

Improving Quality of Life and End of Life Care for People with Dementia Using Personalised music: ‘The Soundtrack to My Life’ Tool

Elaine Argyle and Tony Kelly

Synopsis

Good support at home for people with dementia and their carers is crucial to maintaining their quality of life and helping them to remain in their own home. Person centred packages of care have been shown to be an effective means of providing this support.

In this pilot study we aimed to improve quality of life of people living with dementia at (including at end of life) and their carers. This would be by using and evaluating, a bespoke, person centred music tool: Soundtrack to My Life (STML) with a dementia specialist home care team supporting people with dementia in their own homes. The STML tool is designed to draw together pieces of music representing significance in the life of a person with dementia, as part of a bespoke life history /biographical care plan. In using the tool, it was hoped that engagement of people with dementia by support staff would improve and that support staff would be encouraged to reflect on their practice, enhancing their interpersonal skills.

The research phase of the project aimed to evaluate the way that using such a personalised compilation of music contributed towards improving quality of life. The evaluation used a questionnaire and semi-structured interviews to seek feedback from care workers and key managers about the degree to which the tool had benefitted the person with dementia and their principal carer.

Terminology

Throughout this report the Soundtrack to My Life tool is referred to as STML. When we talk about the 'home support service' we mean those care workers who operate as part of the team, providing care at home for 'people with dementia' (PWD), referred to as 'Clients' within this document. The term 'support staff' refers to care workers within the home support service. The principal family carer is referred to as the 'carer'. In this study carers included husband, wife, son or daughter of the PWD, whilst 'stakeholders' included only those who work for the service in a supervisory capacity.

Summary Findings

The pilot project has demonstrated the benefits that derive from using personalised music as an adjunct to a person centred plan of care. Clients who have a 'Soundtrack' have benefitted from '*new conversations*' with their support staff, who in turn have '*seen new emotions*' from the Client that they work with.

This pilot project also alluded to the importance of appropriate staff training, planning, and organisational leadership as crucial to the success of a implementing a person-centred intervention such as STML. (The challenges and opportunities around these factors have not been evaluated as part of this pilot project report).

Introduction

Dementia is a major public health issue for the 21st Century for which there is presently no cure. The UK National Health Service states that in England there are 570,000 people living with dementia, and this number is expected to double over the next 30 years. The older you get, the more likely you are to develop dementia and it remains a leading cause of dependency and disability among older people. This increasing number of people will lead to an increasing demand for informal and formal sources of care in order to meet their needs. People with dementia often live for many years after their diagnosis. However, dementia is a degenerative condition, with no cure, thus plans for person centred interventions that improve quality at the end of life must be made before thinking and speaking abilities fail. There isn't a single specific point when end-of-life care begins; it very much depends on the individual. To this end, the Prime Minister's Dementia Challenge, launched in March 2012, offers a major opportunity to improve end of life care for people with dementia, by addressing the three key aspects of:

- Improving health and social care (e.g. by using innovative care planning tools)
- Creating dementia- friendly communities (e.g. maintaining links with the community)
- Better research (e.g. evaluating tools that may contribute to enhanced care)

Perspective on home care and person centred support

For many older people, their present home is seen as the most favoured accommodation, even if it becomes too difficult to cope alone (Leeson et al, 2003). The literature on older people and care suggests a wish to remain living as independently as possible, which has been interpreted as a willingness to stay at home with a corresponding reluctance to move into any form of institutional care. It is indeed striking how central *the home* is to the concept of independence both in policy terms and in the statements of older people, to the extent that institutional care does not feature prominently in Government commissioned literature. The Royal Commission on Long Term Care (1999), the Green Paper Independence, Well-being and Choice (2005) and the Department of Health's A Recipe for Care (2007), all recognise the increasing role of home based care over the coming decades, and the right of older people to have access to a range of services over which they can exercise a degree of choice.

Relatives, as well as neighbours, are seen as a resource for caring and enabling people to live 'independently' at home. Indeed research (Gaugler, 2005 and Challis, 2002) suggests that for people with dementia, early provision of in-home care and case management can keep them at home for longer. However, the impact of providing long term care for someone 'at home' may become arduous and strain the 'physical, emotional, intellectual and spiritual resources of [those] individuals [involved]' (Williams, 2002: 147). This has implications for service design in-terms of appropriate support for principal carers, and indeed for frontline service staff.

To be effective, home care for people with dementia needs to be sensitive to the special problems that they present. Commonly concerns exist about possible vulnerability to abuse, inability of the 'client' to act as such (capacity issues), behavioural difficulties and the expectation of progression of the disease, together with likely complication by other deteriorating health and social problems. Typically poor insight can mean failure to recognise risk, and poor cognition, perhaps compounded by pre-existing personality and possible relationship difficulties with family and others can lead to a breakdown in the structures necessary to keep them at home. The evidence suggests a very strong need for agencies to work especially closely with carers (Banerjee, 2003; DoH, 2008; McDonald and Heath, 2008) and to provide a flexible, responsive, individually tailored service (Patmore and McNulty, 2005; 2007).

Person centred care is a major theme in the literature (see De Bellis et al 2009, for an overview). Karlawish (2000) highlights the tendency to lump people with dementia together as if they were a homogenous group, when in fact there are major sources of heterogeneity. Kitwood (1997), the pioneer of person-centred care theory, promotes the equality of the person with dementia by what he calls 'positive person work'. Glynn et al (2008) differentiates between person-centred planning and person-centred support. The latter is often compromised by concerns about risk that tend to restrict rights and choices.

Activity regarded as 'risky' (perhaps to the provider, rather than the client), may be discouraged or prohibited (Taylor and Donnelly, 2006). The recent Department of Health risk guidance (Manthorpe and Moriarty, 2010) has, however, been explicitly endorsed to advocate a risk empowerment approach. Many authors (Innes, 2002; Innes et al, 2005; Patmore, 2006; Patmore and McNulty, 2007; Gladman et al, 2007) discuss the benefits that derive from personalised, user-centred and flexible packages of care, designed around the client and carer, rather than the commissioner, and embracing the person's unique biography and responsible risk taking.

The Use of Music in Care

An important component of the promotion of 'active ageing' and person centred approaches has been the growing popularity of the use of arts in the promotion of health and wellbeing (Kilroy et al, 2007). Thus, as the Arts Council states, such arts based activities 'improve individual and community health and health care delivery' (Arts Council England, 2007: 5). This beneficial impact of arts involvement has been upheld by much research. For example, it can promote a sense of identity, offer new opportunities for self-expression, improve confidence and help build new friendships amongst those at risk of the development of mental health

problems (Argyle, 2005). Similar benefits have been found by research focussing specifically on the use of arts with people with dementia. This research has found that art involvement can help with the management of undesirable symptoms and the promotion of 'enrichment' (Coaten and Jacobson, 2001) or 'empowerment'. It can also give rise to 'hope', 'healing' and 'growth' (Johnson and Sullivan-Marx, 2006). Immediate outcomes such as quality moments and expressions of sadness and loss are therefore seen as valuable (Waller, 1999) and all people with dementia can be 'given voice', 'reached' and 'enriched' (Jonas-Simpson and Mitchell, 2005). While much of this research has adopted a broad focus on the type of art involved (Galloway, 2006), some studies have shown a positive relationship between music and mood (Cassileth, Vickers, and Magill, 2003; Nayak, Wheeler, Shiflett, and Agostinelli, 2000; Hendon, and Bohon, 2008; Hunter, Schellenberg, & Schimmack, 2010; Juslin, Liljeström, Västfjäll, Barradas, and Silva, 2008).

Age UK, also highlight the 'power of music', as an increasingly key feature of dementia care, designed to unlock memories and 'kick start the grey matter'. 'It seems to reach parts of the damaged brain in ways other forms of communication cannot'. A systematic study by Ziv et al (2007) found that music also made people with dementia 'calmer' and seemed to evoke more positive affect. In this study, people with Alzheimer's disease, living in a nursing home, were observed under two conditions: with or without music. When listening to music, residents were less agitated, seemed less uncomfortable, less vocal, and seemed more positive and calm. Wall and Duffy (2010) reviewed thirteen studies relating to the influence of music therapy on the behaviour of older people with dementia. The majority of these studies reported that it influenced their behaviour in a positive way by reducing levels of agitation. The research further identified a positive increase in participants' mood and socialisation skills, with carers.

The Alzheimer's Society, whilst acknowledging the role of music therapy, state however, that 'a review of music therapy for dementia concluded that, based on the available evidence, it is unclear whether or not it is beneficial for people with dementia.

Only a few studies have focussed specifically on the therapeutic benefits of personalised music for people with dementia. For example, an ongoing residential care project, in America (<http://musicandmemory.org>), has shown increases in happiness and sociability and in interpersonal relationships between staff, family and residents, a calmer more supportive social environment, a reduction in behaviour management issues and a reduced reliance on antipsychotic medication.

This research will therefore contribute to the available evidence base. For an overview of the up to date scientific evidence relating to the use of music and music-therapy, in the context of dementia and related issues, see Raglio et al (2012), who provide a detailed review of the most recent (from 2000 to 2011) Clinical Controlled Trials (CCT) and Randomized Controlled Trials (RCT).

Training and Staff Development

Care workers are being required to provide care to people with ever-more complex needs in an increasingly regulated environment, which needs recognition in their training and working conditions. The English CQC highlights the central role played by the care worker where '*many of the people who receive home care support rely on the quality of relationship with the [worker] coming into their home and place little emphasis on the rating of the service*' (2010: 19).

Sawyer (2005) and Rothera (2008) highlight the importance of devolving greater authority to care workers, allowing them to exercise more autonomy in their work, which Sawyer suggests may result in improved staff retention. Managers therefore need to create environments where workers are encouraged to explore and expand the options and possibilities for people with dementia, and not to unreasonably restrict their lives (in Marshall, 1997: 102).

However, task centred approaches to care and a corresponding neglect of the social and activity needs of older people remain widespread (Alzheimer's Society, 2007). A number of reasons have been given for this including

a 'knowledge gap' within the front line workforce (All Party Parliamentary Group on Dementia, 2009), contextual issues such as inadequate resources (Argyle, 2012) and a lack of clarity in the required components of good practice and how it should be implemented (Epp, 2003).

The STML project used, and evaluated, an innovative person centred tool, designed to build a compilation of meaningful and personalised music, representing key aspects of a person's life, to enhance support staff's person centred care skills, in terms of helping Clients to communicate the things that matter to them more effectively. This focus on skills was expected to facilitate a dialogue between support staff and their supervisors about their strengths / abilities and training needs, and subsequently agreeing what skills / confidence building would help in supporting Clients at the end of life. It was further anticipated that the Client's carer would become integral to this care planning and skills development agenda, and therefore part of a solutions based, person centred care planning process (however, the role of the principal carer does not form part of this evaluation).

Project Objectives

1. To review the available evidence base relating to the use of music in the home care setting.
2. To evaluate, as a pilot project, the effectiveness of the STML tool, in improving care outcomes in a typical home care setting.
 - What contribution can the STML tool make to the effective maintenance of the client in their own home, avoiding the need for institutional care?
 - In adopting the STML approach to working with people at the end of life, does it have a positive impact on the care workers skill set?
 - To what extent does a music based care planning tool improve the caring relationship between the person with dementia, their principal carer and the care workers supporting them?
3. To evaluate the effectiveness of the STML tool as an adjunct to enhancing support staff's interpersonal skills, and as an aid to person centred care planning.
4. To identify opportunities to use the STML tool more effectively with a range of home care clients.
5. To disseminate the evidence base arising from this evaluation as widely as possible.

Study Design

Sampling frame

Participants in the study were in two distinct categories: a small number of support staff and Clients (PWD) that they support. An important aspect of the project was the rollout of training across the participating support staff. Training in the background and use of STML tool was delivered by JoCo Learning and Development, who have both developed the STML concept and offer training and consultancy to individuals and organisations in the health and social care sector. The development of support staff competencies was seen as a key aspect of this initiative. Each participating member of staff was asked to complete / annotate their own continuous professional development (CPD) file. This included a diary sheet and reflective journal, which has the potential to show how using STML helped to identify opportunities for learning and improvement.

PWD were then recruited into the study by the support workers who had already established relationships with Clients and carers as part of their job role.

Most projects in the area of arts participation including a personalised music interventions tend to be small scale and anecdotal. This is largely due to the significant methodological problems in measuring the efficacy

of these types of interventions due to the impact of extraneous variables on this impact and the length of the causal chain in linking intervention with outcome (Bryman, 2012). Further problems arise from the difficulty in standardising intervention design and delivery. An STML strength was in offering a standardised design and delivery process but like other interventions remained sensitive to features of the local organisational context and the logistical difficulties in applying experimental intervention methods within an organisation or team. Thus while randomised controlled trials are the generally accepted 'gold standard' when aiming to evaluate the impact of various interventions on health and wellbeing, such an approach was deemed incompatible with the project scale and complexity of the issues that this pilot project aimed to explore.

Method

The design chosen was mixed method, using a combination of qualitative semi-structured interviews and questionnaires administered to a wide range of participants. It had been anticipated that the research could use a before and after design methodology, to assess the impact of using Soundtrack on a number of client related parameters. The team had intended to capture data relating to a range of parameters of interest using interviews, questionnaires and in some cases observations derived from Dementia Care Mapping. The literature suggested that these parameters might include: how calm, or agitated the Client appeared, the Client's affect, their general level of comfort, vocalisation, and socialisation skills, particularly with carers. However, due to operational challenges, much of this baseline and follow up work was not undertaken with Clients, and was not available for analysis or inclusion in this report.

The client's care plan, however, remains a useful source of data relating to mood and levels of positive or negative interactions, but these were not evaluated as part of this pilot study. It is therefore anticipated that work might also be undertaken, at some future date, to harvest even more data relating to the direct impact of STML on those Clients who have been using the tool. In this pilot the established relationship between the support staff and participating PWD and their carers was deemed to enable them to make some significant and insightful observations about the impact of the STML for the purposes of this evaluation.

Evaluating Impact of Soundtrack Using Support Staff Questionnaires

An anonymous questionnaire was designed for support staff in addition, care staff were given opportunity to make free text comments. Equivalent questionnaires and interviews were designed for Clients, carers and stakeholders in the project; however, the availability of resources, and the timetable for analysis and presentation of this report has precluded the use of the Client and carer questionnaires at this time.

Semi-structured Qualitative Interviews

Stakeholders involved in the implementation and management of the project were also invited to participate in a semi-structured interview, designed to elucidate feedback about STML, the enablers, barriers and success factors that might usefully inform future projects. Interviews were tape recorded as an aide-mémoire and where appropriate, to allow the accurate reproduction of participant quotations. The meanings and the themes that derive from these interviews were used, inter alia, to validate other data deriving from, for example, the staff questionnaires. Only feedback from the stakeholder specifically about the impact of the STML tool is quoted in the findings to address the objectives of this study. One Semi-structured interview, conducted by JoCo staff with one carer participant is, however, included in the findings.

Ethical Issues and Informed Consent

In the first instance a concise project information sheet) was distributed to prospective research participants (homecare Clients and their principal carers).

The local manager acted as the initial point of contact between the investigators and the clients in preparation for Soundtrack training and work with Clients. It was the service manager who provided access to local care

workers and who distributed copies of the information sheet to those who would be involved. Prospective participants had the opportunity to discuss the project with the research team, by telephone or during a visit to the client’s home, and to ask questions relating to the participant information sheet. Suitable clients were: aged over 50 years, had a diagnosis of dementia, and were able to participate in the study by engaging with the STML tool.

Identified Clients and their principal carer were first contacted with a view to eliciting their support and involvement in the project. Those Clients / carers who agreed to participate were visited, in a timely manner, so that the logistics of the fieldwork could be worked out and agreed.

Confidentiality and the Management of Data

The research project was undertaken in accordance with the host organisation’s written procedures and the Data Protection Act (DoH, 1998).

The research team therefore:

- Ensured that they had each study participant’s explicit informed written consent to obtain, hold and use their personal information.
- Ensured that security arrangements were sufficient to prevent unauthorised breaches of confidentiality.
- Ensured that personal data was not kept for longer than necessary.
- Ensured that information obtained as a result of research was not disclosed to third parties with the exception of statutory notification.

Findings

The findings are divided into two parts: *first* the feedback provided by care workers in the anonymous questionnaire, and *second* a free text and semi-structured interview feedback provided by support staff, carers and other stakeholders.

Table 1: Care staff responses to set questions about how STML impacted on the Client (PWD), not all staff recorded a comment.

List two things that you think are good about Soundtrack	<ol style="list-style-type: none"> 1. It’s reopened a window to the past. 1. Gives you an awareness of how powerful music that is meaningful can have on an individual. Has enabled the Client to reflect back and share memories that have been important to them throughout their life (the Soundtrack and the life history file). 2. The music communication. 3. Good project gives an opening to talk to the client. 4. Good concept and clearly valuable to help carers connect with people with dementia. 5. In my opinion I see this as a positive, using this with one Client at the moment and it’s worked.
List two ways in which you think Soundtrack has benefitted the Clients your team work with	<ol style="list-style-type: none"> 1. Brings back good memories remembering loved ones and family seeing new emotions and seeing the person they once used to be. Fun singing along and dancing. 2. One client of mine who enjoys music in general – I have seen him become very uplifted and more animated his favourite music is played. 3. Extra quality time (very important). To see happiness in faces when singing. 4. Helps to know the Client more. 5. Improved communication. Getting to know Client better. 6. Empowers Clients, gets teams seeing the person rather than the disease.

<p>List two ways in which Soundtrack has benefitted the staff teams you work with</p>	<ol style="list-style-type: none"> 1. Brings something different other than just day to day our routine care work. Learning new skills. 2. Not sure. Cannot speak on behalf of other members. 3. Willing to engage with the use of music in life.
<p>List two ways in which, in your opinion, Soundtrack has improved care practice</p>	<ol style="list-style-type: none"> 1. It's brought new conversations, seen new emotions. Seen a different side. 2. ...given staff an awareness for them to explore different types of music the client [Client] enjoys. 3. Care practice is always paramount but with Soundtracks knowing a little of what makes a person happy [music] can give more enjoyment for all involved. 4. Talking and listening. 5. Patient contact. Common interest in music. 6. Helps people find common ground.

Free Text Additional Comments Made by Staff

Two care workers included the following comments on their form in the additional comments section:

1. "I feel Soundtrack [STML] is very good. It brings happiness with memories and singing. It would be nice if it was introduced as early as possible, as I have found with my Client reflection of songs (names, words) has been hard. We have both enjoyed taking part".
2. "Until Soundtrack [STML] my Client never used to sing. We talked lots about dancing, but never the music he used to ballroom dance. So this has really opened up all the memories. Other carers have noticed my Client will burst into song at the mention of music, that's with working on Soundtrack. Using YouTube on my phone to find the songs really helped, he would say a few lines of a song, I would find it and play it back. I could see him going into deep thought, he would sing along then the memories would come flooding back – lovely to see'.

Free Text Additional Comments Made by Carer

Father speaking about project impact on daughter:

...“Since [the home support service] decided to do [personalised] music for dementia patients [Clients] the girls [support staff] have been coming in at lunchtime and playing music to her (Client) and she’s reacted a lot to what they’ve been playing to her... Before we used to put her to bed and she’d just lie there and go to sleep. Now we play the music and she seems to be awake a lot more and actually listening to what we are actually playing. It gives her a bit of stimulation, it helps her to think. We don’t know whether she’s thinking about the past or things like that but it’s something to think about and I think it’s really helped.”

Feedback provided by other stakeholder

“Soundtrack is fundamental to how we deliver person centred care because it’s what we are doing that’s special and if we just keep people warm, fed, clean and safe then that’s not specialist dementia care...its giving that quality of life to somebody with dementia. It shouldn’t just be about coming in and doing, it’s about how do we leave people...a care plan shouldn’t be just an audit trail about what you have had done to you it should be about who you are and I think soundtrack really does add to that.”

Conclusion

Whilst this has been a very small scale project, involving only limited numbers of Clients, carers and support staff, there is nonetheless evidence from support staff, that using personalised music has promoted *communication, knowledge of the Client as a person* and *caring skills* (project objectives 2 and 3).

The literature contains a great deal of evidence to suggest that using music can yield significant benefits to a person with dementia and their carer (project objective 1). The STML project has, in some small way made a contribution to this growing body of knowledge. It is unique in its exploration of a distinct strand in music care

interventions, which is the use of personalised music. It reveals that personalised music can be a useful adjunct to person centred care planning and improve quality of life for PWD, within the homecare context. It is perhaps interesting to note here a comment made by Brooker (2003), that whilst 'the term person-centred care has become all-pervasive on the UK dementia care scene.....what lies behind the rhetoric, in terms of practice, may be questionable'. Whilst this statement is now over a decade old, the same appears to hold true in some contemporary practice, meaning that, whilst we may all talk about person-centeredness, the question of what this actually means in terms of support staff delivering this with music, may not be so well addressed. JoCo Learning and development makes explicit through the STML tool how music for individuals in care can be person centred. This research project suggests that overall, respondents felt that STML was a potentially valuable intervention and this 'buy-in' is already helping to address objective 4 of the project: *to identify opportunities to use the STML tool more effectively* as a recognised music based perspective of person centred care.

References and bibliography

Alzheimers Society (2007) *Home from Home: a report highlighting opportunities for improving standards of dementia care in care homes*, Alzheimer's Society: London

Argyle, E. (2005) Art in the community for potentially vulnerable mental health groups, *Health Education*, 105(5): 340-354

Argyle, E. (2012) Person centred dementia care: problems and possibilities, *Working with Older People*, 16 (2): 69 – 77

Arts Council England (2007) *Annual Review 2007*, available at <http://www.artscouncil.org.uk>

Banerjee, S. et al (2003), Predictors of institutionalisation in people with dementia, *Journal of Neurology, Neurosurgery and Psychiatry*, 74, 1315-1316

Banerjee, S. et al (2010), The Stroud / ADI Dementia Quality Framework: a cross-national population-level framework for assessing the quality of life impacts of services and policies for PWD and their family carers, *International Journal of Geriatric Psychiatry*, 25, 249-257

Brooker, D. (2003), What is person-centred care in dementia? *Reviews in Clinical Gerontology / Volume 13 / Issue 03 / August 2003*, pp 215-222 Cambridge University Press

Bryman, A. (2004), *Social Research Methods (Second Edition)*, Oxford: Oxford University Press

Cassileth, B. R., Vickers, A. J. and Magill, L. A. (2003). Music therapy for mood disturbance during hospitalization for autologous stem cell transplantation. *Cancer*, 98: 2723–2729.

Challis, D., Von Abendorff, R., Brown, P. Chesterman, J. and Hughes, J. (2002) Care management, dementia care and specialist mental health services: an evaluation, *International Journal of Geriatric Psychiatry* 17: 315-325

Coaten, R. and Jacobson, N. (2001) Dance Movement Psychotherapy as a Golden Thread of remembrance and a key to communication, *Journal of Dementia and Mental Health Care of older people*, 16: 12-16
Department of Health (1998), The data Protection Act 1998, available at: www.dh.gov.uk

Department of Health (2003), *Domiciliary Care: National Minimum Standards, Regulations*, London: DoH Publications

Department of Health (2008), Commissioning domiciliary care for people with dementia and their carers: An Issue Paper for Commissioners.

Department of Health (2010), Quality outcomes for people with dementia: building on the work of the National Dementia Strategy, Best Practice Guidance September 2010

Department of Health (2010) Nothing ventured, nothing gained: Risk Guidance for People with Dementia

Epp, T. (2003) Person Centred Dementia Care: a vision to be refined, *The Canadian Alzheimer Disease Review*, April, 2003

Ericson, I., Hellstrom, I., Lundh, U. and Nolan, M. (2001) 'What constitutes good care for people with dementia?', *British Journal of Nursing*, Vol. 10, No. 11, pp. 710–14

Galloway, S. (2006) Cultural participation and Individual Quality of Life: a review of research findings, *Applied Research in Quality of Life*, 1: 323-342

Gaugler, J. et al (2005), Early Community-Based Service Utilisation in Dementia Care giving, *The Gerontologist*, 45(2), 177-185

Gladman et al (2007), Person-centred dementia services are feasible, but can they be sustained? *Age and Ageing*, 36: 171-176

Hendon, C., & Bohon, L. (2008). Hospitalized children's mood differences during play and music therapy. *Child: Care, Health and Development*, 34, 141-144.

Hunter, P., Schellenberg, E., & Schimmack, U. (2010). Feelings and perceptions of happiness and sadness induced by music: Similarities, differences, and mixed emotions. *Psychology of Aesthetics, Creativity, and the Arts*, 4, 47-56.

Johnson, A. (undated) *Tune into Your Mood: The Effects of Music on Mood*, Northridge: California State University

Johnson, C. and Sullivan-Marx, E. (2006) Art Therapy: using the creative process for healing and hope among African American older adults, *Geriatric Nursing*, 27: 309-316

Jonas-Simpson, C. and Mitchell, G. (2005) Giving voice to expressions of quality of life for persons living with dementia through story, music and art, *Alzheimer Care Quarterly*, 6(1): 52-61

Juslin, P., Liljeström, S., Västfjäll, D., Barradas, G., & Silva, A. (2008). An experience sampling study of emotional reactions to music: Listener, music, and situation. *Emotion*, 8, 668-683.

Kilroy, A., Garner, C., Parkinson, C., Kagan, C. and Senior, P. (2007) *Towards Transformation: exploring the impact of culture, creativity and the arts on health and wellbeing*, Manchester Metropolitan University: Manchester

Leeson, G., Harper, S. and Levin, S. (2003), *Independent Living in Later Life: Literature Review*, Oxford Institute of Ageing on behalf of the Department for Work and Pensions, [Online] at www.dwp.gov.uk

McDonald, A. and Heath, B. (2008), Developing services for people with dementia: Findings from research in rural areas, *Quality in Ageing* Volume 9 Issue 4 December 2008

NICE-SCIE (2006) clinical guideline 42, Dementia: supporting people with dementia and their carers in health and social care, London: National Institute for Clinical Excellence

Nottingham City NHS (2010), CitiHealth NHS Nottingham Information Security Policy

Oldman, C. and Quilgars, D. (1999), 'The last resort? Revisiting ideas about older people's living arrangements' *Ageing and Society* 19, pp.363-384

Oldman, C. (2001), Housing, theory and later life, HAS conference, Cardiff, September 2001

Patmore, C. (2003), Understanding Home Care Providers: Live issues about management, quality and relationships with Social Services Purchasers, working paper DH1963, Social Policy Research Unit, University of York

Patmore, C. And McNulty, A. (2005), Making home care for older people more flexible and person-centred, York: Social Policy Research Unit

Patmore, C. And McNulty, A. (2007), Caring for the whole person: Home care for older people which promotes well-being and choice, published by the well-being and choice website [online] at: www.well-beingandchoice.org.uk

Raglio A, Bellelli G, Mazzola P, Bellandi D, Giovagnoli AR, Farina E, Stramba-Badiale M, Gentile S, Gianelli MV, Ubezio MC, Zanetti O, Trabucchi M. (2012), Music, music therapy and dementia: a review of literature and the recommendations of the Italian Psychogeriatric Association, *Maturitas*. 2012 Aug; 72(4):305-10. doi: 10.1016/j.maturitas.2012.05.016. Epub 2012 Jun 27.

Rothera I, Jones R, Harwood R, Avery A, Fisher K, James V, Shaw I. and Waite I. (2008) 'An evaluation of a specialist multiagency home support service for older people with dementia using qualitative methods.' *International Journal of Geriatric Psychiatry*, Vol. 23: 65-72.

Ravasi, D., Schultz, M. (2006), "Responding to organizational identity threats: exploring the role of organizational culture", *Academy of Management Journal*, Vol.49, No.3, pp. 433-458.

University of Nottingham (2010), University of Nottingham Code of Research Conduct and Research Ethics, University Research Committee Version 3, January 2010

Wall, M. and Duffy, A. (2010), The effects of music therapy for older people with dementia literature review, *British Journal of Nursing*, Vol. 19, Issue. 2, 27 Jan 2010, pp 108 – 113

Waller, D. (1999) Art therapy: a channel to express sadness and loss, *Journal of Dementia Care*, May/June, 16-17

Williams, A. (2002), Changing Geographies of Care: employing the concept of therapeutic landscapes as a framework in examining home space, *Social Science and Medicine*, 55: 141-154

Ziv N, Granot A, Hai S, Dassa A, Haimov I. The effect of background stimulative music on behavior in Alzheimer's patients. *J Music Ther.* 2007;44(4):329-343.