form that you could mark after every session just to express how you feel.

(At this point we can make up a sheet just so you have an idea how it will look).

Lastly I'd like to ask you about any ways that might help make sure that the research is on track such as that you're listening to music when we've agreed. Do you think there are any ways that would help; such as me phoning to check how its going? Or any other ideas you might have

Discussion Group Prompt Sheet for Carers: 25th October 2012 10am-11.30am

Welcome everyone

Explain reasons for today…to be involved in design and to participate.

Explain about meeting yesterday and what was agreed....length of time to listen, How long a period of time. Check this is ok

Explain about feedback forms and show an example of it.

Explain about their role in prompting with listening and using the equipment, completing feedback and discuss any difficulties they might anticipate or questions

Discuss if there are any ways that I can help to ensure the research is on track… you're listening and not having any problems... problems with MP3 players etc.

Do you think there are ways that would help …phoning or any ideas. Give mobile number for them to contact

Appendix 3 - Semi structured interview (carer)

- Use the diary as a talking point
- How was the week when? listened to the music and what was their reaction?
- During the period they listened to music did you notice any changes to their mood? How did this express itself? how long did this last?
- How did the timing work of their prescription i.e. did they manage to listen to music for the length of time.
- During this period did it make any difference to how you felt or have any impact on you and in what way
- During the period they didn't listen to music did you notice any changes to their mood? (explore any negatives/positives expressed)
- Where there any barriers to listening to music- explore what these were. Could they manage to use the equipment, change music, timing of listening etc
- Do you feel you might continue using music in this way? If not what are the barriers?

Further explore their responses by reflecting back their words, checking anything not sure of. Use as a guide.

<u>Semi structured interview (participant with dementia)</u>

- Looking back at the week you listened to your MP3 player how did that go?
- How did you feel when you were listening to the music?
- When you were listening to the music and afterwards do you think it made any difference to your mood?
- - so it had an effect on you?
- What about the way you were listening to music with headphones?
- if I was to say to you this is going to be prescribed to you as a therapy, what would you think? Would that be good?
- How did you find using the feedback form? Did the photos/words help?

Further explore their responses by reflecting back their words, checking anything not sure of. Tailor to individual if struggling to understand and show player, headphones, feedback form etc.

Participant Feedback Form

Please tick as many boxes that best describe how you feel after listening to music

 LIGHT & BRIGHT ☐	 PENSIVE ☐	 FED UP ☐
 CHEERFUL ☐	 THOUGHTFUL ☐	 DOWN IN THE DUMPS/IN A TANGLE ☐
 HAPPY MOOD ☐	 BORED ☐	 CAN'T BE BOTHERED ☐
 PEACEFUL ☐	 WHAT'S THE POINT! ☐	 FEELING LEFT BEHIND ☐

Ethical

I will complete the Alzheimer Scotland ethical approval questionnairre as I will be asking people with dementia and carers to participate who use our services.

Considerations

As I would like to include people with dementia I will need to ensure they understand as fully as possible what their participation will involve. I am targetting people with dementia in the earlier to moderate stages of their illness.

Approach

I would make the first approach to carers to ensure they are happy participating as a couple and then send them further information so they can read more of what is involved.

Method- consent

Visit each couple to explain and allow for questions. Give them an information sheet explaining the process. Carers will probably have more understanding than the person so can reiterate anything the person with dementia is unsure of when I leave. If they are happy to participate ask them to sign a consent form.

Music preference

At the first meeting leave a questionnairre of what music the person prefers so that this can be sourced either from the couple or Itunes

Confidentiality and anonymity

The consent form will explain re voluntary participation, confidentiality & anonymity, agreement regarding my using an audio tape and how data is protected. All names anonymised in text

Appendix 5a - Research details

Name of researcher	Janice Caine, Service Manager, North Aberdeenshire Services
Project title/lead question	Is Music The Best Medicine? What is the impact on a person with dementia's quality of life if music is prescribed on a daily basis (similar to prescribed exercise) and can this also impact on the carer?
Brief outline of study and its aims	The participants with dementia will listen to personalised music on an mp3 player over a set period of time (10-14days) for 30-45minutes daily at a time to suit. Feedback will be sought daily from both. Objective: To explore if music can be used in the home environment to improve the quality of life for both the person with dementia and carer.
Research methods	This is Participatory Action Research using qualitative methods and will explore the experience of both people with dementia and carer. The participants will be involved in designing aspects of the research i.e. Discussion group (audio taped) with individuals with dementia/carers to devise feedback forms exploring emotional touch points; length of time music played daily, length of time music played overall. Semi structured interview at end of study

Research participants

Who are the research participants?	I aim to recruit 4 men with dementia and their carer. Also 4 women with dementia and their carer. I aim to recruit individuals in the early to moderate stage of their dementia
How will they be recruited?	The participants are known to the service either because they access our dementia café or home support services.
What information will they be given on the research study?	I have briefly described the research to carers firstly and will send out information sheets to the participants. This information sheet details the purpose and what it will involve, voluntary nature of participation, details of confidentiality and how research will be disseminated and anonymised.
Do you anticipate any ethical concerns in relation to this particular group?	No as people will be in the early to moderate stages they should be able to understand the research and participate. The information sheets will act as a reminder too.

Data collection and confidentiality

How will the data collected be used?	I will write a report detailing the research. This will include case studies however all the data will be anonymised. Any leaflets or articles for participants/peers/academics/other professionals will similarly be anonymised
How will the data collected be stored?	Some date will be audio taped or written down. This will be kept securely in a locked filing cabinet within a locked office. Any typed data will be stored on a password protected computer or USB.
Who will have access to this data?	Only myself as the researcher will have full access to all the data. Once it is written up it will be anonymised. No mentor or other interested PROP partner will have access to the raw data.
What assurances can be given in relation to confidentiality and anonymity?	Confidentiality of all data collected and names of other participants will be maintained by the researcher. This will be anonymised in any disseminated information.

Please return completed form to Lindsay Kinnaird lkinnaird@alzscot.org

Appendix 5b - Research information sheet

Project Title
Is Music the Best Medicine?: Using Prescribed Music to Enhance Quality of Life for People with Dementia and their Carer

Study description
This research explores the use of music in the home and aims to look at the impact on a person with dementia's quality of life if music is prescribed on a daily basis (similar to prescribed exercise) and can this also impact on the carer?
I am the Service Manager of Alzheimer Scotland North Aberdeenshire services and also a practitioner. The research is being supervised by Practitioner Research for Older People and has been ethically approved by Alzheimer Scotland.

Invitation
You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully'.

What will happen:

If you agree to take part I would initially visit participants to identify the music they enjoy listening to and obtain consent. I will be asking 4 women with dementia and their carers to take part and 4 men with dementia and their carers to take part. I am hoping that people in the early to moderate stages of their illness will take part so they can be involved in the design and also be fully informed.

As this is participative research people with dementia would be asked to take part in an a discussion group to identify how long a period the music would be listened to and for what period of time e.g. 30minutes daily for 10 days. At this discussion group I will also be exploring ways of feeding back with the group. There would be a similar discussion group with participants who are carers to explore ways of feeding back. This group would take approximately 60 to 90 minutes and take place at Banff Castle, Banff. I would like to audio tape the discussion group and interviews so I can transcribe the conversations.

After this participants with dementia would be asked to listen to 30-45 minutes of music daily at a time that suits. This would last 7-10 days (depending on what was agreed at the discussion group). During this time I would ask participants to keep a brief diary of how they are feeling and any effects. The following 7-10 days would be music free.

Time Commitment
My initial visit to go over the consent form and discuss what music should be recorded on the MP3 player would last 45-60 minutes. The discussion group should take 60-90 minutes with time for refreshments. After listening to the music the participant would need to complete a feedback form/diary however this should take no longer than 5/10 minutes daily over a 7 to 10 day period.
After the study I would like to visit each couple of participants to undertake a semi structured interview. This should take no longer than 30 minutes per person.

Participants' Rights
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form.
If you decide to take part you are still free to withdraw at any time and without giving a reason. This will have no detrimental impact on any services you access from Alzheimer Scotland, North Aberdeenshire Services
You have the right to refuse to answer or respond to any question that is asked of you.
You have the right to have your questions about any of the procedures answered (unless answering these would interfere with the study's outcome)
If you have any questions as a result of reading this information sheet, you should ask the researcher before the study begins

What will happen to me if I take part?
If you agree to take part I will ask you to a discussion group before the study starts and one after. This will be 45minutes in length. I would also ask you to listen to 30-45 minutes of music daily (music you have chosen) at a time to suit you. This would last 10 days. During this time I would ask you to keep a brief diary of how you are feeling. The following 10 days would be music free.

What are the possible benefits of taking part?
The study aims to find out if there is any benefit of listening to music on a daily basis and will further practitioner knowledge & may have benefits to others people with dementia and theirt carers. There are no known risks to you.

Will what I say in this study be kept confidential?
All information collected about you will be kept strictly confidential and at all times confidentiality, privacy and anonymity will be ensured in the collection, storage and publication of research material. Data generated by the study will be retained in accordance with Alzheimer Scotland's confidentiality policy and the Data Protection Act 1998.
The data generated in the course of the research will be kept securely in paper or electronic form for a period of five years after the completion of a research project.
Any case studies will be anonymised and audio tapes will be kept for a period of 2 years.

Cost, Reimbursement and Compensation
Your participation in this study is voluntary. You will have the use of an MP3 Player and headphones for the duration of the study.

What will happen to the results of the research study?
The results of my research will be used in a report and disseminated via the organisation and published. This is so other people with dementia and their carers may benefit from the research. You will be given a copy of the final results.

Who is organising and funding the research?
I am conducting the research as a practitioner in conjunction with Practitioner Research for Older People and Alzheimer Scotland is funding this research to take place.

Who has reviewed the study?
The research and research methods have been approved by Alzheimer Scotland

Contact for Further Information
Janice Caine will be glad to answer your questions about this study at any time.

You may contact her at 01261 819066 or email : JCaine@Alzscot.org or write to Alzheimer Scotland, North Aberdeenshire Services, Clunie Street, Banff. AB45 1JA.

Thank you
Thank you for taking time to read the information sheet.

Date
30th September 2012

Appendix 5c - Consent form

Is Music the Best Medicine? : Using Prescribed Music to Enhance Quality of Life for People with Dementia and their Carer

Researcher: Janice Caine, Service Manager, North Aberdeenshire Services. Clunie Street, Banff. AB45 1JA. Tel: 01261 819066

Please initial box

I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason. ☐

I agree to take part in the above study. ☐

I agree that my data gathered in this study may be stored (after it has been anonymised) in a password protected computer or files that are stored securely as per data protection act 1998. ☐

Please tick box

	Yes	No
I agree to the interview / focus group / consultation being audio recorded	☐	☐
I agree to the interview / focus group / consultation being video recorded	☐	☐
I agree to the use of anonymised quotes and case studies in publications	☐	☐

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

National Office

22 Drumsheugh Gardens

Edinburgh EH3 7RN

Telephone: 0131 243 1453

Fax: 0131 243 1450

19 September 2012

Janice Caine

Dear Janice

Application for ethical approval for research from Alzheimer Scotland

Thank you for your application to access research participants through Alzheimer Scotland's North Aberdeenshire Service.

We are happy to provide ethical consent to the research study on the basis of, and in accordance with the information provided.

Best wishes with your research study.

Yours sincerely

Henry Simmons

Chief Executive

Appendix 6 - May's IPoem

May 's IPoem

Well I didn't do as much as I should have done I don't think...

I did enjoy it. I did find it very calming.

I thoroughly enjoyed that and I wrote down the comments that it made ... so you've got those.

I find music is very good, it calms you, and it makes you just relax which is half my trouble.

I thought it was going to be repetitive but it wasn't.

Yes and I actually did enjoy listening to it because I could sit up there with the headphones on and nobody could distract me.

I think it was, I quite enjoyed it – it was funny, cos I'd never worn headphones before.

I usually just listen and but I thought – you're getting it quite literally into your head aren't you?

Yes, you can't hear anything...

It did ... I think...and other people would be able to say better than me

I think – I'm not as irritable as I was.

I'd be very happy with that as long as I can remember how to use it.

I'm hoping that might be something that I can learn to actually bite my tongue instead of saying something.

I think music is great – Yes

I'd be very happy with that as long as I can remember how to use it.

Now whether it would be as good for everybody cos everybody has different things they like and I like music anyway.

Some of it more than others but it was all different which was nice. You put on a CD you tend to get all the same on it although I do like Pavarotti and Nessum Dorma and I love that...

But I've always liked – I mean – I did not like learning music but have always liked listening to music.

Yes – positive totally positive.

Yes – like that one I can see of clouds and that's very calming – but what I think I need to do is not forget I've done it.

Well it's been really useful to me....

Ella's IPoem (carer)

It went really, really well....

I don't know if he's the best specimen for the survey because he actually loves music and from the minute- always forgot of course, but each day at 2 o-clock

I'd say now it's time for your music and ohhh! – right away and he was ready for it and he would sit and conduct in the seat and sing along with it so he was perfectly happy.

In fact it was ¾ hr I left them on for because he enjoyed it so much and there was no problem

I had to remind him of course, apart from that no, no problem at all – really thoroughly enjoyed it and happy as anything

I noticed this is – at 2 when were sitting doing it – he's more restless, he's more restless in the afternoons.

Aye he's back and forward and actually because he's got a friend in hospital I say I think you should go and see him

I used to laugh sometimes when I heard him..

Oh I would say that it definitely made him happier, definitely affected him – yeah, yeah.

I'll say I think you should go down and see the boys at the golf club and off he goes and that keeps him happy up until lunchtime and then of course he watches the news and that keeps him occupied.

I sort of guided him but basically it was -happy contented, you know but he managed it.

I would say how do you feel? after the music and he'd say "Oh I'm happy", you know he was always happy

I didn't elaborate as there was nothing other than he was really happy and contented.

I don't think so but it is certainly something I would be encouraging him to do – erm – because it's a long winter ahead of us you know.

I've tried jigsaw puzzles again.

I was a bit sorry when the 45 minutes was up and I thought ah well...

Yes yeah – I thought well – we'll just do it for the 45 minutes but no he was perfectly happy, quite contented, anything you suggest he's quite happy with.....It's a different kettle of fish coming from me.

Ah ha – you've always got to be careful for hurting his pride

Appendix 7 - Data analysis in depth

1. Participant with dementia's experience of listening

Four of the participants spoke of being absorbed in the music and really enjoying it; It makes you just relax, I enjoyed it- I love music- You were just gone-you can't talk and listen; It went well- I enjoyed the music- Relaxed and Peaceful; It does work- it was lovely, thanks Molly said it was alright and it made her feel relaxed ; her husband described her as enjoying the music and one day didn't want it to stop. Her husband's diary and interview was able to describe that she had enjoyed the music. The difficulty for Molly was that she couldn't recall her experience two weeks later.

The feedback forms showed that 33 out of 35 occasions of listening improved their mood to how they would feel on a good day. There were 2 out of 35 days with two participants where it didn't alter their mood. One participant had a negative impact on her mood (she didn't like the music as it was in a foreign language). See the table of feedback for further information. Appendix 1

2. Carer's observation of person listening

The experiences of the participants who listened were quantified by their carer, who described how the person was during the listening. All five carers described that there wasn't an issue getting the people they cared for to listen. They also described how the participant had reacted: Quite happy to listen- very settled and relaxed; She is away with the fairies- singing ,swaying with her eyes closed, fully engrossed; Totally absorbed-listening-singing along and conducting-After he listened I would ask how he was- he was always happy; Said she enjoyed the music even though it made her cry-enjoyed the music, found it relaxing and restful- didn't enjoy music today(foreign language)-kept taking headphones off; Enjoying the music- enjoys listening. From all the observations of the participants it was clear the music had had a positive effect on them.

3. Carer's experience

All five carers described their experience of taking part as a positive one. They all felt the listening period provided a break for them: Aye I got half an hours peace- as an experience I thought it was positive but think she prefers music in social settings; Oh it's positive as I can come down and not worry as I know she's listening to her music and enjoying it ;Would like to continue doing this; I would encourage him to do it-it went really well-I was a bit sorry when the 45 minutes were up and I thought ah well; It was nice to see her happy. Each carer got a break during the listening and Ella and Jim said the benefits lasted a few hours whilst Tony said the effects lasted until bedtime which was nearly four hours. There was an exception on one night however despite Maria being depressed the music was still able to have a positive effect on her mood

4. Length of listening/timing;

We had agreed as a group that listening would be 30-45minutes at their prescribed time. Four had chosen 2pm and one had chosen 7pm. This changed in two cases. Grace listened to her music in the morning when she was in bed as she was often 'down in the dumps'. Maria listened at 4pm instead of 2pm as she would have been busy and the focus was to listen to the music without distraction. Barbara and May felt that 7pm had been too late to notice any effects as May would often go to bed so timing is important however comments describing her mood were 'relaxed and settled'.. All participants listened the agreed time although when May wasn't prompted to stop she listened for 2 ½ hours. There were only two occasions when participants with dementia asked to stop listening. When carers were asked if they felt the person would have listened longer they all agreed they probably would have. With hindsight I feel the study didn't require this measure and it would have been more beneficial for carers to note how long they listened for before they wanted to stop. This listening time proved to be a break in all cases so would have benefitted the carer and taken another prompt away.

5. Using Equipment

Other than Jack who needed an initial prompt the other participants all needed help to work the equipment. Grace managed to use the shuffle the music so if she found herself down in the dumps- she would choose one of the classical tracks and it would lighten her mood. This shuffle option was very useful as it also meant the carer wouldn't require keeping changing albums. On shuffle wherever the MP3 was turned off it would recommence from that point and saved repetition- I thought it would be repetitive but it wasn't. Headphones enabled people to focus completely on music and cut out extraneous noise. Each participant had a positive comment regarding the headphones; they felt the carer could be in the same room whilst they listened to their music. It intensified their listening and they weren't distracted- you're getting it quite literally into your head. It concentrated listening and shuts everything out. May thinks of all kinds of things when listening to CD/Radio then thinks it is a true event and accuses her husband of actions he hasn't done. By listening to music via headphones was completely engrossed and it didn't allow for daydreaming or misinterpretation.

6 Expectation of Carers

Every carer was aware they would need to prompt the person they cared for to listen, complete feedback form and to stop listening in varying degrees. They would either have to work the equipment totally or support them to do it.

I relied on the carers to feedback on mood before, during and after and to write up their observations.

One of the expectations expressed by a few carers was that although the participants with dementia all having enjoyed the experience there was almost a surprise at the lack of response ' Took them off- never spoke about it- It's like it never happened and this is what happened every day. The second week she never mentioned it! I thought after one week she might say 'am I not getting the music tonight?'. She's not mentioned it one single bit! Another carer said She never asked to listen to the music (in the washout period) when offered said No. There was an expectation that if it was enjoyable the participant would remember and ask for it. This is the difficult part that my research seeks to address in how people with dementia and their carers can be encouraged to use music to enhance their lives. The onus is always going to be on the carer. The difficulty for people with dementia is they may enjoy music when it is played however due to their cognitive impairment they may have forgotten they actually enjoy music until reminded

7. Preferred Music

All the carers felt that the music choice was important as did the participants with dementia. If it had been any other music it probably wouldn't have worked. Tony said :It doesn't have to be the music she knows but the style of music. On the other hand by giving them music they like and knowing the response will be better- really you're proving what you already know.
I love music if it's music I like. I did like the music. Andre Rieu – he's very much my one.

8. Mood Benefit

The table shows in detail the mood before if noted and the mood after. In 33 out of 35 occasions across the week, music had a positive effect on the participants with dementia. The benefit ranged from 30/45 minutes, couple of hours to four hours in Maria's case. It was also interesting to see that although Maria was depressed the music still had an effect on her and brightened her mood. In May's case it was difficult to pinpoint exactly how long her 'settled and relaxed mood lasted as she went to bed pretty much straight away.

Appendix 8 - Involving people with dementia

I always anticipated some difficulties on involving people with dementia in designing the research . I am well aware as a practitioner that the people with dementia due to their cognitive impairment would probably have difficulty with ideation and abstract concepts such as defining time periods and the abstract washout period. I also wanted to use Participative Action Research in the design of my study so couldn't initially give them full details of how long the study would last as they were going to be involved in deciding this.

Discussion group with individuals with dementia

The participants struggled with these three concepts and wondered why there would be a period whereby they didn't listen to music. These ideas required a lot of prompting even to individuals with early to moderate dementia however I have always felt it was important to try and involve people as much as possible.

I wanted to create a feedback form that determined scale of mood which allowed people to actively participate in identifying their emotions. Using a variety of photographs and 'feeling' words on different coloured card acted as a catalyst to prompt emotions; it also gave participants with dementia something concrete to think about and prompted emotions and memories.

It was a much easier way for the participants to be actively involved in and less taxing. It acted as a catalyst for them to share their experiences of how dementia affected them and produced a lot of rich data. Even this format has flaws as different words mean different things to individuals however a consensus was agreed. For me that was better than using a feedback design they had no involvement in and therefore wouldn't have had any meaning to them.

Devising the feedback form in a this more creative way similar to emotional touch points is something I have used before with good effect. I hoped individuals with dementia would be able to tick the boxes and that feeding back how music had affected them would prove easier. As I do not have experience of having dementia I felt it was more meaningful for participants to describe their own mood scale. (See Appendix 4).

Carer's discussion group

I wanted to use a similar discussion group with carers too so they were involved and participated in the research design. They also needed to agree to keep a dairy. By being part of the design of the research and having influence on its design I felt they were more likely to actively participate.

On reflection the discussion group was really useful and I hadn't thought of some of the difficulties the carers felt may occur so was able to build in additional measures to ensure the study worked better for the participants.

A couple of carers felt they may have difficulty stopping the people they cared for listening to the music after the agreed period. I was able to build in a proviso and just asked carers to note the length of time people listened rather than let it become an issue.

Another issue was that a couple of carers felt the person they cared for may refuse to do certain things because they wouldn't believe or listen to the carer. I ensured that the folder the individuals with dementia received stated the time of listening and length of time so it was my research instructions that reminded them and the onus of proof wasn't on the carer.

Semi structured interviews: 5 with individuals with dementia and 5 with carers

I chose this method over questionnaires as the latter wouldn't have collected the experiences or narrative of the people with dementia and their carers. Questionnaires would have been difficult for people with dementia to complete due to their cognitive difficulties and with semi structure interviews I would be able to visually prompt with equipment, feedback forms etc and remind them as necessary.

For carers it was beneficial as the diaries were completed either very fully with details and the interview allowed me to check the information. It was also surprising that some carers had forgotten the detail of what impact the music had on the individuals with dementia. One carer apologised for the lack of effect it had on her mother in law yet in the diary it repeatedly stated ' very settled and relaxed'. With hindsight I was glad to have used both methods.

Feedback Forms:

These were completed by the participants with dementia on a daily basis over the 7 days. I wanted to determine how they felt after listening to the music and compare this with how they felt every day. The method had to be straightforward so they could complete with minimal prompting and intervention and were to be completed after every listening.

Each participant had their own folder with their personal prescription in to remind them when they were listening and for how long. After every session it prompted them to complete the feedback form. The carer was also instrumental in prompting.