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McDermott, Orii

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The Development and Evaluation of Music in Dementia Assessment Scales (MiDAS)

Thesis submitted for the degree of Doctor of Philosophy

Orii McDermott



AALBORG UNIVERSITY
DENMARK

Declaration

I hereby declare that neither this thesis nor part of the thesis have previously been submitted for a higher degree to any other University or Institution in Denmark or abroad.

Orii McDermott

Date

Abstract

Evaluation of music therapy is a complex task. The majority of quantitative music therapy studies in dementia use standardised psychiatric outcome measures to evaluate the impact of music on the reduction of neuropsychiatric symptoms. However, clinically important changes are highly individual and there are concerns that these measures may not portray what matters most to the client. There was a need to develop a clinically relevant and scientifically robust outcome measure incorporating the values and view of people with dementia.

A narrative synthesis systematic review found consistent evidence for short-term improvement in mood and reduction in behavioural disturbance but there were no high-quality longitudinal studies that demonstrated long-term benefits of music therapy. The review also confirmed that no psychometrically validated outcome measure specifically designed for music therapy with people with dementia was used in the current literature.

In order to develop a clinically meaningful outcome measure, focus groups and interviews with people with dementia, family carers, care home staff and music therapists were conducted to explore the value of music for people with dementia and the observed effects of music. The accessibility and immediacy of musical experiences for people at all stages of dementia, a close link between personal identity and music and the importance of shared musical experiences were particularly highlighted. Key comments and recurring themes were transcribed and scrutinised through expert and peer consultations to identify scale items and ensure the content validity of the new outcome measure.

Music in Dementia Assessment Scales (MiDAS) comprises of the five Visual Analogue Scales (VAS) items: levels of *Interest*, *Response*, *Initiation*, *Involvement* and *Enjoyment*, and a supplementary checklist of major reactions from the individual with dementia consisting of three ‘positive reactions’ (*attentive/interested*, *cheerful/smiling*, *relaxed mood*) and three ‘negative reactions’ (*agitation/aggression*, *withdrawn/low in mood*, *restless/anxious*). A space for a rater’s own comment is provided to aid clinical interpretations of MiDAS. MiDAS version 1 was field-tested by a music therapist and staff in a care home. Feedback from the clinicians and further peer consultations were

incorporated during the refinement stage of the scales. MiDAS version 2 was produced for the main study.

In order to evaluate the reliability and the validity of MiDAS, weekly MiDAS ratings were collected from music therapists and care home staff. Nineteen care home residents with moderate to severe dementia attended group music therapy for up to 10 sessions. A total of 629 MiDAS forms were completed during the main study. The statistical analysis revealed MiDAS has a high therapist inter-rater reliability, a low staff inter-rater reliability, an adequate staff test-retest reliability and a fair concurrent validity. Factor analysis revealed high factor loadings between the five VAS items. MiDAS was found to be sensitive to change and feedback from the study participants confirmed the clinical relevance of MiDAS.

This is the first study attempted to develop a psychometrically validated outcome measure from the qualitative data exploring the values of music for people with dementia. Future recommendations include further evaluation of MiDAS in a randomised controlled trial, an investigation of the benefits of music therapy on apathy in people with dementia, and the development of MiDAS self-rating version.

Dansk resumé

Det er komplekst at evaluere musikterapi. Størsteparten af kvantitative musikterapiundersøgelser indenfor demensområdet anvender standardiserede psykiatriske måleredskaber til at evaluere om musik kan reducere neuropsykiatriske symptomer. Afgørende kliniske ændringer er imidlertid meget individuelle, og spørgsmålet er om disse måleredskaber kan indfange hvad der er af størst betydning for den enkelte klient. Der er således behov for at udvikle et klinisk relevant og videnskabeligt robust måleredskab som omfatter demensramte personers værdier og synspunkter.

Med udgangspunkt i en litteraturgennemgang (et såkaldt ”narrative synthesis systematic review”) blev der fundet samstemmende beviser for kortsigtet forbedring i humør og en reduktion i adfærdsmæssige forstyrrelser som følge af musikterapi til demensramte. Der var dog ikke longitudinelle undersøgelser af høj kvalitet der kunne demonstrere langsigtede fordele ved musikterapi. Litteraturgennemgangen bekræftede endvidere at der i den aktuelle litteratur ikke var anvendt psykometrisk validerede måleredskaber specielt designet til musikterapi med personer med demens.

Med henblik på at udvikle et klinisk relevant måleredskab blev der gennemført fokusgruppeinterviews og interviews med personer med demens, pårørende, plejepersonale samt musikterapeuter for at undersøge værdien af musik til demensramte og den observerede effekt af musik. Der blev i særlig grad sat fokus på tilgængeligheden og muligheden for musikalske oplevelser for demensramte i alle stadier af sygdommen, den tætte sammenhæng mellem personlig identitet og musik og på vigtigheden af fælles musikoplevelser. Centrale udtalelser og tilbagevendende temaer blev transskriberet og videre undersøgt ved hjælp af ekspert- og fagfælle vurderinger for at identificere elementer til skalaer og for at sikre indholdsvaliditet af det nye måleredskab.

Måleredskabet (Music in Dementia Assessment Scales, MiDAS) består af 5 visuelle analoge skalaer (VAS) hvor der spørges ind til følgende elementer: grad af Interesse, Respons, Initiativ, Involvering og Nydelse. Herudover er der en supplerende tjekliste med afgørende reaktioner fra personen med demens bestående af tre ’positive reaktioner’ (opmærksom/interesseret, munter/smilende, afslappet) og tre ’negative reaktioner’ (agitation/aggression, tilbagetrukkethed/nedtrykt, rastløs/ængstelig). Herudover gives der

en mulighed for at den, der foretager målingen, kan tilføje egne kommentarer, hvilket kan bidrage til senere kliniske fortolkninger af MiDAS. En første version af MiDAS blev afprøvet af en musikterapeut og personale i et plejecenter. Feedback fra klinikerne og yderligere fagfælle-vurdering blev indarbejdet i videreudviklingen af skalaerne, og en MiDAS/version 2 blev udarbejdet til hovedundersøgelsen.

For at kunne vurdere pålideligheden og gyldigheden af MiDAS blev ugentlige MIDAS-ratings indsamlet fra musikterapeuter og omsorgspersonale. 19 moderat til svært demensramte plejehjemsbeboere deltog i gruppemusikterapi i op til 10 sessioner. I alt blev 629 MiDAS-skemaer udfyldt i løbet af hovedundersøgelsen. Den statistiske analyse viste at MiDAS har en høj terapeut interrater-reliabilitet, lav personale interrater-reliabilitet, en adækvat personale test-retest-reliabilitet og en passende samstemmende validitet. En faktoranalyse viste høj faktorladning mellem de 5 VAS-elementer. MiDAS viste sig at være sensitiv nok til at måle forandring, og feedback fra deltagerne i undersøgelsen bekræftede den kliniske relevans af MiDAS.

Denne undersøgelse er det første forsøg på at udvikle et psykometrisk valideret måleredskab baseret på kvalitative data til udforskning af værdien af musik for personer med demens. Videre anbefalinger omfatter en yderligere evaluering af MiDAS i en randomiseret, kontrolleret undersøgelse, en undersøgelse af fordelene af musikterapi ved apati hos demensramte og en udvikling af et MiDAS-skema som demensramte selv kan udfylde.

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Peggy: *“Hello...! Hello...! Hello...!”*

Esther (nurse): *“Peggy, why are you shouting?”*

Peggy: *“...so people know I am still here.”*

This work is dedicated to you, Peggy.

I feel so privileged to have worked with you for four years.

You made me realise how much you and your fellow residents had things to say
in both words and music.

You have been the driving force of this work, and I am eternally grateful.

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- McDermott, O., Crellin, N., Ridder, H.M. & Orrell, M. (2013). Music therapy in dementia: a narrative synthesis systematic review. *International Journal of Geriatric Psychiatry*, 28(8), 781–794. doi:10.1002/gps.3895
- McDermott, O., Orrell, M. & Ridder, H.M. (2014a). The importance of music for people with dementia: the perspectives of people with dementia, family carers, staff and music therapists. *Aging & Mental Health*, doi:10.1080/13607863.2013.875124
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1. INTRODUCTION

1.1 Clinical context

(Music making is a) “... totally different (experience)... mixture of... great sound... excluding everything else, great picture of sound... that is dynamic, series of sound... flowing through.” (James: care home resident)

In the U.K., 800,000 people currently live with dementia (Alzheimer’s Society, 2013). A number of government policies on dementia have been implemented by the Department of Health during the last five years. One of the key documents: *A National Dementia Strategy* (2009) aims to “provide a strategic framework within which local services can deliver quality improvement to dementia services and address health inequalities relating to dementia”. On improving the care of people with dementia in care homes, the Strategy recommends: “the provision of therapeutic activities within care homes, such as art therapy, music therapy or drama therapy, may have a useful role in enabling a good-quality social environment and the possibility for self-expression where the individuality of the residents is respected.” “Enabling a good-quality social environment” and “respect for the individuality of the residents” are not only applicable to therapeutic activities, but are an absolute minimum requirement for dementia care as a whole. If therapeutic activities are expected to contribute to the maintenance of the wellbeing of individuals, planning a study on therapeutic activities should perhaps start from exploring what people with dementia themselves value in the activities.

Music therapy is an established clinical discipline in the U.K. and is regulated by the Health and Care Professions Council. The number of music therapists working in dementia care is increasing, and music therapy is widely accepted as a beneficial intervention for people with dementia by health care professionals, families and people

with dementia themselves. On the other hand, there is an increasing demand to provide rigorous evidence of the benefits of music therapy to service providers and commissioners as well as to senior managers within health organisations.

Twelve years ago, I started working as a music therapist in a National Health Service (NHS) Trust in inner London. The Trust provided a wide range of inpatient and outpatient services to adults, older adults and adolescents with acute and chronic mental illnesses. I have worked across the adult and older adult services including people at early stages of dementia attending the Day Hospital and people at late stages of dementia in continuing care. It has always struck me how the core of the person was maintained throughout all the stages of dementia, even though the individuality became less visible and accessible as the dementia progressed. Collaborative music making: whether exploring the instruments together, improvising music as the person paced up and down, or vocalising as the person breathed quietly, often allowed me to meet *the person*. Music making not only enabled me to access the person but also offered an opportunity to share meanings when the person initiated an interaction. The Master's thesis I completed in 1998 explored the relationship between creative music therapy and Kitwood's Positive Person work (Kitwood, 1997a, 1998). It was evident many components of the Positive Person work: *recognition*, *negotiation*, and *validation* of each other's musical ideas, *holding*, musical *facilitation* and *collaboration*, often happened naturally in music therapy sessions.

In 2009, I was asked to examine the impact of music therapy on agitation levels of care home residents using the Cohen-Mansfield Agitation Inventory (CMAI) (Cohen-Mansfield, 1986; Cohen-Mansfield, Marx & Rosenthal, 1989) while conducting a service evaluation on a pilot music therapy service in the care homes. CMAI assesses the frequency of 29 agitated behaviours such as grabbing onto people, screaming, general

restlessness, and asking repetitive questions on a scale of 1 (never) to 7 (several times per hour). When CMAI score decreases, an intervention is deemed as effective. CMAI is frequently used as the main outcome measure in music therapy and music activities studies (e.g. Gerdner & Swanson, 1993; Brotons, 2003; Ledger & Baker, 2007; Vink et al., 2012).

Care home staff completed biweekly CMAI ratings for four months. It soon became evident to me that several factors could easily influence staff scores. One issue was how the differences in staff perception of challenging behaviour influenced their scores. For one staff member, a resident's repetitive vocalisation was "just part of her, how she expresses herself" but another staff member found the vocalisation "annoying – just non-stop all day". Despite the same rating instruction given to the two staff members and monitoring their ratings, the CMAI score given by the first staff member was 64 and the score given by the second staff member was 90 on the same day. Had this been an evaluation of inter-rater reliability of CMAI, the outcome would not be favourable. Another emerging factor was the need for staff to be heard and valued. Staff were often under time pressure to complete their daily tasks and some were less keen to be approached for extra paper work. However, most of them were willing to share their struggle with challenging residents and stress of working in residential settings while they were completing CMAI ratings with me, and appeared to value the space to discuss their own experiences. I found that once a rapport was established, many took more time to reflect before completing the CMAI forms. It is very likely there were differences in the scores when a staff member completed the form with reluctance and when the same member took more time to reflect on the resident before completing the form.

I started questioning the clinical relevance of CMAI, and this view was shared with my arts psychotherapists colleagues who had also been asked to use CMAI as a clinical evaluation tool. Any music therapy clinical work starts *where the client is* and individual

clinical goals emerge after an assessment period. The reductions of “problematic behaviours” such as agitation often occur as result of the intervention, but this can be achieved only after exploring what may be the underlying factors for “problematic behaviours”. A simple reduction in the frequencies of agitated behaviours is not an aim of a therapeutic intervention. The reduction in the CMAI scores may not necessarily contradict with the outcome of therapy. Nevertheless, measuring agitation levels on its own does not portray an accurate picture of the impact of music therapy as a clinical intervention. Music therapy clinicians working with people at any stage of dementia frequently report: increased awareness in their clients, increased confidence in musical and social interactions with other group members and therapists, and sustained ability to express themselves and communicate through music making despite the progression of their dementia. Another issue was raised during the service evaluation; there did not seem to be another alternative outcome measure that was scientifically robust and clinically relevant to music therapy with people with dementia.

The use of a proxy measure may always carry the risk of rater bias that may be introduced by the professional attitudes of the rater, the rater’s relationship with the individual being rated, and the culture of care where the rater works. This may be particularly the case when proxy measures are used for people with moderate to severe dementia living in care homes, and it is possible that carers’ scores do not always correlate with the views of people with dementia themselves. The study by Orrell et al. (2008) found discrepancies between staff and residents in identifying unmet needs. Recognising psychological distress of residents was particularly poor among care home staff. However, the study also found that residents with moderately severe dementia were able to articulate and communicate their met and unmet needs. Similarly, Thorgrimsen et al. (2003) found that people with dementia had “a

more positive outlook on their lives and roles than their caregivers or health care professionals”. Whilst the challenge of using a proxy measure in a care home will be on going, I believe there are a need and also an advantage of incorporating staff observations into research on therapeutic activities. Health care assistants and nurses are the people who work most closely with residents, and they will be able to notice small changes in mood and behaviours of the residents that may not be noticed by music therapists who provide weekly sessions. Sensitive observations of staff that provide day-to-day care to the residents will be invaluable for music therapy research, but an outcome measure to evaluate the intervention also needs to be sensitive to change.

This may be summarised as: 1). Measuring the reduction of problematic behaviour on its own does not convey an accurate picture of the benefits of music therapy, 2). There is no alternative clinically appropriate and scientifically rigorous music therapy outcome measure, 3). There are many factors that can influence proxy measures of care home staff, but staff observations can potentially provide invaluable information for research in music therapy, and 4) People with moderate to severe dementia can still express their views, their positive experience of music therapy is frequently observed by clinicians, and their views and values should be incorporated into research.

1.2 Dementia

1.2.1 Worldwide impact of dementia

The World Alzheimer Report 2009 by Alzheimer’s Disease International (ADI) estimated that there were going to be 35.6 million people living with dementia worldwide in 2010, 65.7 million by 2030 and 115.4 million by 2050 (ADI, 2009). Nearly two-thirds of all people with dementia live in low and middle income countries and the numbers are set to rise sharply. The following year, *the World Alzheimer Report 2010* revealed that the total

estimated worldwide cost in 2010 was US\$604 billion accounting for around 1% of the world's gross domestic product (ADI, 2010). Costs of informal care (unpaid, usually provided by families and friends) and direct costs of social care (provided by community care professionals and in residential care settings) contribute similar proportions (42%) of total cost worldwide whilst direct medical costs were much lower (16%) (ADI, 2010). Dementia has a huge impact on the individuals living with dementia, their families and friends, not only on the financial level but also on personal, emotional and social levels. Dementia may have become more prominent in the public domain in the recent years largely to do with media coverage, but the stigma attached to dementia still remains.

The World Alzheimer Report 2012: Overcoming the Stigma of Dementia (ADI, 2012) conducted an analysis of 2500 responses from 54 countries. Nearly two thirds of respondents, both people with dementia and family carers, felt there is a very limited understanding of dementia in their countries; 40% of people with dementia reported the experience of marginalisation and the loss of friends was particularly highlighted; and 24% cited stigma as a reason to conceal their diagnosis from others. Research shows a significant impact of dementia on carers' psychosocial, physiological and general health (e.g. Coen, Swanwick, O'Boyle & Coakley, 1997; Sörensen, Duberstein, Gill & Pinquart, 2006) and there is consistent evidence for the importance of caregiver interventions (e.g. Mittelman et al., 1995; Schulz et al., 2002; Brodaty, Green & Koschera, 2003; Mittelman, Haley, Clay & Roth, 2006). All these factors: the high global prevalence, economic and psychological impact of dementia on families, caregivers, and communities and the associated stigma and social exclusion present an enormous public health challenge (World Health Organisation (WHO), 2012).

1.2.2 Definition and diagnostic features

Dementia is defined as a clinical syndrome, usually of a chronic or progressive nature, characterised by a cluster of symptoms and signs manifested by difficulties in memory, disturbances in language, psychological and psychiatric changes, and impairments in activity of daily living (Burns & Iliffe, 2009; WHO, 2012).

In the DSM IV-TR (Diagnostic and Statistical Manual IV Text Revision) (American Psychiatric Association, 2000), the essential feature of dementia is described as: “the development of multiple cognitive deficits that include memory impairment and at least one of the following cognitive disturbances: aphasia (deterioration of language function), apraxia (impaired ability to execute motor activities despite intact motor abilities, sensory function, and comprehension of the required task), or a disturbance in executive functioning”. Agnosia (failure to recognise objects or people despite intact sensory function) and impairment in abstract thinking are also common (American Psychiatric Association, 2000). Notable skills and abilities affected by the disturbance of multiple higher cortical functions include: memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Deteriorations in cognitive functions often result in deterioration in emotional control, social behaviour, and motivation (International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10), 2010).

Recently published DSM-5 (American Psychiatric Association, 2013) re-defined dementia as “major and mild Neurocognitive Disorders (NCD)” although “the term dementia is not precluded from use in the etiological subtypes where that term is standard”. The core diagnostic feature of major and mild NCDs is “acquired cognitive decline in one or more cognitive domains” based on “both 1) a concern about cognition on the part of the individual, a knowledgeable informant, or the clinician, and 2) performance on an

objective assessment that falls below the expected level or that has been observed to decline over time.” (American Psychiatric Association, 2013)

1.2.3 Summary of common types of dementia and clinical features

Alzheimer’s disease

Alzheimer’s disease (AD) is the most common form of dementia and is characterised by accumulating amyloid plaques and neurofibrillary tangles typically in medial temporal structures and the cerebral cortex (Rodda, Boyce & Walker, 2008). The prevalence of AD is age-dependent, doubling every 5 years after the age of 60 years with around 1% of those aged 65-69 years affected rising to almost 20% in those aged 85 years or over (Rossor et al., 2009). One of the most prominent clinical features of AD is progressive memory impairment. All types of memory: explicit long term-memory (episodic and semantic), short-term memory, and implicit memory are affected (Rossor et al., 2009; Newhouse & Lasek, 2006). Additionally, one or more cognitive disturbances: aphasia, apraxia, agnosia or disturbances in executive functions is necessary to determine a diagnosis of AD (American Psychiatric Association, 2000).

Vascular dementia

Vascular dementia (VaD) is caused by cerebrovascular disease and is the second most common form of dementia after AD (Agronin, 2008). A history of stroke is sometimes linked with VaD. Memory impairment is frequent, but it is more variable and more dependent on attentional factors and more responsive to cueing than in AD (Rossor et al., 2009). Personality and insight are relatively preserved in the early stages of VaD, but emotional lability, depression, early impairment of attention and executive function are common (Rodda et al., 2008).

Dementia with Lewy bodies

Dementia with Lewy bodies (LBD) is characterised by a particularly high prevalence of neuropsychiatric symptoms. Recurrent, complex visual hallucinations are found in up to 80% of individuals with LBD and are frequently accompanied by illusions and misidentification phenomena in many cases (McKeith & Cummings, 2005). Other core features of LBD are fluctuating cognition with pronounced variations in attention and alertness, and spontaneous features of parkinsonism (McKeith et al., 2005). Apathy, anxiety, depression and delusions are also common (Newhouse & Lasek, 2006).

Frontotemporal Dementia

Frontotemporal Dementia (FTD) occurs primarily between the ages 35 and 75 years, and characterised by gradual and progressive changes in behaviour, or gradual and progressive language dysfunction (McKhann et al., 2001). FTD often has a devastating affect on families and friends due to its huge impact on personalities and social functions of the individuals affected. The damage to frontal cortex often triggers emotional outbursts, socially inappropriate behaviours, or apathy and emotional detachment. Pharmacological treatment is limited. (Rossor et al., 2009).

1.2.4 Behavioural and Psychological Symptoms of Dementia

It is not only declining cognitive functions but also behavioural and psychological disturbances that dementia causes that have a huge impact on the quality of life of people with dementia and their carers (Finkel, Costa E Silva, Cohen, Miller & Sartorius, 1997; McKeith & Cummings, 2005). Behavioural and Psychological Symptoms of Dementia (BPSD) are common and can happen at any time of dementia but are particularly common amongst care home residents with an estimated prevalence of 80% (Margallo-Lana et al., 2001). BPSD include “agitation, anxiety, depression, apathy, delusions, sleep and appetite

disturbance, elation, irritability, disinhibition and hallucinations” (Byrne, Collins & Burns, 2006). Presentations of BPSD differ greatly between individuals, but certain types of dementia are often associated with specific types of BPSD. Apathy, depression and anxiety tend to occur early in the course of AD, and individuals with LBD often experience visual hallucinations, delusions and sleep disturbances, and those with VaD may show signs of apathy, depression and delusions (McKeith & Cummings, 2005; Rossor et al., 2009). Whilst some symptoms are strongly linked to the aetiology of disease itself (e.g. visual hallucination and LBD), there is a general consensus that all biological, psychological and social factors contribute to the types and the severity of BPSD.

Risk of pharmacological interventions for BPSD has been highlighted in numerous studies. Antipsychotic drugs are often used to treat agitation, aggression and psychosis, but research has shown only moderate effects and serious adverse events including sedation, Parkinsonism, and an increased risk of stroke and death. (e.g. van de Glind et al., 2013; Ballard et al., 2011; Ballard & Howard, 2006).

1.3 Experience of Dementia

The centrality of understanding the underlying reasons for behavioural and psychological symptoms of the individual and addressing their aetiologies, while not only focusing on eliminating or managing the symptoms, has been debated widely throughout the literature (e.g. Goldsmith, 1996; Kitwood, 1997a; 1997c; Brooker, 2007; Bird & Moniz-Cook, 2008).

The essentiality of engaging directly with the experience of people with dementia and understanding the stand-point of the person with dementia became prominent in the 1990s (Brooker, 2007). Bender and Cheston (1997) proposed the “three stage model of the subjective world of dementia suffers”: 1) the emotional responses and the feelings evoked

by the process of dementia, 2) the behavioural responses to the process of decline, and 3) the social context of emotional behaviour. This model has a strong link with the personal and social psychology in dementia care debated extensively by Kitwood (1990, 1993a, 1997a). Kitwood is probably most well known for *person-centred care* where the *personhood* forms the basis of care (Kitwood, 1993a; 1997a; Kitwood & Bredin, 1992; Brooker, 2007; Baldwin & Capstick, 2007). Kitwood defined *personhood* as: “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust” (Kitwood, 1997a). Sustaining *personhood* relies on the *relatedness* (Kitwood, 1994; Kitwood, 1997b) with other people where the uniqueness of the person is valued and responded to. Kitwood states clearly: “to be a person is to live in the world where meanings are shared” (1997a). This has a particular relevance to music therapy where the process of musical interactions between a therapist and a client involves what Kitwood (1997a) termed *Positive Person Work* (Ishizuka 1998, now McDermott).

When the personhood is undermined or not supported by others, it can lead to “Malignant Social Psychology” (MSP), that may include *Treachery*, *Disempowerment* and *Infantilization*, (Kitwood, 1990, 1993b, 1997a; Brooker, 2007): which can have profound effects upon the individuals with dementia beyond neuropathology (Sabat, 1994). Brooker et al. (2011) emphasises that MSP rarely happens intentionally, however, “episodes of MSP become interwoven into the care culture”. Kitwood also presented the dialectical model of dementia (1990) emphasising the interrelationship between neurological pathology and psychological factors. The “equation of the clinical manifestation of a dementia (SD)” may be “understood as arising from a complex interaction between five factors: $SD = P$ (personality) + B (biography) + H (physical health) + NI (neurological impairment) + SP (social psychology)” (Kitwood, 1993b). Baldwin and Capstick (2007)

emphasised that the equation and Kitwood's theory "involved more than simply an argument for more holistic approach to dementia care – the dementing process was seen as a dialectic where each of the factors in the equation interacted with the others to *create* dementia" (Baldwin & Capstick, 2007).

1.4 Biopsychosocial model

Downs, Clare and Anderson (2008) described dementia as a biopsychosocial condition with interacting neurological and psychosocial components. They acknowledged Engel (1977) first articulated the idea that the social, psychological and behavioural dimensions of ill health needed to be incorporated into the medical model of disease. Dementia as a biopsychosocial condition strongly interlinks with the Kitwood's equation. In discussing the clinical implications of dementia as a biopsychosocial condition, Downs, Clare & Anderson highlighted that: "there are many aspects of a person's life that are amenable to change and change in these areas can affect well-being and quality of life" and emphasised the need for "the range of evidence, from patients as experts to professional expertise to in depth qualitative studies to randomized controlled designs" (2008).

Spector and Orrell (2010) reviewed the existing literature and reconceptualised the biopsychosocial model of dementia "amalgamating key features from past models and research" and proposed a "pragmatic, diagrammatic model" to help clinicians formulate cases clearly and tailor interventions to meet individual needs (Spector & Orrell, 2010). One of the strengths of this model is the disaggregation of psychosocial and biological processes to explore the inter-relationship between the two. Both the psychosocial and the biological processes contain fixed factors ("aspects related to history or risk factors and therefore not amenable to change" e.g. personality traits, previous life events, health prior to dementia and genetic factors) and tractable factors ("aspects that may be amenable to

change” e.g. mental stimulation, personal and social psychology, physical health to some degree). Some factors may overlap with each other, and identifying each factor may not be so straightforward in some clinical cases. Nevertheless, the diagrammatic biopsychosocial model presents dementia as a process: starting from aging process and organic change, moving to diagnosis of dementia and increasing dependency, and eventually institutionalisation, end of life care, and death. This offers a clear pragmatic framework that the majority of front-line clinicians will be able to relate to, thus making the use of the model in clinical practice a more realistic option. The biopsychosocial model “helps to work against the assumption” that “the behaviour and actions of a person are solely attributed to the illness” by “taking a more individual and biopsychosocial perspective” (Spector & Orrell, 2010).

Figure 1.1 suggests the interrelationship between BPSD, personal experience of dementia, and the biopsychosocial model, and is presented here as a summary of this section. BPSD will be most visible or noticeable as an external presentation of the person since they are often perceived as behaviours or symptoms that need to be managed. BPSD may be part of the process of neurological impairment or the individual reaction to the experience of dementia (less visible, internal experience of the person). Understanding the individual’s experience of dementia is crucial for supporting the personal psychology of the person, as Malignant Social Psychology in the care culture can have a huge impact on the person beyond the neuropathology of dementia. Dementia care needs to be considered from biological, psychological, and social aspects, and individualised biological and psychosocial interventions have to be provided to maintain the personhood and the wellbeing of the person.

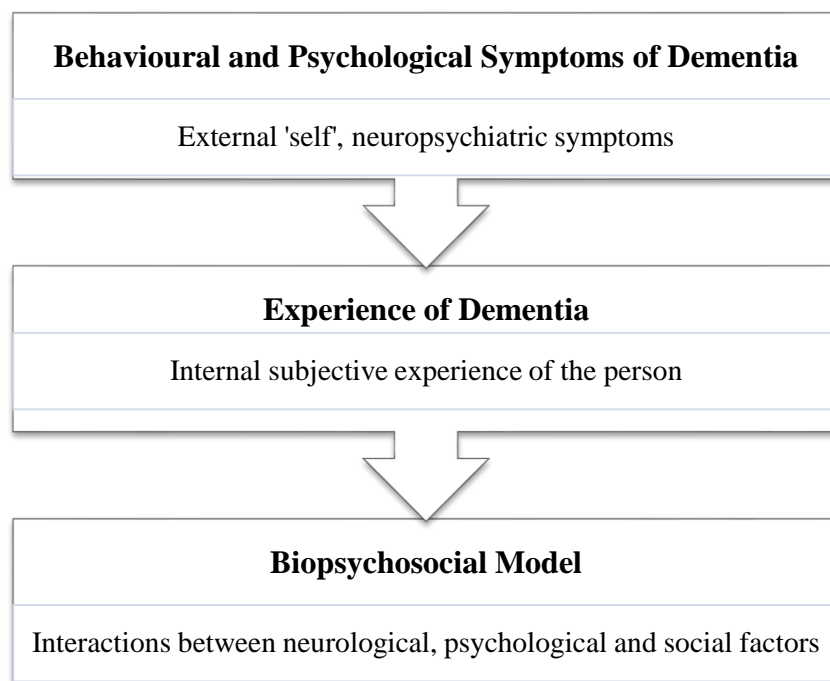


Figure 1.1 The interrelationship between BPSD, personal experience of dementia, and the biopsychosocial model

1.5 An overview of literature review on music therapy and music activities in dementia

Music-based interventions are popular in dementia care and distinguishing between music therapy studies and music activity studies is not always easy. Some reviews used generic terms, for example “music, music therapy and dementia” (Raglio et al., 2012), and “music interventions for people with dementia” (Sherratt, Thornton & Hatton, 2004) to cover all music-based interventions. Some reviews made no attempt to differentiate music therapy from music activities when included in a review on non-pharmacological treatment of behavioural and psychological symptoms (e.g. Douglas, James & Ballard, 2004).

The reviews that the authors explicitly specified as “music therapy reviews” include those by Vink, Bruinsma and Scholten (2011) and Ueda, Suzukamo, Sato and

Izumi (2013). Ueda et al. (2013) conducted a meta analysis on randomised controlled trials (RCTs) and controlled trials (total n=20) focusing on the effects of music therapy on BPSD. Moderate effect on anxiety, and small effect on “behaviour” and depression were found. Cognitive function and Activities of Daily Living (ADL) did not improve. The authors were unable to identify a particularly effective music therapy intervention or specify a patient group particularly benefitting from music therapy (Ueda et al., 2013). A Cochrane review on music therapy in dementia (Vink, Bruinsma & Scholten, 2011) aimed to “assess whether music therapy can diminish behavioural and cognitive problems or improve social and emotional functioning”. Out of the ten included studies, seven studies were classified as targeting *behavioural problems*, one study assessed *cognitive skills*, and two studies investigated *social and emotional functioning*. Although the authors use the definition of music therapy by the World Federation of Music Therapy (2010) as their definition of music therapy, the inclusion and exclusion criteria for the review are not explicitly described. This makes it uncertain how the authors differentiated music therapy studies from music activities studies. For instance, a RCT on “the effects of group music with movement intervention” is not described as music therapy by the authors (Sung, Chang, Lee W & Lee M, 2006) and the intervention was provided by “a nursing researcher and two research assistants trained in music therapy intervention”. However, this study was included in the Cochrane review on music therapy in dementia. The review also “accepted all behavioural and psychological tools reported by the authors of the identified primary studies” (Vink et al., 2011), indicating that the authors may not have checked that all the outcome measures had been validated. The study results were not pooled due to the heterogeneity of the studies and low quality of reporting. Despite some weaknesses in the review method and the lack of information, it is evident that the use of active group music therapy to reduce behavioural symptoms is the most common aim of current music therapy

studies in dementia, and that the weaknesses in the study designs include the lack of information on adequate sequent generation, allocation concealment and handling of the uncompleted outcome data.

The review on music therapy and other music-based interventions in dementia by Raglio et al. (2012) included 32 “Randomized Controlled Trials or Clinical Controlled trials”, but did not specify exact numbers for each study type. The review found twenty studies investigated the effects of music on BPSD (eight music listening, 12 active music making studies), six studies investigated the effect of music on cognitive functions, two studies investigated the effects of acoustic stimulus or the influence of recorded music during a “motor rehabilitation programme” and exercises, and four studies investigated physiological parameters including heart rate, cortisol level, blood pressure, and salivary levels of chromogranin A to assess stress level. The authors conclude that there is little evidence to support the benefits of music on cognitive function and physiological changes, but there is sufficient evidence for the improvement in BPSD following active music activities or active music therapy. However, no statistical results have been provided in this review.

Music activity studies and multi-modal activity studies with music components are frequently included in the systematic reviews on non-pharmacological treatment and psychosocial intervention on BPSD. (e.g. Douglas, James & Ballard, 2004; Hulme, Wright, Crocker, Oluboyede & House, 2009; Livingston, Johnston, Katona, Paton & Lyketsos, 2005; O’Connor, Ames, Gardner & King, 2009a; 2009b). There is a general consensus in these reviews that music is considered as beneficial to the wellbeing of people with dementia and music-based interventions are worth further investigations, despite the weaknesses in the study designs in the included studies and the lack of consistent, rigorous evidence. On the other hand, music therapy and music activity studies

included in some of these reviews are either not up-to-date or not the most representative study of the interventions. This highlights the inconsistency of the understanding of the benefits of music-based interventions amongst health professionals and researchers.

A narrative review on music interventions studies (n=21) (Sherratt et al., 2004) aimed to examine “methodological and theoretical issues relating not just to problem behaviours such as agitation but also behaviours of engagement and participation”. Issues in the use of direct observational method, including the potential influence on the behaviour of the participants, and the importance of the ratio of observer to participant, were raised. Methodological problems included the lack of information on reliability of the reported study outcomes, the use of frequency data collection resulting in the less accurate picture of participants’ responses to music, questionable internal validity and the lack of discussion on possible confounding factors. The progressively lowered stress threshold model (PLST) (Hall & Buckwalter, 1987) was identified as the most frequently cited theoretical framework, but the authors highlighted that the crucial impact of severity of dementia on the levels stress threshold was not sufficiently explored. Additionally, the nature of PLST stressor (“perceived stressors”) attributing “the internal world of the person with dementia” and the difficulty of obtaining “measurements of or information” on the stressors from people with severe dementia was highlighted. Thus, the authors conclude: “with regard to those studies that used the PLST model as a theoretical framework the above limitations may serve to weaken the construct validity of these studies”. The review makes a link between the theory of Kitwood’s personhood and the PLST model, and includes the development of “the theory of personhood approach within the context of music therapy research” as one of the future recommendations, highlighting the aim of music therapy is “to promote the use of preserved skills and abilities and increase

subjective well-being as well as aid the management of behavioural problems” (Sherratt et al., 2004).

1.6 Measuring outcomes in music therapy research in dementia

Music therapy is a complex intervention and choosing an appropriate instrument to evaluate both the therapy process and therapy outcome is not always straightforward both in practice and in research with any client group. It is not the scope of this section to provide a summary of all music therapy assessment scales, outcome measures and evaluation tools, but it aims to provide an overview of outcome measures currently used in music therapy research in dementia.

Quantitative outcome measures used in music therapy studies in dementia may be divided into three main categories: 1) psychometrically validated music therapy outcome measures, 2) music therapy outcome measures that have not been validated and 3) psychometrically validated outcome measures commonly used in psychiatric research. (Figure 1.2)

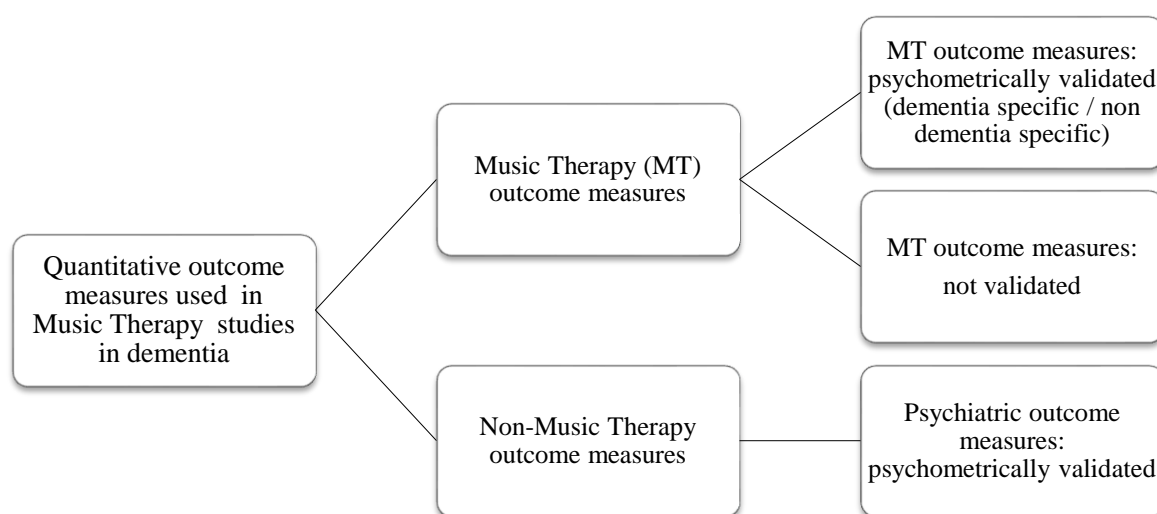


Figure 1.2 Overview of quantitative outcome measures used in music therapy studies in dementia

A psychometrically validated music therapy outcome measure is rarely used in music therapy research in dementia. The only validated music therapy measure used in a music therapy study with clients with dementia was the Music Therapy Coding Scheme (MTCS) (Raglio, Traficane & Oasi, 2006). The MTCS was used in a RCT investigating the effects of music therapy on BPSD to evaluate “empathetic or non-empathetic behaviour” and to conduct “an assessment of smile, body movement and singing that shows the acceptance of the MT approach” (Raglio et al., 2008). The MTCS was developed through the video analysis of music therapy with children diagnosed with Pervasive Developmental Disorder and is not a dementia specific music therapy outcome measure. The authors have not provided the rationale for the appropriateness of using a scale developed for working with children to be used with clients with dementia or the necessity of using the MTCS for the study.

The three measures developed in the USA in the early 1990s: the Music Therapy Assessment Tool (Glynn, 1992), the Residual Musical Skills Test (York, 1994), and the Music Performance Tasks (Lipe, 1995) typically investigated musical reactions and responses of people with dementia, either during and after listening to taped music “which can be provided by nurses” (Glynn, 1992), or during musical skills test (York, 1994; 2000), or during music performance task (Lipe 1995). Lipe explained that “quantifying music tasks performance in a way which is both reliable and meaningful” would “make it easier for music therapists to communicate with a health care profession which is increasingly demanding more rigorous validation of treatment protocol, thus contributing to the professional credibility” (Lipe, 1995). This suggests that constructing these measures might have been part of the professional development of music therapy before music therapy became established as a clinical discipline.

Music therapists' own evaluation tools have been used in some studies (e.g. Ashida, 2000; Brotons & Marti, 2003) in addition to the validated psychiatric outcome measures such as Cornell Scale for Depression (Alexopoulos, Abrams, Young & Shamoian, 1988) and Neuropsychiatric Inventory (Cummings et al., 1994). These evaluation tools have not been validated and were used as supplementary tools to evaluate clinical process rather than as research outcome measures.

Measuring therapy outcomes can also be achieved using qualitative methods. For instance, rigorous, systematic video analysis of music therapy sessions (e.g. Ridder, 2003) with care home residents allowed measuring clinically significant changes that may not be captured by Likert scales. A disadvantage of the video analysis method is that it is extremely time consuming and heavily relies on the skills of an investigator, thus it is not easy to ensure the rigor of the evaluation process.

The majority of music therapy studies in dementia have used standardised psychiatric outcome measures as primary outcome measures. In particular, the outcome measures to evaluate BPSD: Cohen-Mansfield Agitation Inventory (Cohen-Mansfield, 1986) and Neuropsychiatric Inventory (Cummings et al., 1994), and various depression scales are frequently used. Mini Mental State Examination (MMSE) (Folstein, M., Folstein, S. & McHugh, 1975), a well-known cognition test in dementia, was often used in the studies in the early 90s (e.g. Groene, 1993; Aldridge, 1992). The use of a quality of life outcome measure (Ridder, Wigram & Ottesen, 2009) is relatively new in music therapy studies in dementia.

There is no psychometrically evaluated dementia specific music therapy outcome measure that is appropriate for research. The use of well-established validated psychiatric outcome measures such as the CMAI and the NPI may provide trustworthy evidence. Nevertheless, this does not guarantee these scales measure what people with dementia

themselves would value when they attend music therapy. The reduction of neuropsychiatric symptoms will certainly be beneficial for an individual, but music therapy is not a tool to fix behavioural problems. Consistent anecdotal evidence from clinicians suggests that music therapy helps to increase the wellbeing of a person with dementia by offering a vehicle for self-expression and a space for building musical and interpersonal relationships with others.

It may be easy to assume people with dementia are unable to provide reliable verbal feedback. However, Mozley et al. (1999) have found that over 77% of care home residents with an MMSE score of 10 or more were able to express their views. Woods (2001) agrees the findings “remind us that we should first ask the person him/herself, before moving to proxy and observational measures”, and adds: “the goals that are set in order to evaluate approaches to dementia care must be realistic, but based on changes of importance and relevance to the individual with dementia”, and “a more relevant and important outcome (than improving MMSE scores) might be a measure of mood or of social interaction within the session”, because “what is important to the individual may well change as their disabilities change” (Woods, 2001). The need for more sensitive and appropriate measure tools to evaluate the benefits of an intervention “supporting personhood as the person’s capacities lessen” is also acknowledged.

It is necessary to understand why and how music therapy works from the perspective of people with dementia themselves in order to determine what will be meaningful to investigate and evaluate in music therapy research in dementia. The choice of outcome measure should reflect what people with dementia themselves value in music. It is evident that there is a need to develop a scientifically robust and clinically meaningful music therapy outcome measure specific for people with dementia.

1.7 Research questions

1. What is the evidence for the effectiveness of music therapy for people with dementia?
2. What do people with dementia value in music therapy and music activities? What do family and professional carers value about music for people with dementia?
3. What is required in a new outcome measure for music therapy in dementia?
4. Will the new outcome measure have adequate psychometric properties as a standardised outcome measure in dementia research?

2. AIMS

In order to answer the four research questions, the following four corresponding aims were identified:

1. To conduct a systematic review on music therapy in dementia and evaluate the benefits of music therapy.
2. To investigate the meanings and value of music for people with dementia and the observed effects, and develop a theoretical model.
3. To develop a clinically relevant and scientifically robust observational music therapy outcome measure of the impact of music for people with dementia.
4. To evaluate the psychometric properties and the clinical relevance of the new outcome measure.

3. OVERVIEW OF METHODS

This doctoral thesis contains four papers. Each paper is presented as a study with its own method section. The main purpose of this section is to provide an overview of the methods and describe an overall study design of the doctoral project.

3.1 Project Framework

The project was developed using the framework of the Medical Research Council (MRC) *Developing and evaluating complex interventions: new guidance* (2008): 1). *Developing a complex intervention*, 2). *Assessing feasibility and piloting methods*, 3). *Evaluating a complex intervention*, and 4). *Implementation*. The *developing a complex intervention* stage involved a systematic review to determine evidence of the benefits of music therapy, focus groups and interviews to collect qualitative data and the analysis of the qualitative data to develop a pilot outcome measure. The *assessing feasibility and piloting methods* stage involved the field-testing of the pilot outcome measure and refinement of the measure. The *evaluating a complex intervention* phase comprised of music therapy intervention, data collection and psychometric evaluation of the measure. The *implementation* stage involved publication of research papers and it is still on going. Near future plans include dissemination of the study findings to the study participants through a newsletter.

3.2 Research Design

The purpose of this project was to produce a clinically relevant and scientifically rigorous quantitative music therapy outcome measure from the evidence of the literature review and the qualitative data obtained from people with dementia, families, staff and music therapists. The research design of the measure development may be described best as the

“mixed methods sequential exploratory design: the instrument development model” as defined by Creswell and Plano Clark (2007). The sequential exploratory design consists of two distinctive stages that “starts with qualitative data to explore a phenomenon, and then builds to a second, quantitative phase” (Creswell & Plano Clark, 2007). The procedure consists of three phases: gathering and analysis of qualitative data (Phase 1), using the analysis to developing an instrument (Phase 2) that is subsequently administered to a sample of population (Phase 3) (Creswell & Plano Clark, 2007; Creswell, 2009). Our qualitative data on the value and meaning of music were collected through focus groups and interviews, and were analysed utilising the general inductive approach (Thomas, 2006) and the long-table approach (Krueger & Casey, 2000). The qualitative data was analysed further independently from the measure development to develop a deeper understanding of the meaning and value of music for people with dementia using the theoretical framework of the biopsychosocial model (Spector & Orrell, 2010). The themes that emerged out of the qualitative analysis were used to build a quantitative outcome measure. Peer and expert consultations were conducted at each stage of the measure development to ensure the rigor and transparency of the data transformation. Following the piloting and refinement of the new measure, it was evaluated through music therapy intervention in two care homes. Finally, statistical analysis was conducted to evaluate reliability and validity of the outcome measure.

Although the clinical relevance of the new outcome measure is a crucial element, the rigorous evaluation of its psychometric properties ultimately determines the outcome of this project. It can be argued the quantitative aspect of the project weighs more than the qualitative aspect. This is in line with the description of the mixed methods sequential exploratory design: the developmental model (Creswell & Plano Clark, 2007).

3.3 Systematic review on music therapy in dementia

As the first step of developing a new dementia specific music therapy outcome measure, it was necessary to update and examine the evidence of the effectiveness of music therapy for people with dementia. A number of narrative literature reviews (e.g. Brotons, Koger & Pickett-Cooper, 1997; Brotons, 2000; Wall & Duffy, 2010) and meta-analysis (e.g. Koger, Chapin & Brotons, 1999; Vink et al., 2003; 2011) on music therapy in dementia have previously been conducted. However, some common issues have been found in these reviews. These included: the term *music therapy* was not clearly defined, inclusion and exclusion criteria of the studies were unclear or not specified, quality assessment of the included studies was not conducted, validity and reliability of the outcome measures used in the studies were not assessed, and synthesis of the results and theory development beyond summarising the findings was limited. An additional issue is that standard systematic reviews tend to include only RCTs, or RCTs and non-randomised controlled studies, but exclude studies of any other types. The implication is that many existing reviews on music therapy in dementia offer only a partial review of existing literature. There was a need to conduct a new literature review using a transparent and systematic search and analysis method, applying an explicit inclusion and exclusion criteria based on a clear definition of music therapy. The review also needed to include high quality music therapy studies of other study designs in order to gain a deeper understanding of how and why music therapy may be beneficial for the wellbeing of people with dementia.

In order to answer the first research question: “what evidence on music therapy with people with dementia is available in the current literature?” a systematic review on music therapy literature in dementia using a narrative synthesis method was conducted. A systematic review using a narrative form, the narrative synthesis (NS), seemed most appropriate for our review. The *Guidance on the conduct of narrative synthesis systematic*

reviews (Popay et al., 2006) was developed “to make the process of NS more transparent and minimise bias” so that the evidence on the effectiveness of interventions which cannot be analysed in meta-analysis on its own can be rigorously reviewed and synthesised. Statistical analysis of the studies were included in our review, but the statistical results were not pooled, since the core aim of the review was to examine each study individually and explore the relationships between the studies in order to develop a conceptual model on how and why the intervention might have worked.

3.4 Qualitative data collection: focus groups and interviews

Focus groups and interviews with people with dementia, their families, care home staff and music therapists were conducted in order to explore the second research questions: *What do people with dementia value in music therapy and music activities? What do family and professional carers observe when music is meaningful to the person with dementia?*

The new measure was going to be designed as an observational instrument for music therapy with people with moderate to severe dementia who may be unable to provide consistent verbal feedback or use a self-rating scale. It was crucial to develop a deeper understanding of the views and values of people with dementia during this phase of scale development to ensure the clinical relevance of the measure at a later stage. Family members were invited to join residents’ focus groups and interviews so that they could help interpreting the residents’ comments when necessary and add further insights into the study from the family perspectives. In order to increase the transparency and rigor of the qualitative data analysis, the initial analysis was conducted applying the general inductive approach (Thomas, 2006) and the long-table approach (Krueger & Casey, 2000). The ultimate aim of the qualitative data analysis was to identify what people with dementia themselves might regard as meaningful to measure. Particular attention was paid on the

observable effects of music and visible responses to music for the scale development purpose. The outcome of the initial analyses was presented to PhD researchers and professors at the Doctoral Programme in Music Therapy for scrutiny.

The development of the music and the biopsychosocial model

Further qualitative data analysis was conducted in order to gain a deeper understanding of the meaning and value of music for people with dementia and develop a theoretical model. The researcher reinvestigated the transcription cards produced for the long-table approach. Consistency checks and stakeholder checks (Thomas, 2006) were conducted on the identified themes to establish credibility. The themes were explored further using the psychosocial factors described in the biopsychosocial model (Spector & Orrell, 2010). The music and the psychosocial model emerged.

3.5 Development of Music in Dementia Assessment Scales (MiDAS)

The emerged themes were examined further to identify potential scale items and decide the most appropriate type of scale. An expert consultation with a senior clinical psychologist experienced in dementia psychosocial interventions as well as a number of peer consultations with music therapy clinicians and researchers were held to ensure the clinical relevance and the rigor of data transformation from the qualitative data to the quantitative scale items. An observational outcome measure, Music in Dementia Assessment Scales (MiDAS) version 1 was produced. MiDAS version 1 was field-tested by a music therapist and staff in a care home. Feedback from the clinicians, inspection of completed MiDAS forms, further peer consultations were incorporated for the refinement of the scale. MiDAS version 2 was produced for the main study.

3.6 Evaluation of MiDAS

Selected care home residents attended group music therapy for up to 10 sessions. Staff and music therapists completed weekly MiDAS ratings. In order to answer the fourth research question: *Will the new outcome measure have adequate psychometric properties as a standardised outcome measure in dementia research?* a full psychometric evaluation of MiDAS was conducted. Inter-rater reliability for staff and therapists, test-retest reliability for staff were evaluated with Intraclass Correlation Coefficients. Face and content validity of MiDAS were evaluated qualitatively through on-going peer and expert consultations. A non-parametric test (Spearman's rho) was conducted for MiDAS concurrent validity with QoL-AD (Logsdon, Gibbons, McCurry & Teri, 1999), and factor analysis with Principal Component Analysis was conducted to evaluate construct validity. The evaluation of MiDAS sensitivity to change was conducted, and feedback from staff and therapists was collated to examine whether MiDAS is clinically relevant as well as scientifically robust.

The following four papers aim to answer the four research questions: 1) Music therapy in dementia: a narrative synthesis systematic review, 2) The meaning and the value of music for people with dementia from the perspectives of family carers, staff, music therapists and people with dementia themselves, 3) The development of Music in Dementia Assessment Scales (MiDAS), 4) Evaluation of the psychometric properties of Music in Dementia Assessment Scales (MiDAS).

4. PAPER 1

Music therapy in dementia: a narrative synthesis systematic review

International Journal of Geriatric Psychiatry, 28(8), 781–794.

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Music therapy in dementia: a narrative synthesis systematic review

Orii McDermott^{1,2,3}, Nadia Crellin^{1,4}, Hanne Mette Ridder² and Martin Orrell^{1,4}

¹Mental Health Sciences Unit, Faculty of Brain Sciences, University College London, London, UK

²Doctoral Programme in Music Therapy, Aalborg University, Aalborg, Denmark

³Central and North West London NHS Foundation Trust, London, UK

⁴Research and Development, North East London NHS Foundation Trust, London, UK

Correspondence to: Orii McDermott, E-mail: o.mcdermott@ucl.ac.uk

Objective: Recent reviews on music therapy for people with dementia have been limited to attempting to evaluate whether it is effective, but there is a need for a critical assessment of the literature to provide insight into the possible mechanisms of actions of music therapy. This systematic review uses a narrative synthesis format to determine evidence for effectiveness and provide insight into a model of action.

Method: The narrative synthesis framework consists of four elements: (i) theory development; (ii) preliminary synthesis of findings; (iii) exploration of relationships between studies; and (iv) assessment of the robustness of the synthesis.

Results: Electronic and hand searches identified 263 potentially relevant studies. Eighteen studies met the full inclusion criteria. Three distinctive strands of investigations emerged: eight studies explored behavioural and psychological aspects, five studies investigated hormonal and physiological changes, and five studies focused on social and relational aspects of music therapy. The musical interventions in the studies were diverse, but singing featured as an important medium for change.

Conclusions: Evidence for short-term improvement in mood and reduction in behavioural disturbance was consistent, but there were no high-quality longitudinal studies that demonstrated long-term benefits of music therapy. Future music therapy studies need to define a theoretical model, include better-focused outcome measures, and discuss how the findings may improve the well-being of people with dementia. Copyright © 2012 John Wiley & Sons, Ltd.

Key words: music therapy; systematic review; narrative synthesis

History: Received 29 May 2012; Accepted 26 September 2012; Published online 18 October 2012 in Wiley Online Library (wileyonlinelibrary.com)

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Introduction

Evidence for the benefits of music therapy in dementia remains inconclusive. Literature reviews on music therapy in dementia conducted to date (Brotons *et al.*, 1997; Koger *et al.*, 1999; Brotons, 2000; Vink *et al.*, 2003, 2011; Ridder, 2005) have found short-term reductions in behavioural disturbance and improved mood, but evidence for long-term benefits is lacking (Livingston *et al.*, 2005). Despite this, music therapy remains popular, and feedback from practitioners supports the idea that it has beneficial effects.

Meta-analyses of randomised controlled trials (RCTs) generally provide more reliable evidence in

evaluating healthcare interventions (Evans, 2003). However, RCTs are not always the most suitable research design for psychosocial interventions because provisions of double blinding to treatment or placebo condition are not always practically possible or ethically suitable. Individual cases are explored in more detail in qualitative studies or in single-case studies, but these studies are automatically excluded from standardised quantitative meta-analysis. Although Vink *et al.* (2003, 2011) 'accepted all behavioural and psychological tools reported by the authors of the identified primary studies' for their Cochrane review on music therapy in dementia care, reported outcomes of RCTs may not always guarantee their validity if the

5. PAPER 2

The importance of music for people with dementia: the perspectives of people with dementia, family carers, staff and music therapists

Aging & Mental Health

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The importance of music for people with dementia: the perspectives of people with dementia, family carers, staff and music therapists

Orii McDermott^{a,b,c,*}, Martin Orrell^{a,d} and Hanne Mette Ridder^b

^a*Mental Health Sciences Unit, Faculty of Brain Sciences, University College London, London, UK;* ^b*Doctoral Programme in Music Therapy, Institute for Communication and Psychology, Aalborg University, Aalborg Øst, Denmark;* ^c*Central and North West London NHS Foundation Trust, St Charles Hospital, London, UK;* ^d*Research and Development, North East London NHS Foundation Trust, Goodmayes Hospital, Essex, UK*

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Objectives: Despite the popularity of music-based interventions in dementia care, there is a limited knowledge of how and why people with dementia find music beneficial for their well-being. A qualitative study was conducted to develop further insights into the musical experiences of people with dementia and explore the meaning of music in their lives.

Method: Separate focus groups and interviews with (1) care home residents with dementia and their families, (2) day hospital clients with dementia, (3) care home staff, and (4) music therapists, were conducted. The findings of the thematic analysis were investigated further in the light of psychosocial factors with the aim of developing a theoretical model on music in dementia.

Results: Six key themes were identified. The accessibility of music for people at all stages of dementia, close links between music, personal identity and life events, the importance of relationship-building through music making were particularly highlighted as valuable. The *psychosocial model of music in dementia* was developed. The model revealed the importance of music to support the personal psychology of people with dementia and the social psychology of the care home environment.

Conclusion: The effects of music go beyond the reduction of behavioural and psychological symptoms. Individual preference of music is preserved throughout the process of dementia. Sustaining musical and interpersonal *connectedness* would help value *who the person is* and maintain the quality of their life.

Keywords: music; dementia; personal psychology; social psychology; psychosocial model

Introduction

Music-based interventions including music therapy, community singing groups and music listening are widely accepted as beneficial for the psychological well-being of people with dementia. Music may be valued as an easily accessible and stimulating medium, which can be enjoyed alone or with others even in the context of severe dementia. Care home residents with dementia and families have highlighted music listening, singing and dancing as particularly meaningful amongst all care home activities (Harmer & Orrell, 2008). Sixsmith and Gibson (2007) conducted interviews with 26 people with dementia and their carers and found that music was not only enjoyed in its own right, but was also valued as a social activity. The ability to appreciate and engage with music remained intact even as cognitive functions deteriorated. A disadvantage of their study may be that it made a limited attempt to link the study findings with a theoretical framework of dementia care, other than mentioning that the study was 'guided by the ecological model of well-being' (Sixsmith & Gibson, 2007, p. 129). A recent narrative synthesis systematic review on music therapy in dementia also identified a limited use of relevant theoretical frameworks (McDermott, Crellin, Ridder, & Orrell, 2013). To understand how and why music interventions may be beneficial for the

psychological well-being of people with dementia, it is necessary to go beyond summarising the study findings and contextualise the study outcome with the aim of developing a theoretical model for music in dementia.

The centrality of engaging directly with the experience of people with dementia and trying to understand the viewpoint of the person with dementia became prominent in the 1990s (Brooker, 2007). Kitwood is particularly known for establishing the concept of person-centred care in dementia where the personhood of an individual with dementia forms the basis of care (Brooker, 2007; Kitwood, 1993a, 1997; Kitwood & Bredin, 1992). Kitwood (1997) defined *personhood* as: 'a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust' (Kitwood, 1997, p. 8). He argued how the personal psychology of the person with dementia is affected by the social psychology of the care culture and debated how the clinical manifestation of a dementia may arise from a complex interaction between *personality, biography, physical health, neurological impairment, and social psychology* (Kitwood, 1993b). The quality and sensitivity of the interpersonal process between a person with dementia and a carer is one of the key components of person-centred care. This has a

*Corresponding author. Email: o.mcdermott@ucl.ac.uk

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6. PAPER 3

The Development of Music in Dementia Assessment Scales (MiDAS)

(In press)

Abstract

Objectives

There is a need to develop an outcome measure specific to music therapy in dementia that reflects a holistic picture of the therapy process and outcome. This study aimed to develop a clinically relevant and scientifically robust music therapy outcome measure incorporating the values and views of people with dementia.

Methods

Focus groups and interviews were conducted to obtain qualitative data on what music meant to people with dementia and the observed effects of music. Expert and peer consultations were conducted at each stage of the measure development to maximise its content validity. The new measure was field-tested by clinicians in a care home. Feedback from the clinicians and music therapy experts were incorporated during the review and refinement process of the measure.

Results

A review of the existing literature, the experiential results and the consensus process enabled the development of the new outcome measure “Music in Dementia Assessment

Scales (MiDAS)”. Analysis of the qualitative data identified five key areas of the impact of music on people with dementia and they were transformed as the five Visual Analogue Scale (VAS) items: levels of *Interest*, *Response*, *Initiation*, *Involvement* and *Enjoyment*. MiDAS comprises of the five VAS items and a supplementary checklist of notable positive and negative reactions from the individual.

Conclusion

This study demonstrates that it is possible to design and develop an easy to apply and rigorous quantitative outcome measure which has a high level of clinical relevance for people with dementia, care home staff and music therapists.

7. PAPER 4

A preliminary evaluation of the psychometric properties of Music in Dementia Assessment Scales (MiDAS)

International Psychogeriatrics

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A preliminary psychometric evaluation of Music in Dementia Assessment Scales (MiDAS)

Orii McDermott,^{1,2,3} Vasiliki Orgeta,¹ Hanne Mette Ridder² and Martin Orrell^{1,4}

¹Division of Psychiatry, Faculty of Brain Sciences, University College London, UK

²Doctoral Programme in Music Therapy, Institute for Communication and Psychology, Aalborg University, Denmark

³Central and North West London NHS Foundation Trust, London, UK

⁴Research and Development, North East London NHS Foundation Trust, London, UK

ABSTRACT

Background: Music in Dementia Assessment Scales (MiDAS), an observational outcome measure for music therapy with people with moderate to severe dementia, was developed from qualitative data of focus groups and interviews. Expert and peer consultations were conducted at each stage of the scale development to maximize its content validity. This study aimed to evaluate the psychometric properties of MiDAS.

Methods: Care home residents with dementia attended weekly group music therapy for up to ten sessions. Music therapists and care home staff were requested to complete weekly MiDAS ratings. The Quality of Life Scale (QoL-AD) was completed at three time-points.

Results: A total of 629 (staff = 306, therapist = 323) MiDAS forms were completed. The statistical analysis revealed that MiDAS has high therapist inter-rater reliability, low staff inter-rater reliability, adequate staff test-retest reliability, adequate concurrent validity, and good construct validity. High factor loadings between the five MiDAS Visual Analogue Scale (VAS) items, levels of *Interest*, *Response*, *Initiation*, *Involvement*, and *Enjoyment*, were found.

Conclusions: This study indicates that MiDAS has good psychometric properties despite the small sample size. Future research with a larger sample size could provide a more in-depth psychometric evaluation, including further exploration of the underlying factors. MiDAS provides a measure of engagement with musical experience and offers insight into who is likely to benefit on other outcomes such as quality of life or reduction in psychiatric symptoms.

Key words: music therapy, dementia, outcome measure, psychometric evaluation, assessment

Introduction

Music-based interventions are popular in clinical practice with people with dementia. Systematic reviews on psychosocial treatments of behavior and psychological symptoms in dementia have found sufficient evidence to support the effectiveness of individually tailored music interventions (O'Connor *et al.*, 2009a; 2009b). A number of systematic reviews on music therapy have also found consistent evidence for short-term reductions in behavioral disturbance and improved mood in people with dementia (e.g. Koger *et al.*, 1999; Vink *et al.*, 2013; Ueda *et al.*, 2013). On the other hand, music therapy studies have been criticized for the lack of

evidence of long-term benefits (Livingston *et al.*, 2005) and for the weaknesses in study designs (McDermott *et al.*, 2013; Vink *et al.*, 2013). All the reviews agree that the potential benefits of music-based interventions for the well-being of people with dementia are promising, but the effects of the interventions require further investigations.

There is also concern whether the outcome measures used in the current music therapy studies are most appropriate to evaluate the intervention. Our recent systematic review (McDermott *et al.*, 2013) found that the Neuropsychiatric Inventory (NPI; Cummings *et al.*, 1994), the Cohen-Mansfield Agitation Inventory (CMAI; Cohen-Mansfield, 1986), and various depression scales are most frequently used to evaluate the impact of music therapy on behavioral and psychological symptoms. On the other hand, there is consistent anecdotal clinical evidence that people with dementia benefit from “positive experiences” of music therapy, for instance, opportunities for

Correspondence should be addressed to: Orii McDermott, Division of Psychiatry, Faculty of Brain Sciences, University College London, Charles Bell House, 67–73 Riding House Street, London W1W 7EJ, UK. Phone: +44-(0)20-7679-9064; Fax: +44-(0)20-7679-9426. Email: o.mcdermott@ucl.ac.uk. Received 4 Sep 2013; revision requested 7 Dec 2013; revised version received 20 Jan 2014; accepted 21 Jan 2014.

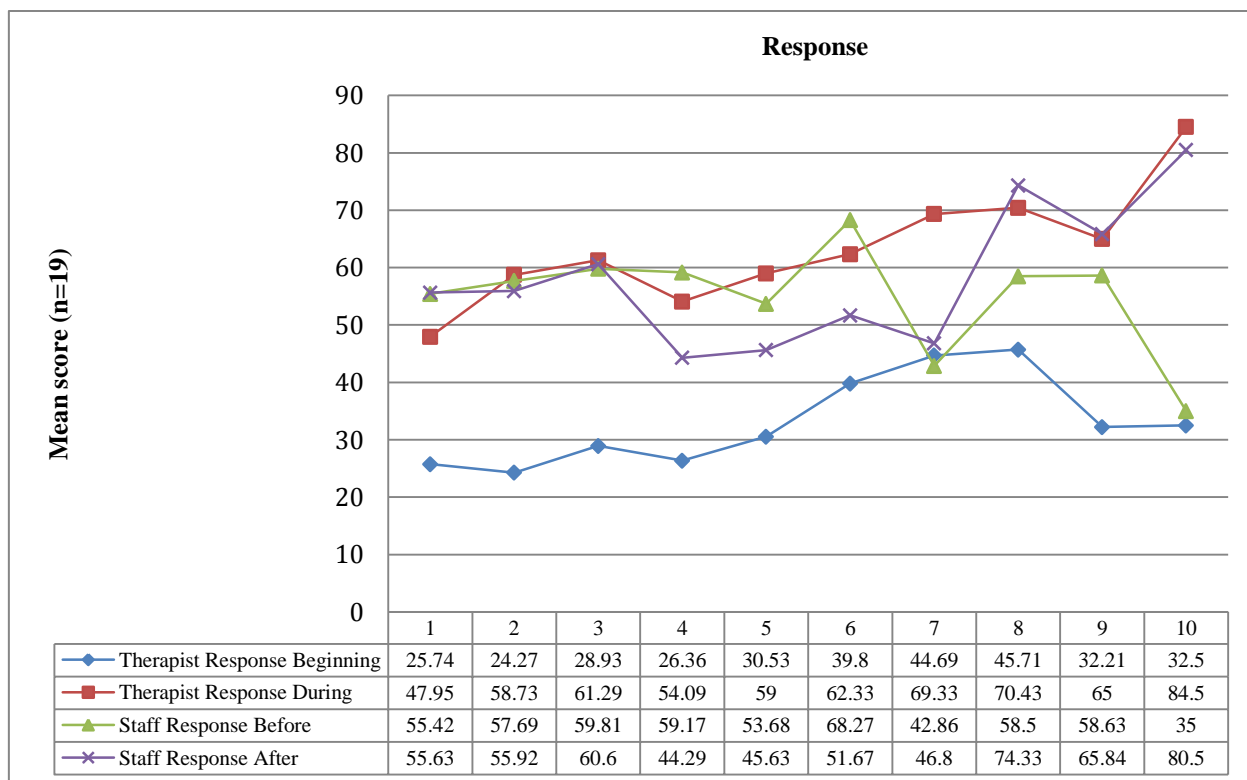
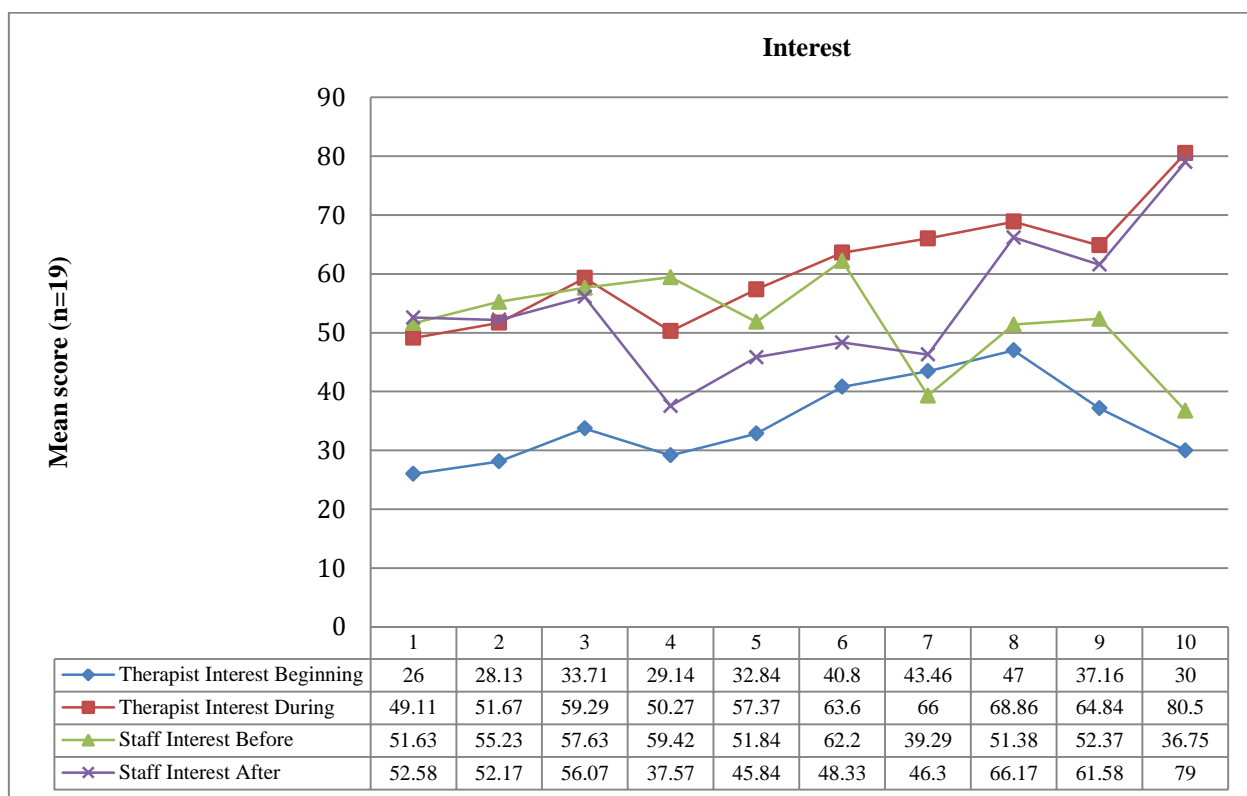
8. MiDAS sensitivity to change

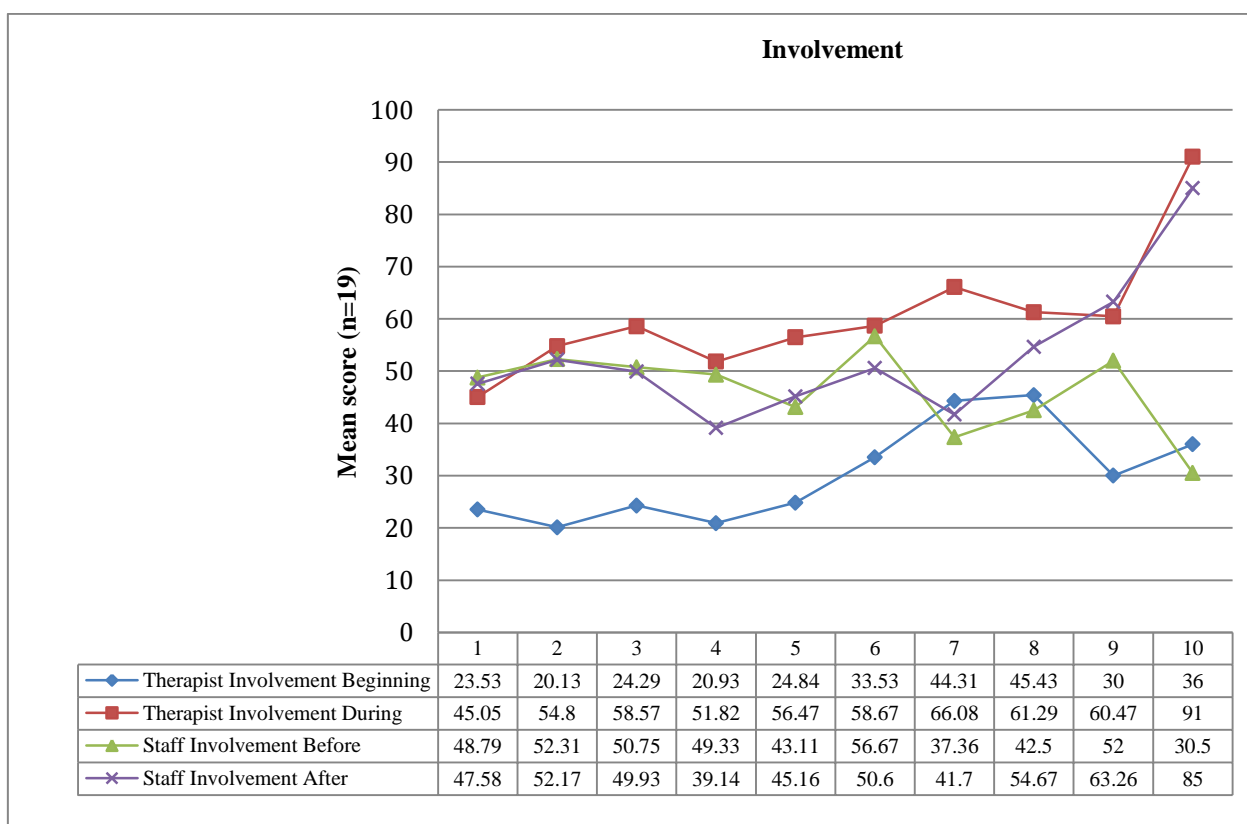
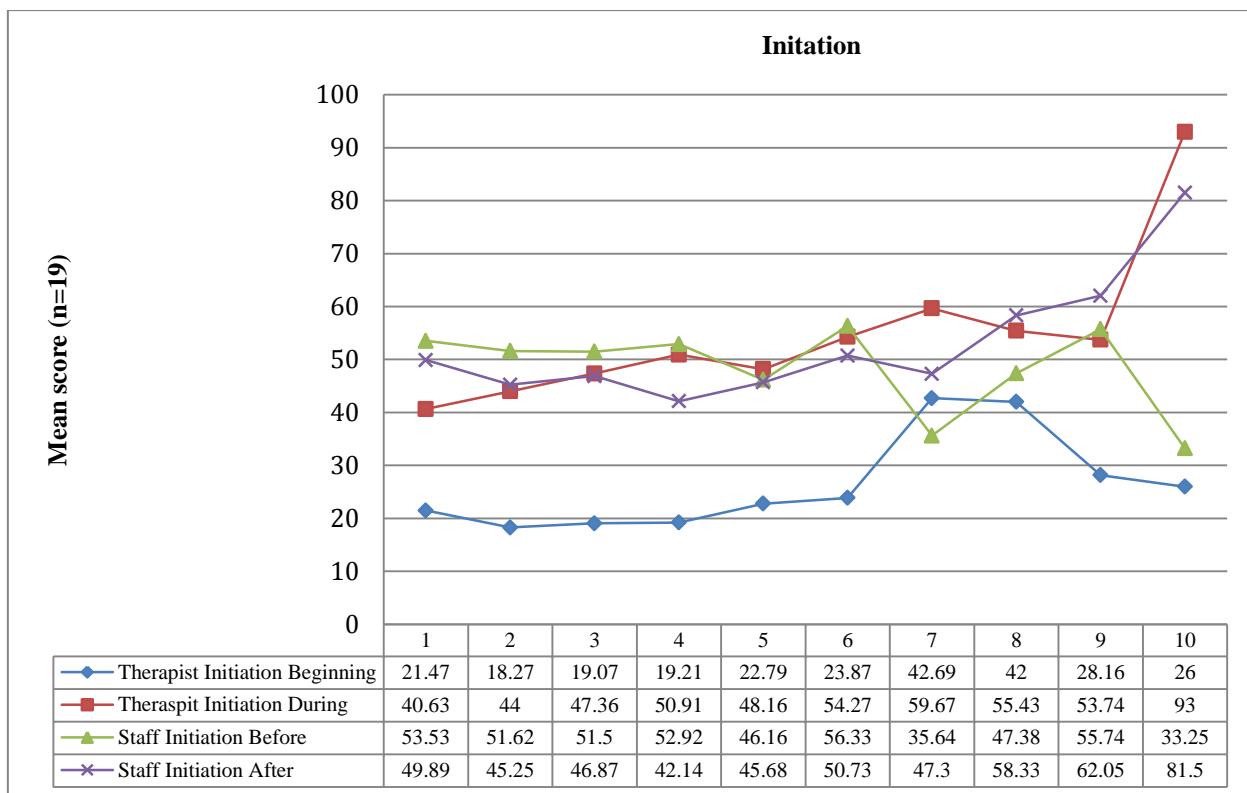
The previous paper focused on the reliability and validity of MiDAS. An investigation of the sensitivity to change was not included in the paper. This section provides a summary of the changes in the MiDAS mean scores of the 19 residents over the course of therapy in order to evaluate MiDAS sensitivity to change.

During the data collection, the researcher collected the completed MiDAS forms every week and measured all the VAS items. Therapists and staff were encouraged to rate each resident based on their observation on the day, and were not informed of the actual MiDAS scores. They also confirmed that they did not remember how the ratings of the same resident looked like from the previous week. This implies that the raters were less biased when they completed the forms every week, and it suggests their MiDAS ratings were genuine observations on the day. Figure 8.1 *Changes in MiDAS mean scores over 10 sessions* shows the score changes in the individual VAS items as well as the changes in the total MiDAS mean scores. Table 8.1 shows the therapist mean score changes within the session. Table 8.2 shows the staff mean changes following the session on the same day.

Only two residents attended session 10, therefore the sudden improvement in the scores in session 10 need to be interpreted cautiously. Most of the residents (15 out of 19) were offered nine sessions, but one of the therapists decided to offer ten sessions to one group for clinical and practical reasons (session interruptions due to the therapist being on leave). The group consisted of four residents but two of them were not on site that day, hence only two other residents attended session 10.

Figure 8.1 Changes in the MiDAS mean scores over 10 sessions





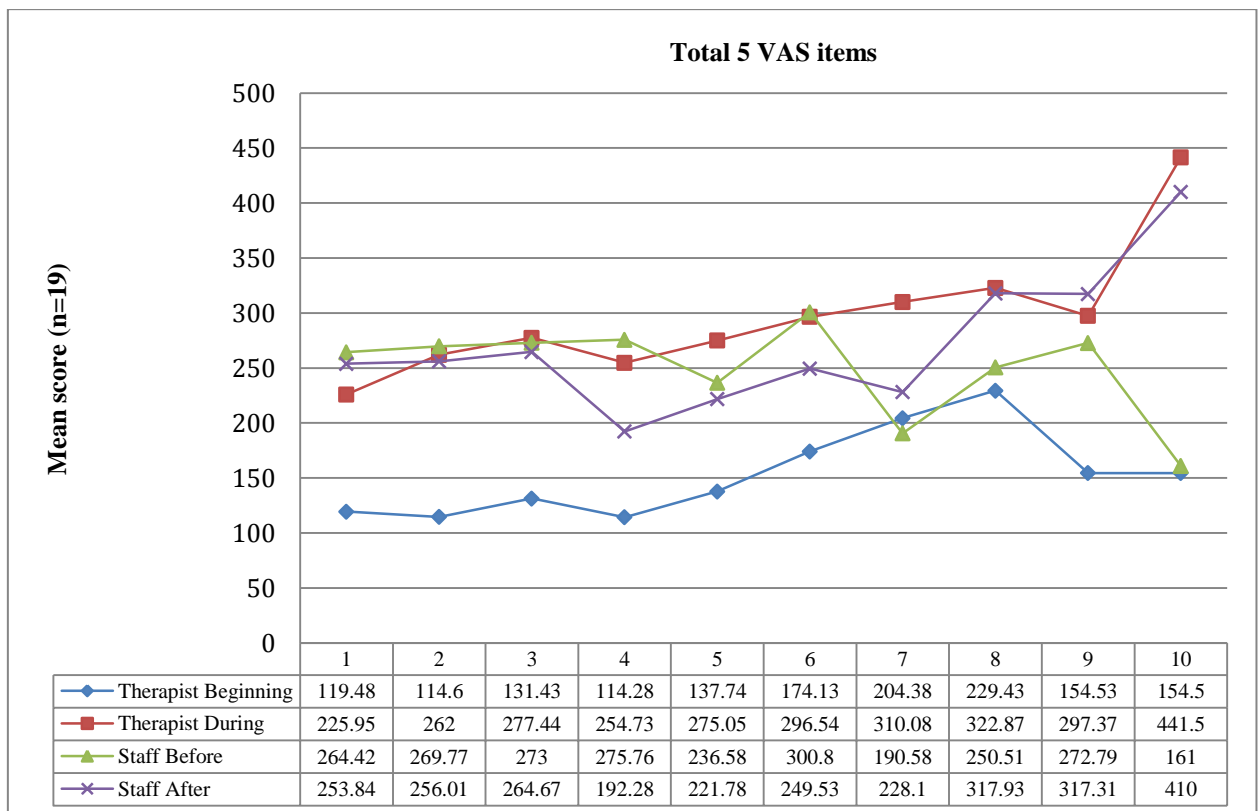
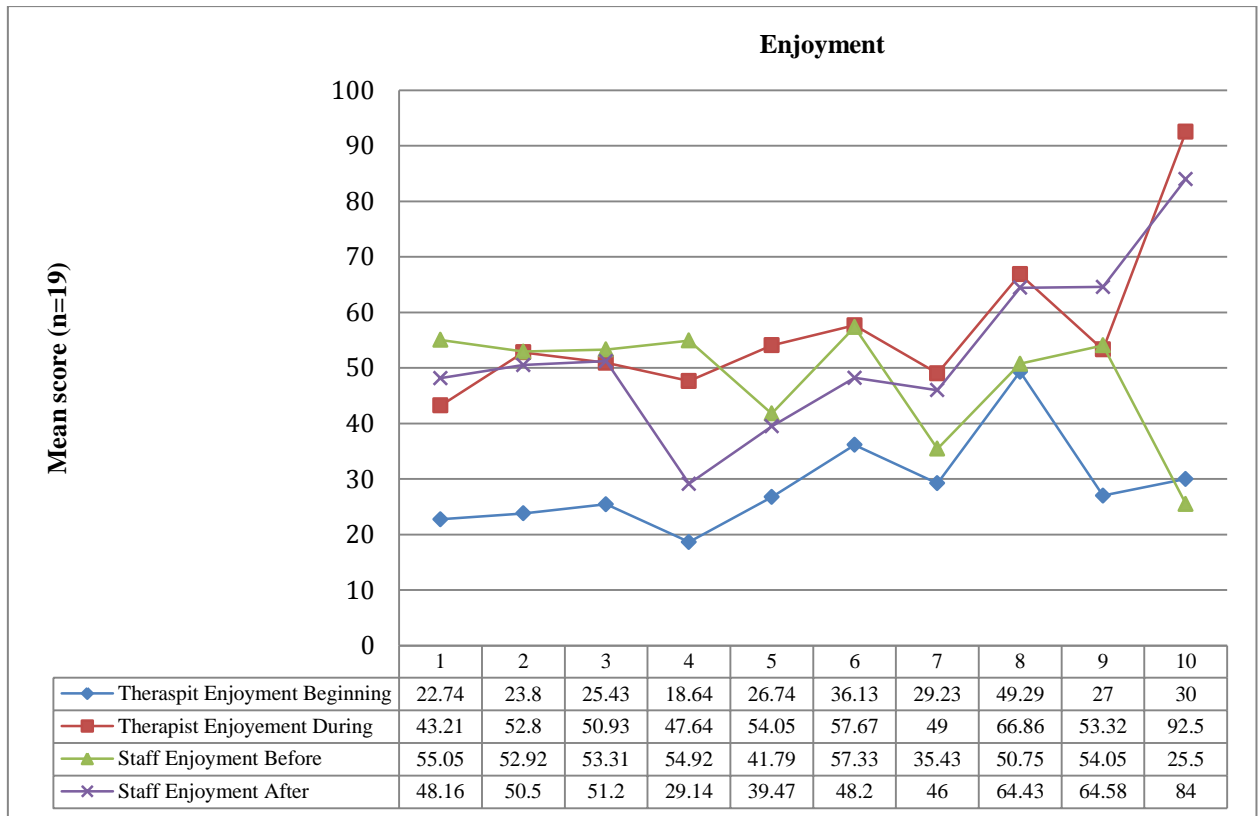


Table 8.1 Therapist mean score changes over 10 sessions from *Beginning* to *During* within the session

Therapist Mean Changes for 19 residents within the session over 10 sessions (from Beginning to During)	Minimum	Maximum	Mean improvement within the session	Standard Deviation
Interest	21.13 (S.4)	50.50 (S.10)	26.32	8.70
Response	22.21 (S.1)	52.00 (S.10)	31.19	8.80
Initiation	13.43 (S.8)	67.00 (S.10)	28.36	14.79
Involvement	15.86 (S.8)	55.00 (S.10)	30.12	10.70
Enjoyment	17.57 (S.8)	62.50 (S.10)	27.89	12.80

(S.) = Session number

Table 8.2 Staff mean changes over 10 sessions from *Before* to *After* following the session on the same day

Staff Mean Changes for 19 residents after the session over 10 sessions (from Before to After)	Minimum	Maximum	Mean improvement after the session	Standard Deviation
Interest	-21.85 (S.4)	42.25 (S.10)	2.78	17.57
Response	-16.60 (S.6)	45.50 (S.10)	3.12	17.79
Initiation	-10.78 (S.4)	48.25 (S.10)	4.56	17.12
Involvement	-10.19 (S.4)	54.50 (S.10)	6.58	18.18
Enjoyment	-25.78 (S.4)	58.50 (S.10)	4.46	22.22

(S.) = Session number

Changes in Therapist MiDAS scores

Overall, the therapist MiDAS scores show gradual and steady progress across the five VAS items and the MiDAS total scores. The changes within the session (changes from *Before* ratings to *During* ratings) are fairly consistent.

Therapist Interest: Gradual and steady improvement in the scores are observed up to session 8 apart from the dip in session 4, in which the minimum change between *Beginning* and *During* scores was observed (Table 8.2). There are notable decreases in the *Beginning* scores of session 9 and 10, but there is 140% increase in *During* score from session 1 to session 8 (peak session for the majority), and 164% increase from session 1 to session 10.

Therapist Response: The pattern of gradual improvement is similar to that of Interest but *Response Beginning* scores tend to be slightly lower than *Interest Beginning* scores, though *Response During* scores tend to be slightly higher than *Interest During* scores, implying bigger changes within the sessions. 147% increase in *During* score from session 1 to session 9, and 176% increase from session 1 to session 10 were found.

Therapist Initiation: *Beginning* scores stay low until session 6 even though *During* scores gradually increase. In session 7, there is a suddenly leap (179% increase from session 6) in *Beginning Initiation* score. This is the peak week for *Initiation Beginning* and *During* scores for the majority of the residents since only two attended session 10. This is also the week *Staff After* score is notably higher than *Staff Before* score across the five VAS items. This suggests there may be a link between the residents taking an initiative and staff noticing the benefits of music therapy.

Therapist Involvement: The overall *Involvement* pattern is similar to that of *Response*. The peak *During* score for the majority of the residents is session 7, 147% increase from session 1, and the scores stay fairly stable, even though there is a notable decrease in *Beginning* in session 9. This is also a common pattern for other VAS items.

Therapist Enjoyment: Scores fluctuate most amongst the five VAS items. Slight dip in session 4 is observed in also observed in other VAS items, but the sudden decrease in session 7 scores, the sharp increase in session 8 scores followed by the sharp decrease in

session 9 scores are only observed in *Enjoyment*. The pattern of the changes from session 7 to 8 is almost identical for therapists and staff.

Changes in Staff MiDAS scores

Overall, Staff *Before* and *After* scores and Therapist *During* scores are very close to each other during the first three sessions. Up to session 6, the majority of *Before* scores are higher than *After* scores and the changes between the two ratings are not consistent, indicating the lack of visible benefits of music therapy. In session 7, *After* scores become higher than *Before* scores across the five VAS items for the first time, and the pattern stays consistent whilst both *Before* and *After* scores improve during sessions 7 to 9.

Staff Interest: A sudden drop in *After* score is observed in session 4, in line with therapist scores, *After* scores then gradually improve, and the scores increases sharply in session 8. Less obvious pattern is observed in the changes in *Interest Before* scores, but there is a trend towards decreased scores from session 1 to 10.

Staff Response: The general pattern is very similar to that of *Interest*, except *Response* scores tend to be slightly higher than *Interest* scores. *Response* scores for Staff *Before* and *After* and Therapist *During* are very close to each other in sessions 2 and 3. The sharp increase in *After* scores from session 7 to 8 (159%) is notable.

Staff Initiation: *Initiation Before* scores are generally lower than *Interest* and *Response* scores and the differences between *Before* and *After* scores are less than other scales until session 7 when *Before* score sharply decreases while *After* score remains stable. The improvement in the score changes from session 7 to 9 is consistent and *After* score continues to improve until session 10.

Staff Involvement: *Before* and *After* scores in sessions 1 to 3 are almost identical. The scores fluctuate during sessions 4 to 6, then sharp, consistent increase in *Involvement After*

scores are observed session 7 onwards (152% from session 7 to 9, 204% from session 7 to 10).

Staff Enjoyment: Similar to *Involvement*, *Before* and *After* scores in sessions 1 to 3 are very similar. There is a sudden drop in *After* score in session 4 (also the lowest Enjoyment score for Therapists). The pattern of changes in *Enjoyment After* scores mirror the pattern of Therapist *Beginning* scores. *Enjoyment Before* scores fluctuate sessions 4 onwards, but the increase in the score from session 7 to 8 mirrors Therapists' and Staff *After* scores.

Staff *Before* scores up to session 6 are higher than *After* scores, suggesting music therapy had a negative impact on the residents, whilst the therapists recorded positive changes during sessions 1 to 6. Consequently, the "Mean improvement after the session" in Table 8.2 is very low because Staff *Before* scores are higher than *After* scores for the majority of the time up to session 7. Staff *After* scores become higher than *Before* scores across the five VAS items for the first time in session 7. This pattern remains the same for the remainder of the sessions. The similarity between the changing patterns in both therapist and staff *Interest* and *Response* may indicate the two items are closely related to each other. A similar changing pattern can be found between Therapist *Initiation* and *Involvement*, but the similarity between Staff *Initiation* and *Involvement* changes is less. This may suggest initiation and involvement during Here and Now music making is related and visible, but not necessarily observable outside of the session. The fluctuating pattern in *Enjoyment* may be a reflection of the changeability of the residents' mood, or a reflection of the difficulty of evaluating the experience of enjoyment as a proxy measure. Some residents expressed their disappointment at the sessions ending, and it is noticeable Therapist *Enjoyment* score decreases sharply in session 9 (the last session for the majority

of the residents) whilst Staff *Enjoyment* score remains stable. Taking all the observations and the findings together, there is a strong indication MiDAS is sensitive to change.

9. DISCUSSION

9.1 Summary of the key study findings

This doctoral study aimed to develop and evaluate a scientifically rigorous and clinically meaningful observational outcome measure for music therapy with people with moderate to severe dementia. The study was designed using the four key elements of the development and evaluation process proposed in the Medical Research Council (MRC) *Developing and evaluating complex interventions: new guidance* (2008): 1) Developing a complex intervention, 2) Assessing feasibility and piloting methods, 3) Evaluating a complex intervention and 4) Implementation. Developing an outcome measure is different from developing a complex intervention *per se*. However, Music in Dementia Assessment Scales (MiDAS) was developed with a view of evaluating a complex intervention, hence the guidance became particularly valuable during the early stage of planning the study. A summary of the key study findings in this section will be formulated using these four key elements.

Development

The development stage of this study included “identifying the evidence base” with a systematic review and “identifying and developing a theory” (MRC, 2008) using the qualitative data from the focus groups and interviews before constructing a new outcome measure.

The literature review (McDermott et al., 2013) to identify the evidence of the benefits of music therapy for people with dementia was conducted according to the *Guidance on the conduct of narrative synthesis in systematic review* (Popay et al., 2006). A narrative synthesis approach rather than a meta-analysis was chosen in order to include high-quality literature of any study designs that met the full inclusion criteria in the review. A narrative approach also allowed exploring a possible mechanism of change. This was the first narrative synthesis systematic review on music therapy, and the explicit narrative approach proved to be suitable to evaluate a complex intervention. Out of the 263 potentially relevant studies, 18 studies met the full inclusion criteria comprising of RCTs (n=6), non-randomised controlled studies (4), pre-post studies (5), qualitative studies (1) and mixed methods studies (2). The quality assessment scores of the 15 quantitative studies (RCTs, non-randomised controlled studies and pre-post studies) with the Downs and Black checklist (1998) varied from 44% to 92% (mean=64.60%, SD=15.19%). The mixed methods and qualitative studies (n=3) were assessed by the Critical Appraisal Skills Programme (CASP) (2006). Each study scored 90% (nine out of ten CASP items). Three distinctive strands of investigations emerged during the synthesis process: eight studies explored behavioural and psychological aspects, five studies investigated hormonal and physiological changes, and five studies focused on social and relational aspects of music therapy. The musical interventions in the 18 studies were diverse, but singing featured as an important medium for change. The review particularly highlighted the need for an application of defined theoretical models and the use of more clinically appropriate outcome measures. The review also confirmed that there was no outcome measure specific to music therapy in dementia that has undergone a full psychometric evaluation and appropriate to be used not only in clinical practice but also in research.

The next step was to identify the meaning and value of music for people with dementia for the conceptual development of the new outcome measure, and to build a theoretical model for music in dementia care. Focus groups and interviews were conducted with families, care home staff, music therapists and people with dementia. Following the transcriptions and the identifications of the key comments for the scale development, the qualitative data was explored further using the framework of the biopsychosocial model (Spector & Orrell, 2010). The *Music and Psychosocial Model* was developed. Three key components: *Here and Now* (music as an accessible medium for people at all stages of dementia, its stimulating and mood enhancing effect), *Who you are* (music as personal identify, reminder of life events), and *Connectedness* (relating to other people through music making and listening, positive effects on care home environment) emerged. The three components were found to be closely linked to the Psychosocial (PS) factors discussed in the biopsychosocial model: *Here and Now* (PS factors: Mental stimulation and Mood), *Who you are* (PS factors: Life events and Personal psychology) and *Connectedness* (PS factors: Social psychology and Care home environment). Individual preference of music was preserved throughout the process of dementia. Sustaining musical and interpersonal *connectedness* would help value *who the person is* and maintain the quality of his/her life (McDermott et al., 2014a).

In order to develop scale items, transcriptions of the key comments from the focus groups and interviews were analysed using the long table approach. The five key categories on the effects of music for people with dementia began to emerge. The categories were designated: 1. *Interest*, 2. *Response*, 3. *Initiation*, 4. *Involvement*, and 5. *Enjoyment* as the main scale items for Music in Dementia Assessment Scales (MiDAS). The key features for each category were identified as follows:

1. *Interest*: attention, alertness, mental stimulation, accessibility of music to people at all stages of dementia.
2. *Response*: increased awareness of people around them and their environment during music intervention.
3. *Initiation*: increased assertiveness: suggesting their personally meaningful music, exploring new instruments.
4. *Involvement*: sustained engagement with other people and their environment during music intervention.
5. *Enjoyment*: mood enhancement, enjoyment of shared music making, “calming effects” of music, music making people “happy”.

Since MiDAS aimed to evaluate the observed effects of music therapy on individual clients, Visual Analogue Scales (VAS), rather than likert scale, was deemed the most suitable scale type for MiDAS. VAS is commonly used to evaluate intensity of a subjective experience such as pain (e.g. Huskisson, 1974) and mood (Folstein & Luria, 1973). The use of VAS for a proxy measure can be a challenge as a rater’s observational skills or personal bias can influence the scores. Nevertheless, MiDAS needed to capture the quality and intensity of observed musical experiences of a person with dementia, rather than frequencies of observed behaviours (e.g. Cohen-Mansfield Agitations Inventory) thus VAS was chosen. VAS is unique to each individual and this is particularly advantageous to assess the optimum level of a person with dementia, since the optimum level may not only differ between individuals but may also shift as the dementia progresses (McDermott et al., 2014b). Finally, in addition to the main five VAS items, a checklist of notable reactions and a space to provide a rater’s own comment was provided on the form to aid clinical interpretations of MiDAS ratings.

Feasibility and piloting

MiDAS was designed as a *same-day scale*. Care home staff were to complete two MiDAS forms on the day of the resident's music therapy (one before, another after the session). Music therapists were also to complete two MiDAS forms immediately after the resident's music therapy (one based on the presentation of the resident at the beginning of the session, another based on the presentation during "the best 5 minutes" of the session). The pilot version of MiDAS was tested by a music therapist and staff for six weeks in care home. The field-testing of MiDAS revealed that it was appropriate to use in a clinical setting and the feedback from the participants confirmed its clinical relevance. At the same time, it was also noted that several staff members struggled to grasp the concept of VAS because it required the rater to take a moment to stop and reflect what would be the optimum level for each resident. Some staff fed back that this was not an easy task especially when they were under time pressure to complete other daily tasks. Following the completion of the field-testing and review of the pilot MiDAS, some changes on the staff rating procedure and the wordings in the MiDAS forms were made. One of the key modifications was that staff were no longer asked to observe a resident for 5 minute before MiDAS rating but were asked to reflect on the overall presentation of the person on the day. Several external music therapists and a staff member pointed out that some raters might find the concept of the two scale items, *Initiation* and *Involvement* unclear. Alternative wordings were discussed but no consensus was achieved, therefore, the five items remained unchanged. (McDermott et al, 2014b)

Evaluation

A rigorous evaluation of MiDAS psychometric properties was a key aim from the very beginning of planning this study. Focus groups and interviews, transparent qualitative data

analysis, peer and expert consultations at each stage of MiDAS development and the use of consensus method all contributed to maximise face and content validity of MiDAS. A full psychometric evaluation to evaluate reliability and validity of MiDAS as a scientific instrument followed. A total of 629 (Staff=306, Therapists=323) were completed over eight months and were included for the psychometric evaluation of the MiDAS. Inter-rater reliability for music therapists was high (ICC range: .768–.820) but inter-rater reliability for staff was low (.127–.362). Test-retest for staff was acceptable (.498–.609). Concurrent validity with QoL-AD (Logsdon, 1999) resulted in Spearman's ρ = .480. Principal Component Analysis for construct validity revealed high correlations between the five VAS items, ranging from *Initiation* and *Enjoyment* (.791) to *Response* and *Involvement* (.921). Cronbach's alpha for internal consistency showed high correlations (α = .967) between the five VAS items (McDermott et al. 2014c). Feedback from music therapists and care home staff confirmed the clinical relevance of MiDAS.

During the evaluation of MiDAS sensitivity to change, a slight decrease in the session 4 scores and a notable decrease in the session 9 scores were observed (Fig. 8.1). Session 8 scores were the highest over the course of therapy. These changes represent a common therapy process, where: therapeutic progresses tend to fluctuate during the clients' earlier sessions, clinically significant changes often happen in the penultimate session (session 8 for most of the participants), but clients are often subdued in their last session (session 9 for seventeen residents). One resident clearly expressed her disappointment during her last session: "I was getting into that (but the group is ending now)". The changes in the *Enjoyment* scores are the most fluctuating for both therapists and staff among the five VAS items. One of the therapists explained: "There were times I found clients were really well engaged, sustaining and communicating, but expressing a great deal of anger." This comment highlights the importance of investigating the changes

in the individual VAS items and making sure the raters also provide other notable observations (qualitative data) in the MiDAS forms when MiDAS is used in clinical settings.

The changes in the residents following music therapy were also observed by staff, but it is only after the sixth session that staff *After* scores show a consistent improvement when compared to staff *Before* scores (Fig. 8.1). It is possible that the changes in the residents observed by the therapist during a session were important but not visible once the residents left the room and it took several sessions before staff recognised the impact. It is also possible that some staff needed a time to get accustomed to the concept of the MiDAS rating procedure before providing more precise scores for their observations. It is also likely that the mean MiDAS scores were not able to pick up all subtle changes that varied between the residents. However, there is consistent evidence that MiDAS is an outcome measure that is sensitive to clinical changes.

The results of the MiDAS psychometric evaluation need to be interpreted cautiously due to the small sample size and nature of the data. Nevertheless, it will be possible to conclude that MiDAS has acceptable to good overall psychometric properties and it is sensitive to change when used in clinical settings.

Implementation

Publication in research literature is essential for the implementation of a complex intervention (MRC 2008). The narrative synthesis systematic review (McDermott et al., 2013), the qualitative data analysis (McDermott et al., 2014a) and the evaluation of MiDAS (McDermott et al., 2014c) have been published. The development of MiDAS (McDermott et al., 2014b) is in press. “Getting evidence into practice” (MRC 2008) and

further evaluation of MiDAS in a wider clinical setting will be an appropriate follow-up from this project.

9.2 Methodological Difficulties

9.2.1 Development of MiDAS

It was crucial to obtain as much raw data as possible from people with dementia themselves. However, recruitment of people with dementia living in the community apart from the four Day Hospital clients who could provide their own consent was not possible. This was due to the time limitation of this project and the availability of music therapists for the field-testing and the main evaluation in the two care homes, and due to the restriction of the site-specific ethics approval that did not cover people with dementia living in community who may or may not have capacity to consent, or who may be cared by a different health service. It can be argued that the views of people with dementia, particularly these people at earlier stages of dementia, are under-represented in this study.

Most of the residents, families and care home staff had known the researcher as the music therapist working in the two care homes. Whilst the familiarity of the researcher was generally advantageous, it is also possible that how the researcher asked questions and how the participants responded to the researcher during the focus groups and interviews were biased in some situations. For instance, one care home assistant acknowledged she wanted to emphasise “good things about music therapy” to support the researcher’s work, whilst the researcher sometimes found it awkward to explore why the residents and families valued music therapy sessions that were provided by the researcher. An additional external interviewer might have succeeded to gain further insights into the values of music therapy for people with dementia whilst keeping an objective distance. Similarly, conducting a few more focus groups in other care settings where the researcher is not known (e.g. private

sector nursing homes, charity organisations running day services for people with dementia) might have added further insights into the meanings of music for people with dementia.

Qualitative data analysis was conducted utilising the general inductive approach (Thomas, 2006). This method allowed the researcher to focus on extracting reoccurring themes and common comments without verbatim transcription and analysis of all the focus groups and interviews. However, the selective transcriptions of themes and key comments were insufficient to conduct an in-depth validation of the qualitative data with an external researcher. Although peer and expert consultations were conducted at each stage of the scale development process to ensure the content validity of MiDAS, it is still possible the selection of key themes and key comments were biased by the researcher's preference.

9.2.2 MiDAS Data Collection and Rating procedure

An activity co-ordinator was allocated as the regular MiDAS rater for the Home A residents but it was not feasible to allocate the same staff members as regular MiDAS raters for the residents in Home B due to the nature of their shift work. All *Before* and *After* staff MiDAS forms were completed by the same members of staff on the day of music therapy, but having a different rater every week would have affected the residents' scores; since some staff would have known the residents better than others and it is likely they would have picked up small signs in the residents. Home B music therapist also expressed her concerns over some of the staff ratings: "I question the usefulness and validity of some of the staff forms as I do not think staff were truly able to engage with the process or to reflect sufficiently to give a meaningful or accurate portrayal of how they found patients. I often had the impression that some of them were just going through the motions when completing forms."

It is a challenge to use a proxy measure in a care home where shift work is the norm. The influence of staff stress levels on the perception of challenging behaviour (Silver, Moniz-Cook & Wang, 1998) and the influence of the differences between the staff role and experience (Moniz-Cook, Woods, Gardiner, Silver & Agar, 2001) have been discussed in previous literature. In addition, a willingness to reflect on the wellbeing of the residents and a willingness to participate in the research project will not only be influenced by the individual carers but also by the care home culture. Both Home A and B went through management structure changes during this study and have been under pressure to meet the UK government targets for the quality of care in dementia. All these factors have had an impact on the view of the staff on their work and their feelings towards “an additional task (MiDAS rating)”.

The two music therapists that provided music therapy sessions had over ten years of experience of working with people with dementia but their theoretical orientations were different (one therapist with a more psychoanalytical approach, while the other therapist with a more music-centred approach). This was helpful to assess the generalisability and the content validity of MiDAS. One of the factors hindering further generalisability of MiDAS may be that both therapists ran sessions on Monday mornings and both worked with people with moderate to severe dementia in NHS care homes. General presentations of the residents before and after music therapy would be fairly similar, and only 19 residents were offered music therapy due to the time limitation of the project. Therefore, it can be argued that the usability and sensitivity of MiDAS need to be tested further in different care settings with people with mild to moderate dementia and music therapy sessions being offered at different times of day and week.

9.2.3 Data preparation for statistical analysis

A total of 629 MiDAS forms were completed between October 2012 and May 2013. The mean of each five VAS item was: *Interest* (50.17, SD=26.96), *Response* (51.57, SD=28.32), *Initiation* 44.34 (SD=30.10), *Involvement* 46.63 (SD=29.58), and *Enjoyment* 46.17 (SD=29.95). The large SD and the Kolmogorov-Smirnov test indicated non normal distribution of the MiDAS scores. Intraclass Correlation Coefficient (ICC) and Principal Component Analysis (PCA) require normally distributed data; hence square root transformation for some of the skewed data was conducted. Square root transformation, rather than log transformation, was chosen since all the VAS items (*Interest*, *Response*, *Initiation*, *Involvement* and *Enjoyment*) had score 0 (13/629, 11/629, 38/629, 18/629, 15/629 respectively), and this would have been excluded from analysis if log transformation was utilised. Square root transformation normalised skewness and kurtosis of the data, but the Kolmogorov-Smirnov test still indicated non normal distribution.

An alternative nonparametric test for inter-rater reliability of a continuous scale was investigated. However, the researcher could not identify an appropriate alternative test for Model B two-way random ICC that would not require an input from a specialist statistician. At this point, the researcher decided not to investigate an alternative nonparametric method since it was deemed not the priority of the project at that time.

Both Principal Axis Factoring (PAF) and PCA were conducted to evaluate concurrent validity. PAF is a descriptive method for the data that does not aim to generalise the results beyond the specific data, therefore it is suitable when the assumption of normality cannot be established (Fabrigar et al., 1999). However, the results of PAF and PCA analyses revealed that the factor loadings were identical, and the differences in the Component Matrix were very small (.003–.028 for the five VAS items). The results of

PCA were quoted for the MiDAS concurrent validity, as the Bartlett's test of sphericity (Bartlett 1954) supported the factorability of the correlation matrix of PCA ($p < 0.001$).

Although a substantial number of MiDAS forms were completed, the sample size for the study was small (19 residents). Because of the small sample size, missing data (e.g. uncompleted QoL-AD forms for concurrent validity) had a large impact on the statistical analyses, as uncompleted cases would usually be excluded from statistical analysis. This issue was discussed with MO at length and the researcher also consulted an internal statistician (UCL) and an external statistician (University of Cambridge). It was deemed acceptable to treat the 52 matched pairs for the therapist inter-rater reliability and the 629 MiDAS forms for factor analysis as individual cases, rather than analysing the 19 residents as 19 cases. Although this method was deemed suitable for this project, it can still be argued that the psychometric properties of MiDAS needs further investigation with a larger number of cases.

9.2.4 Evaluation of MiDAS validity and reliability

MiDAS inter-rater reliability (staff)

The evaluation of staff inter-rater reliability was feasible only in Home A where two members of staff were allocated as the MiDAS raters by the unit manager. One member was an activity co-ordinator who worked from 9 a.m. to 5 p.m. and provided therapeutic group activities to all the 27 residents. The other member was an associate health practitioner who worked on shifts and mainly worked with the residents on an individual basis often helping them with daily self-care. Their relationships with the residents were very different due to the differences in their professional roles and the differences in their experiences of working with people with dementia. The health practitioner explained to the researcher that she spoke to the residents before completing MiDAS forms if they appeared

asleep or had been showing little response on the day. The activity co-ordinator acknowledged the lack of time to spend enough time with individual residents. Therefore, lower correlations between their scores might have been expected. Although the overall correlations were low, the VAS items *Initiation* and *Involvement* had higher inter-rater reliability than *Interest*, *Response*, and *Enjoyment*. It is possible the less active residents' *Initiation* and *Involvement* were more visible than their *Interest* and *Response* because that required more staff time to evaluate and possibly a deeper knowledge of individual residents. Nevertheless, this does not go beyond speculation and further inter-rater reliability needs to be investigated in a future study.

A study by Moniz-Cook et al. (2001) tested inter-rater reliability and test-retest reliability on the Challenging Behaviour Scale (CBS) with different health care professionals (qualified/unqualified staff, matron/care assistant), some of whom had training for rating CBS and others who did not. The difference in the agreement was striking (e.g. .27 to .85 inter-rater for the *Challenge* domain of CBS). The authors also noted that staff “found it easier to agree on whether a problem existed (incidence) and the frequency of its occurrence, than they did on whether the problem presented management difficulties” (Moniz-Cook et al. 2001) and concludes: “the difficulty rating is perhaps more subjective and dependent on rater perception”. Visual Analogue Scales assess the degree of intensity and any proxy VAS ratings depend on a rater's perception. This suggests that it is more likely to have a wide range of inter-rater reliability for an observational VAS outcome measure (e.g. MiDAS) than inter-rater reliability of observational measures with other scale types.

MiDAS concurrent validity

Since there was no gold-standard music therapy outcome measure to compare MiDAS with, Quality of Life scale QoL-AD (Logsdon, 1999) was chosen to evaluate the MiDAS concurrent validity. QoL-AD consists of 13 items and it can be administrated as a self-rating by a person with dementia or as a proxy measure by a carer (Logsdon 1999). It is a Likert scale but the score is added numerically (Poor=1, Fair=2, Good=3, Excellent=4) and is easy to compare with a continuous scale (e.g. MiDAS). QoL-AD has been used successfully in the previous studies with people with moderate to severe dementia (e.g. Spector & Orrell, 2006). It was hoped that some of the 19 residents in this study might be able to complete the self-rating version but none of them were able to follow the instructions fully, and the researcher decided to collect only QoL-AD carer version from staff at the end. QoL-AD was administrated at baseline, mid-treatment, and end-treatment. Although Spearman's rank correlation for each time point was acceptable (.524, .469, .474 respectively), the sample size was small and some QoL-AD data were missing which affected the significance level (.060, .045, .060 respectively), until all the three ratings were combined. ($\rho=.480$, $\text{sig}=.003$). The QoL-AD proxy version may be comparable to MiDAS since it is an observational measure. However, as the ultimate goal of MiDAS was to reflect the views of people with dementia as much as possible, it would have been useful if self-rating quality of life scales were completed by the participants themselves.

9.3 Findings in the context of previous research

9.3.1 Findings in the context of music therapy outcome measures in dementia

MiDAS was developed aiming to fill the gap between a clinically relevant assessment tool but not suitable to use as a main research outcome measure (e.g. RMST, MTCS) and a well-established psychiatric measure commonly used in research but might not measure

what clients attending music therapy may feel most meaningful to them (e.g. NPI, CMAI). MiDAS may be one of the first psychometrically evaluated music therapy outcome measures that prioritised what clients valued most rather than what researchers or carers thought should be measured. Previous music therapy outcome measures have been tested for some of their psychometric properties but not in full (e.g. inter-rater reliability and test-retest reliability for RMST, inter-rater reliability for MTCS). MiDAS has undergone a full psychometric evaluation and evaluated: inter-rater reliability, test-retest reliability, internal consistency, face and content validity, concurrent validity and construct validity.

Aldridge (1992, 1993, 1994) suggested the idea of an evaluation of musical responses could contribute to an assessment of cognitive functions of people with dementia. Aldridge drew a comparison between “medical elements of assessment” and “musical elements of assessment” and discussed how “improvised playing” with a client could provide more sensitive assessment of his/her cognitive function, progressive visuo-spatial skills, ability to perform complex motor tasks and memory disintegration as well as testing his/her previous musical training. Both York (1993) and Lipe (1995, 2007) evaluated their measures against MMSE. Correlation of Residual Musical Skills Test (RMST) (York) with MMSE was $r=.61$, Music Performance Tasks (Lipe, 1995) was $r=.78$ to $.93$ (four subscales). Although it is possible that an assessment of musical responses can contribute to an assessment of cognitive abilities of a person with dementia, it is questionable whether these measures will be the most suitable as research outcome measures in evaluating the benefits of music therapy. MiDAS, on the other hand, enables the monitoring of how music therapy affects the levels of *Interest*, *Response*, *Initiation*, *Involvement* and *Enjoyment* of an individual during therapy (therapist rating) and after therapy (staff rating). MiDAS is suitable to evaluate the therapy process by monitoring weekly MiDAS scores as well as to evaluate the therapy outcome. MiDAS may also help

non-music therapy clinicians to understand how the individuals they care for are benefitting from music therapy.

The appropriateness of the use of Music Therapy Coding Scheme (MTCS), which was developed from the work undertaken with children with pervasive developmental disorder (Raglio, Traficane & Oasi, 2006), in music therapy with people with dementia was questioned in the Introduction. The third paper (The development of MiDAS) found that the musical interactions discussed in the focus groups and interviews had strong resemblances to *communicative attempt* and *communicative act* that Kitwood proposed and drew a parallel to the psychology of infancy and early childhood (Kitwood, 1993). The five MiDAS VAS items: *Interest*, *Response*, *Initiation*, *Involvement* and *Enjoyment* also echo aspects of an infant and parent interaction (McDermott, Orrell & Ridder, 2014b). It can be argued the essence of musical interactions is the “outward signs of human communication” (Trevvarthen & Malloch, 2009) and the experience is universal regardless of age or individual medical conditions. It is possible that the MTCS that was constructed from the musical reactions of the children is applicable to music therapy work with people with dementia. Nevertheless, the authors would still need to justify the strengths and appropriateness of the MTCS when used with another client group.

One of the strengths of MiDAS is that the effects of the sessions are assessed by both music therapists and staff. Even though the importance of Here and Now meaningful musical experiences had been emphasised by the focus groups attendees and interviewees, it is still necessary to evaluate medium to long term benefits of music therapy for people with dementia. There is sufficient evidence that MiDAS is sensitive to change. The use of MiDAS for a longer period of time (e.g. six months to one year) may show if the changes observed during the session are sustainable and/or still observable by staff members when other aspects of clients’ conditions deteriorate.

It should also be noted that although the effects of music on reducing problematic behaviours such as agitation and anxiety, were welcomed by several care home staff and one family member (e.g. “music calms her down”), there was a consensus amongst the study participants that increased meaningful interactions, improved mood and increased awareness were more important for the residents than the reduction of problematic behaviours as such. Taking into account the majority of current music therapy research in dementia focuses on the effects of music on problematic behaviours and symptoms, it may be worth reconsidering what would be the most meaningful research outcomes from the perspectives of people with dementia. Vink et al. (2012) stated that: “in relatively few studies, a possible increase in positive behaviours is addressed. There are still few validated outcome measures available for this purpose. More research studying the effect of music therapy on aspects of positive wellbeing is welcomed”. An investigation of increased wellbeing tends to be conducted as a small-scale study or case series (e.g. Ridder & Aldridge, 2003; Brotons, 2003; Ridder & Aldridge, 2005). Although MiDAS has its limitations, it contributes to the range of outcome measures that address increased positive behaviours and wellbeing in people with dementia.

9.3.2 Findings in the context of the meanings and value of music for people with dementia

Sixsmith and Gibson (2006) conducted interviews with 26 people with dementia living in their own homes or in care homes investigating the role and importance of music in everyday life of people with dementia. The study identified the four key categories of the beneficial impacts of musical activities for people with dementia: 1). enhanced feelings of wellbeing (e.g. emotionally meaningful experience, music enjoyed “as it was heard” even if for many the experience was forgotten soon), 2). supporting valued activities (e.g.

background music to make household tasks and other daily routine enjoyable, helping to maintain a person's previous interests and pastimes), 3). encouraging social interactions (e.g. communal music activities shared with carers, singing and dancing together), and 4). offering a sense of empowerment and control (e.g. playing music to help the person engaging with an activity).

One of the limitations of this study may be that the use of the “ecological model of wellbeing” as a theoretical framework is minimum. According to the authors, the ecological model “is a useful framework because it highlights the way personal and contextual factors influence wellbeing” and the interviews were conducted to “explore the various components of the ecological model” (Sixsmith & Gibson, 2006). However, no synthesis between the study findings and the model that “draws on the work of Powell Lawton and Tom Kitwood” is provided, and there is no further explanation on how the model has been developed. In addition, the method for the qualitative analysis of the interviews is unclear as the authors do not describe how they ensured the rigor of data analysis beyond explaining that “the conversations were transcribed and coded prior to data analysis” using “an analysis template, based on the conceptual model of wellbeing”. Despite these limitations, the study concludes that “the ability to appreciate and engage with music may remain relatively intact when other cognitive processes, such as verbal communication, are severe impaired” and recommends further research on the importance and role of music that “may also point to new avenues for therapeutic intervention for people with severe dementia” (Sixsmith & Gibson, 2006).

The second paper explored the meaning and the value of music for people with dementia from the perspectives of the four identified groups: family carers, staff, music therapists and people with dementia themselves (McDermott et al., 2013b). The majority of the interviews and focus groups were conducted with either care home residents with

moderate to severe dementia, their families, or professionals involved in working with people with moderate to severe dementia. One of the limitations of this doctoral study is the possibility that people with mild to moderate dementia are underrepresented. Nevertheless, the findings from this study can complement the study findings of Sixsmith and Gibson (2006) whose interviewees were at earlier stages of dementia than our study participants. A study investigating “meaningful activities” in care homes also identified music as one of the four key activity themes together with “reminiscence”, “family and social”, and “individual” activities (Harmer & Orrell, 2008). Focus group participants included 17 care home residents with dementia of MMSE score ranging from 5/30 to 25/30. Engagement through music and stimulating effect of music were highlighted, and communal music listening and singing were identified as particularly enjoyable experiences in the care home lives of the residents. The study highlights the meaningfulness of music in context of all the therapeutic activities in care homes. The findings from this study, as well as the four key categories identified by Sixsmith and Gibson (2006), have strong links with the three key components identified in our second paper: *Here and Now* (music as an accessible medium for people at all stages of dementia, its stimulating and mood enhancing effect), *Who you are* (music as personal identify, reminder of life events), and *Connectedness* (relating to other people through music making and listening, positive effects on care home environment).

The findings of our study also echo the results of the two studies by Hays and Minichiello (2005a, 2005b) with “older people” living in Australia involving two focus groups and 38 in-depth interviews to explore personal meaning and importance of music in the lives of older people. Whether any of their interviewees had dementia has never been specified in the study, since their selection criteria of the study participants focused on those actively involved in music making as amateur or professional musicians and those

without formal musical background. The transcriptions of the interviews were analysed “using the methodological principles of open and axial coding described by Strauss and Corbin (1998)”. Repeated examination of the recurring themes and cross-checking of the codes were conducted. The study found that there were no major differences on the meaning and importance of music between the responds of those with formal musical training and those without. Their study findings included: music had a positive impact on a sense of self, helped to protect self-identity, nurtured spirituality, held strong associations to particular life events, lessened feelings of isolations and loneliness, and helped the development of relationships with other people. The fact the outcome of our study with people dementia has strong similarities to the findings of the study with independent older people suggest that the importance of the musical identity of an individual and the need for shared meaningful experiences is retained throughout the ageing process despite presence or absence of neurological impairments (McDermott et al., 2014b).

9.4 Limitation of the study

9.4.1 Limited understanding of expected therapy outcomes for residents with moderate to severe dementia

MiDAS was designed as an observational measure for people who may not be able to provide their own verbal feedback due to the severity of their dementia. Most of the residents in the two care homes where the study was conducted had moderate to severe dementia and required a high level of individualised care. Many presented with challenging behaviours or had other psychological symptoms such as apathy or depression though these might not have been formally diagnosed. Both therapists and staff raters as well as focus group participants acknowledged the changeability of residents’ mood. All emphasised the importance of Here and Now musical interactions but many doubted if the

residents remembered their music therapy experience half an hour later. Additionally, they explained that residents' observable mood and behaviour were more likely to be influenced by the Here and Now of daily routine such as personal care and interactions with fellow residents during meal time, which may not be linked to therapy outcomes. If a resident experience an increased sense of wellbeing as a result of music therapy, it is also possible that such an internal experience may not be measurable using standardised outcome measures. Additionally, the music therapists felt that it was unrealistic to expect the changes observed during music therapy sessions to be observable by care home staff or family members if the resident had attended only ten sessions. It was suggested a longer intervention (beyond four months) with more frequent input (twice weekly) would "quicken the therapy process" and make the potential changes more visible, even though the therapy process is unique to each individual and the visibility and the measurability of the therapy outcome cannot be guaranteed.

All these factors are linked to our limited knowledge of what the expected therapy outcome for people with moderate to severe dementia would be after a three-month music therapy intervention. The lack of this knowledge makes it harder to distinguish the sensitivity (or non-sensitivity) of an outcome measure from the clinical reality where minimum visible changes may be expected to happen in the first place. A randomised controlled trial will be required to evaluate the measure's sensitivity-to-change. The use of MiDAS in music therapy with people at earlier stages of dementia where more visible changes can be expected may also help assessing its sensitivity to change.

9.4.2 Same-day Scale

MiDAS was developed as a same-day-scale as the raw data from the focus groups and interviews did not support the potential observable effects of music beyond the day of

music therapy. MiDAS may be most suitable to measure the in-the-moment presentation of a resident and changes taking place within and immediately after a session and may help to understand how music works with the resident. Although the clinical relevance of MiDAS has been confirmed by the study participants, it is not known yet whether MiDAS is suitable to be used as a research tool to evaluate the medium- to long-term potential benefits of music therapy or not. It may be necessary to use MiDAS in conjunction with commonly used instruments such as Cornell Scale of Depression (Alexopoulos et al., 1988), NPI (Cummings et al., 1994) or Quality of Life measures in order to aid the interpretation of MiDAS scores.

The potential bias when completing two forms on the same day was pointed out by the therapists and a staff rater. The two music therapists acknowledged the challenge of completing a *Beginning* and *During* form immediately after the session. One therapist explained: "...unconsciously, I am sure there is always a desire to see a change and this may have affected how I filled these forms". Two staff MiDAS forms were completed several hours apart (one before music therapy, another after music therapy). However, a similar view was still expressed by a staff rater: "some of the scores might have been influenced... because we may want to please you (researcher), or because we don't want to fail (by not recognising possible changes in residents)... people often don't want to say activities did not work". The possibility of bias will always be present.

Even if we had more evidence for the potential observable effects of music beyond the day of music therapy, it is still uncertain whether rating MiDAS *Before* and *After* scores several days or one week apart will decrease bias and be more beneficial for research purposes. An advantage of the same-day scale is that raters will still remember small yet potentially significant changes they observed on that day but may forget several days later. The best way to deal with this issue may just be to keep encouraging self-

awareness of MiDAS raters but keep MiDAS as a same-day scale. Continuing with MiDAS ratings over four to six months, evaluating the medium-term scores changes and comparing the outcomes against other serial measures such as Quality of Life scales (e.g. QoL-AD) or with cognitive and psychological assessment may help further evaluate the scientific and clinical value of MiDAS.

9.4.3 MiDAS construct

In evaluating construct validity of MiDAS, five components were extracted for the initial eigenvalues but only one component was retained for both PCA and PAF, with a single underlying factor that explained 88.5% of the variance. Correlation between the VAS items Response and Involvement was the highest (.921) and the lowest correlation between Initiation and Enjoyment was still .791 (McDermott et al, 2014c). This may indicate the five VAS items are too similar to distinguish one from one another. On the other hand, other psychiatric and psychological measures used in dementia care often have more scale items: for instance, the ‘Sense of Competence in Dementia Care Staff (SCIDS)’ (Schepers, Orrell, Shanahan & Spector, 2012) consists of 17 items. Therefore, it is expected that more factors will be extracted for SCIDS and item correlations will vary greatly between the scale items. SCIDS reported that “no support for positive association of sense of competence with dementia knowledge” but “some support for a positive association of sense of competence with job satisfaction”. It may be acceptable for MiDAS to have retained only one component since MiDAS tried to capture one factor: meaningful engagement with music. Nevertheless, it still raises the question whether the five items were too similar for the raters to differentiate between them, or whether the instructions given to the raters were unclear. Having one component does not necessarily have to be a limitation if the purpose of the scale is to evaluate one construct (meaningful engagement

with music), yet MiDAS users should perhaps be informed that the purpose of MiDAS is to measure the *one outcome* using the five VAS items.

9.5 Future Research

The narrative synthesis systematic review on current literature, the comments from focus group attendees and interviewees, and the evaluation of MiDAS highlighted several key areas where little research has been undertaken or is in need of further investigation. Almost all the literature review on music therapy in dementia, or literature reviews that included music therapy or music activities as part of the review (e.g. review on non-pharmacological interventions in dementia) pointed out the weaknesses in study designs and methods in current literature. Although this is too broad of a statement to make if no specific issues are addressed, it is evident that there is a need to conduct further rigorous evaluation on how and why music therapy works as a replicable clinical intervention for people with dementia. A future study needs to: 1) plan a study based on a clear theoretical framework, 2) define study aims accurately and provide an explicit rationale for the study before deciding a study type and designing an intervention, 3) define a replicable music therapy intervention and justify the choice of the intervention, and 4) choose appropriate outcome measures after finalising the study aims and considering clinically realistic goals to achieve.

9.5.1 Randomised controlled trial on the benefits of music therapy on apathy

Psychosocial studies, including music therapy, targeting the behavioural symptoms of dementia such as agitation are very common. However, fewer studies on the psychological symptoms of dementia (e.g. anxiety, depression, apathy) have been conducted to date (O'Connor et al., 2009b). In particular, little research has been undertaken on the benefits of music on apathy in people with dementia. Although several music therapy studies that

used NPI (e.g. Raglio, 2008; 2010a) reported NPI subscale apathy improved following music therapy, no music therapy study specifically investigating apathy has ever been conducted. Apathy is defined as “a loss of motivation and manifests in behaviours such as diminished initiation, poor persistence, lowered interest, indifference, low social engagement blunted emotional response, and lack of insight” (Landes, Sperry, Strauss & Geldmacher, 2001). The prevalence of apathy among people with Alzheimer’s disease is particularly high, occurring in 61% to 92% of the people, and its huge impact on caregiver burden is well documented (Mega, Cummings, Fiorello & Gornbein, 1996; Landes, Sperry & Strauss, 2005). Apathy symptoms are often undetected or ignored in clinical settings. Differentiating cognitive decline from apathy and depression may not be easy, but it is often the case that quiet residents with no “management problems” get less attention from staff and less effort is made to investigate their psychological wellbeing. It is also the researcher’s experience that many quiet residents suddenly start to deteriorate quickly, or their deterioration suddenly becomes more visible. Whilst some aspects of the progression of dementia are unpredictable and unavoidable, it is very likely that their psychological wellbeing might have been maintained for a longer period of time had an appropriate psychosocial intervention been implemented earlier.

The only music activity study that has explicitly targeted apathy was a RCT on the effects of live music and recorded music on the engagement levels of care home residents with moderate to severe dementia (Holmes, Knights, Dean, Hodkinson & Hopkins, 2006). 32 residents “from residential and care homes in the south of England” with ICD-diagnoses of dementia and apathy were “exposed to live interactive music, passive pre-recorded music or silence for 30 minutes” (Holmes et al., 2006). The engagement levels of the residents were assessed by Dementia Care Mapping (DCM) (Bradford Dementia Group, 1997) category E (engagement in expressive or creative activity). The study

reported “a significant and positive engagement to live music, regardless of dementia severity” (Holmes et al., 2006). Although the study states the muted video recordings of the sessions were analysed by “an independent fully trained DCM rater”, the rigor of the evaluation process is questionable. The only reference the authors make on DCM is “Kitwood (1997) Dementia Care Mapping: the DCM method (7th ed.)” and there is no information on how the accuracy and consistency of the mapping procedure was ensured, since it appears the conclusion of the whole study is based on the analysis by one mapper alone. DCM is often completed by two mappers to ensure reliability and using only one behavioural category code of the DCM reduces reliability further. No information on how the choice of music, both live and recorded, was made is provided. The procedure for choosing clinically appropriate music for the intervention should involve consultations with the residents and/or care homes and a planned programme with the musicians. If the choice of music was left to the musicians, the rationale for this approach and the background of the musicians need to be clarified, otherwise this intervention will not be replicable. The weaknesses in this study particularly highlight the importance of ensuring the clinical appropriateness of music. Our qualitative study (McDermott et al., 2014a) revealed that the preference of music was highly individual; music was strongly liked to personal history and cultural background, and the choice of music need to be judged sensitively according to individual needs and preferences since music could also trigger painful memories. Possible adverse effects of music need to be considered more carefully in the future research. MiDAS evaluates the levels of engagement. The five MiDAS items: *Interest*, *Response*, *Initiation*, *Involvement* and *Enjoyment* will be appropriate to evaluate the levels of psychological symptoms in dementia including apathy and depression in conjunction to other psychiatric measures such as NPI. MiDAS also needs further psychometric evaluation in a RCT to test its suitability as a research instrument. Testing

MiDAS in a RCT on the benefits of music therapy for apathy in people with dementia and evaluating its concurrent validity with NPI may be also useful for evaluation purposes.

9.5.2 Feasibility study on the chorus intervention for people with dementia and their family carers and the development of MiDAS self-rating version

With the increasing number of people with dementia living in the community, the development of music activities as a clinical intervention to maintain the wellbeing of people with dementia and their family carers may become important in the near future. Focus group participants and interviewees emphasised the value of songs. Singing was also identified as particularly beneficial for the clients in our systematic review (McDermott et al., 2013).

A feasibility study on a chorus intervention for people with dementia living in the community and their family carers may be a possible future study. The chorus intervention may not be run as a music therapy group, yet musical and therapeutic skills of an experienced music therapist will still be required to accommodate individual needs of the participants and still keep the focus on the development of shared musical experience and social interaction between group members. The choice of songs/music will be participants-led as much as possible.

In the U.K., community-based music groups such as “Singing for the Brain” run by Alzheimer’s Society have become very popular, but a limited number of studies on singing interventions for people with dementia and their families have been conducted to date. For example, Camic, Williams and Meeten (2013) conducted a pilot study on a 10-week singing intervention with people with dementia (n=10) and family carers (n=10). Quantitative data using standard outcome measures (e.g. Quality of Life scale, depression scale) did not indicate the intervention was beneficial, but the positive impact on their

wellbeing was confirmed by the study participants. The importance of introducing a controlled group was highlighted. Davidson and Fedele (2011) used a standardised group format for their 6-week joint singing program (total n. of participants=48). No significant changes were found in quantitative results, but qualitative analyses indicated many participants experienced improved social interaction. These studies highlight the fact that standardised instruments are not always sensitive to measure meaningful experiences study participants identified: such as enjoyment, increased social interactions and a sense of empowerment.

This raises a possibility of developing a self-rating version of MiDAS (MiDAS-S) that can be completed by a person with dementia and also a MiDAS family-carer version (MiDAS-F). MIDAS has adequate psychometric properties therefore the five VAS items should probably be kept the same. However, focus group discussions are necessary to achieve consensus on the conceptual understanding of each VAS, and examples for each VAS also need to be appropriate for self-rating and for family-carer-rating. The new scales may be used as secondary outcome measures in the chorus study in conjunction with other established psychiatric measures to enable the psychometric evaluation of MiDAS-S and MiDAS-F.

9.6 Conclusion

The Development and Evaluation of Music in Dementia Assessment Scales (MiDAS) is the first study that attempted to develop a psychometrically validated outcome measure from the qualitative data exploring the values of music for people with dementia and the observed effects of music. MiDAS has overall fair to good psychometric properties but still needs further evaluation in a randomised controlled trial. It should also be tested by clinicians in wider clinical settings working with people at different stages of dementia. Not withholding its limitations, the outcome of this study confirms it is possible to incorporate the views of people with dementia, families, care home staff and music therapists into research and develop a scientifically robust outcome measure.

Focus group participants and interviewees highlighted the effects of music on increased positive behaviours and improved mood in people with dementia including an increased alertness and meaningful social interactions. The sustainability of such effects was questioned by some of the participants due to the severity of dementia of the residents as well as due to the influence other variables in care homes that affected the residents' mood. However, all emphasised this did not diminish the importance of Here and Now musical experiences for people at all stages of dementia. The close link between music and personal identity of the person, and the need to value the individual preferences of music were also highlighted. The benefits of music on reducing psychological and behavioural symptoms were discussed infrequently. Challenging behaviours affect not only the wellbeing of the person himself/herself, but also the wellbeing of other residents, staff and families. It is important to acknowledge the potential benefits of music on the reduction of problematic behaviours. Nevertheless, the findings of this study highlight that the benefits of music therapy and music activities go beyond the reduction of neuropsychiatric symptoms. This has an implication in clinical practice as well as in research, and calls for a

more holistic approach. The five MiDAS items: levels of *Interest*, *Response*, *Initiation*, *Involvement* and *Enjoyment* evaluate meaningful engagement with music. The use of MiDAS in conjunction with psychiatric measures such as NPI and evaluating both reduction of symptoms and increased meaningful engagement may help developing a deeper understanding of how and why music may work with people with dementia.

The use of a proxy measure inevitably involves a rater's personal interpretation. The challenge of ensuring the rigor in using observational measures in care home settings has been highlighted in the study. There is a risk to the reliability of MiDAS if a rater does not fully understand the concept of Visual Analogue Scales or the rater for the resident is not consistent. On-going monitoring and training of MiDAS raters will be important. Once a rater becomes familiar with MiDAS, it may be possible to use MiDAS as a part of reflective practice. Some staff raters found stopping, reflecting and rating MiDAS challenging when they felt pressurised to complete other daily tasks. It is perhaps even more important then, to have a tool that allows them to stop and reflect on the residents they provide care for.

The meaning and experiences of music are highly unique to individuals regardless of the severity of dementia. Capturing and measuring such personal experiences with a standardised quantitative measure has its limitations. Nevertheless, a wide range of validated outcome measures are necessary to conduct a rigorous music therapy study closely linked to clinical needs of study participants. It is hoped MiDAS can contribute to the development of such outcome measures.

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11. APPENDICES

The names of the care homes have been anonymised to protect the identities of the study participants.

‘Music and Me’ was the project name given at a request of the ethics committee to clarify this is a research project and not a part of usual music therapy service.

‘Study participants’ information sheet and consent form were produced for day hospital clients.



Co-author statement in connection with submission of PhD thesis

With reference to Ministerial Order no. 18 of 14 January 2008 regarding the PhD Degree § 12, article 4, statements from each author about the PhD student's part in the shared work must be included in case the thesis is based on already published or submitted papers.

Paper title:

Music therapy in dementia: a narrative synthesis systematic review

Publication outlet:

Published in International Journal of Geriatric Psychiatry (2013)

List of authors:

Orii McDermott, Nadia Crellin, Hanne Mette Ridder, Martin Orrell

Description of authors' roles:

O. McDermott was the main researcher responsible for designing and conducting the review, data analysis and synthesis, and writing the article. N.Crellin was involved in the designing of the study and conducted the quality assessment of the included studies as the second reviewer. H.M. Ridder provided expert opinion in the field of music therapy in dementia. M. Orrell supervised the designing and conducting of the study and provided expert advice during the data analysis and writing up. All authors have approved the final draft of this article.

We hereby confirm the statement above is true and accurate.

Orii McDermott

Nadia Crellin

Hanne Mette Ridder

Martin Orrell



Co-author statement in connection with submission of PhD thesis

With reference to Ministerial Order no. 18 of 14 January 2008 regarding the PhD Degree § 12, article 4, statements from each author about the PhD student's part in the shared work must be included in case the thesis is based on already published or submitted papers.

Paper title:

What music means to me: the importance of music for people with dementia from the perspectives of family carers, staff, music therapists and people with dementia themselves

Publication outlet:

Submitted to a peer-reviewed journal. Under revision.

List of authors:

Orii McDermott, Martin Orrell, Hanne Mette Ridder

Description of authors' roles:

O. McDermott was the main researcher responsible for designing and conducting the study, conducting focus groups and interviews, the data collection and analysis, and writing the article. M. Orrell supervised the designing and conducting of the study and provided expert advice during the data analysis and writing up. H.M. Ridder provided expert opinion in the field of music therapy in dementia. All authors have approved the final draft of this article.

We hereby confirm the statement above is true and accurate.

Orii McDermott

Martin Orrell

Hanne Mette Ridder



Co-author statement in connection with submission of PhD thesis

With reference to Ministerial Order no. 18 of 14 January 2008 regarding the PhD Degree § 12, article 4, statements from each author about the PhD student's part in the shared work must be included in case the thesis is based on already published or submitted papers.

Paper title:

The Development of Music in Dementia Assessment Scales (MiDAS)

Publication outlet:

Submitted to a peer-reviewed journal. Under review.

List of authors:

Orii McDermott, Martin Orrell, Hanne Mette Ridder

Description of authors' roles:

O. McDermott was the main researcher responsible for designing and conducting the study, conducting focus groups and interviews, the data collection and analysis, and writing the article. H.M. Ridder contributed to the conceptual development of the MiDAS and to the initial analysis qualitative data and provided clinical expert opinion. M. Orrell supervised the designing and conducting of the study and provided expert advice during the data analysis and writing up. All authors have approved the final draft of this article.

We hereby confirm the statement above is true and accurate.

Orii McDermott

Martin Orrell

Hanne Mette Ridder



Co-author statement in connection with submission of PhD thesis

With reference to Ministerial Order no. 18 of 14 January 2008 regarding the PhD Degree § 12, article 4, statements from each author about the PhD student's part in the shared work must be included in case the thesis is based on already published or submitted papers.

Paper title:

Evaluation of the psychometric properties of Music in Dementia Assessment Scales

Publication outlet:

Submitted to a peer-reviewed journal. Under review.

List of authors:

Orii McDermott, Vasiliki Orgeta, Hanne Mette Ridder, Martin Orrell

Description of authors' roles:

O. McDermott was the main researcher responsible for designing and conducting the study, data collection, the data analysis and writing the article. V. Orgeta was involved in the data analysis and provided statistical support. H.M. Ridder was involved in the development of the MiDAS and provided clinical expert opinion. M. Orrell supervised the designing and conducting of the study and provided expert advice during the data analysis and writing up. All authors have approved the final draft of this article.

We hereby confirm the statement above is true and accurate.

Orii McDermott

Vasiliki Orgeta

Hanne Mette Ridder

Martin Orrell

MiDAS

Music in Dementia Assessment Scales

Version 6

Name:	Time:
Completed by:	Date:

MiDAS (Music in Dementia Assessment Scales) aims to assess if there have been changes in the wellbeing of a person with dementia participating in Music Therapy. Both staff and therapist complete **two forms each per session** to evaluate the potential changes. MiDAS uses Visual Analogue Scales; the 'Highest' score on the scale should be set as **the optimum level the individual can achieve**. This means that each individual will have a unique set of 'Highest' levels for each category.

Instruction for Staff

It is important **the same staff member completes both forms on the same day**.

1. Before form should be completed **before** the person's music therapy session. Please take a moment, reflect on the person's **wellbeing today** and decide the **average rating** for each item below and mark clearly with a vertical line on the scale.

2. After form should be completed **several hours after** the person's music therapy session **on the same day**. Rate the person's **average wellbeing after today's session**.

If you are a staff rater, indicate which rating this is:

1. Before ☐

2. After ☐

Instruction for Music Therapist (MT)

Both forms should be completed immediately after the session.

1. Beginning form should be completed based on the observation of the person during **the first 5 minutes** of the music therapy session. Decide the **average rating** for each item below and mark clearly with a vertical line on the scale.

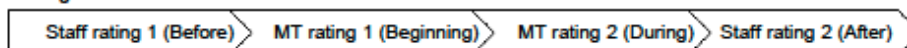
2. During form should be completed based on the observation of the person during **the clinically most significant 5 minutes** of that session.

If you are a music therapist, indicate which rating this is:

1. Beginning ☐

2. During ☐

Order of rating:



If the person appeared asleep for most of the time, do not score question 1-6, but continue to question 7.

1. Levels of Interest in objects/activities/people around him/her (**attention**). For example:

- Did he/she show his/her **interest in an activity** or **other people** around him/her?
- Did his/her **posture** or **facial expression** change if activities or music catch his/her attention?
- Did he/she become **animated** if activities or music catch his/her attention?

None at all 0 Highest 100

SCORE

2. Levels of Response in communication/activity (awareness, interaction). For example:

- Did his/her **facial expression** or **body-movements** indicate his/her awareness of staff or therapist?
- Did he/she make **eye-contact** with staff, therapist or other group members?
- Did he/she join in **conversation, music making** or make **vocal sound**?

None at all _____ Highest
0 100

3. Levels of Initiation in communication/activity (intention). For example:

- Did he/she **try to communicate** with staff, therapist or other group members?
- Did he/she **start conversation, start music making, or initiate vocalisation**?
- Did he/she talk about his/her life experiences (**reminiscence**) or **mention music** meaningful to them?

None at all _____ Highest
0 100

4. Levels of Involvement in communication/activity (participation). For example:

- Did he/she become **engaged** in conversation, music making, or any forms of communication?
- Did he/she show his/her **enthusiasm** in activities that interest him/her?

None at all _____ Highest
0 100

5. Levels of Enjoyment during communication/activity. For example:

- Smiling, laughing, **brighter mood**
- **Playfulness**, sense of humour
- **Relaxed mood**

None at all _____ Highest
0 100

SCORE: A numerical score can be added by measuring the distance from 'None at all' to your mark with a ruler. Record the score in the box for each VAS (e.g. 60mm as '60'). Each line needs to be exactly 100mm for evaluation purposes.

6. During this period of time did you notice any *major reactions from the person*?

Indicate if only major reactions are observed. Use this list as supplementary information to the five VAS.

Agitation/aggression ☐

Relaxed mood ☐

Withdrawn/low in mood ☐

Attentive/interested ☐

Restless/anxious ☐

Cheerful/smiling ☐

7. Any comments?

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'Music and Me'**Information Sheet for Residents****What is 'Music and Me'?**

'Music and Me' is a music therapy project for residents and their care-home staff at Home A and Home B.

We are interested to find out: 'Is music therapy beneficial in the maintaining of the well-being of care home residents?' - and if it is, 'Have you noticed any changes after participating in music therapy sessions?'

In order to achieve this;

1. We will hold Focus Groups to gather your views on why music might be helpful to maintain your well-being.
2. We will offer music therapy sessions to people living at Home A or Home B, and ask music therapists and care home staff to fill in feedback forms. We will also keep a record of feedback from the residents attending music therapy.
3. We will then collate all the information together, analyse the results and inform the outcome of the project to you.

Why have I been approached?

You are a resident at the Home A or Home B.

What happens if I decide to participate?

We will arrange a time to meet with you to explain a little more about the project and answer any questions you may have.

What happens next?

We plan to hold Focus Groups in December 2011/January 2012. Music therapy sessions will be offered to 15-20 residents in autumn and winter 2012.

What happens if I decide not to participate, or if I decide to withdraw from the project?

You can choose not to participate or withdraw from the project at any point. Your legal rights and the quality of the service you receive will not be affected.

Consent

We will seek permission from all the project participants for us to use the data we collect for research purposes.

If you would like further information, please contact:

Orii McDermott, Music Therapist
 UCL Department of Mental Health Sciences
 Charles Bell House
 67-73 Riding House Street
 London W1W 7EJ
 mobile: 07876 734496
 email: orii.mcdermott@nhs.net



Information Sheet for Residents' Families

We hope this Information Sheet provides enough information about the project. However, if you would like to ask further questions or discuss any aspects of the project, please refer to the contact details at the end of this document.

Music therapy for the wellbeing of people with dementia

People living with dementia, carers and families have long acknowledged the importance of music for the psychological wellbeing of residents in care homes. The National Dementia Strategy published by the Department of Health, England and Wales, in February 2009, states that there should be a: 'Provision of therapeutic activities within care homes such as art therapy, music therapy or drama therapy, may have a useful role in enabling a good quality social environment and the possibility for self expression where the individuality of the resident is respected'.

Active music therapy offers a space for a client to explore various melodic and percussion instruments and to improvise freely with a music therapist. The musical style will vary depending on needs and preference of the client. The client will be encouraged to interact through joint music-making and develop a musical relationship with the therapist.

More information on music therapy can be found at Association of Professional Music Therapists website (<http://www.apmt.org/>).

What is 'Music and Me'?

'Music and Me' is a music therapy project for residents and their care-home staff at the Home A and Home B.

We are interested to find out: 'Is music therapy beneficial for the well-being of care home residents?' - and if it is, 'Are there any changes in the residents after participating in music therapy sessions?'

In order to achieve this;

1. We will hold Focus Groups to gather the views of the residents and care home staff on why music might be helpful to maintain the well-being of the residents.
2. We will offer music therapy sessions to between 15 and 20 residents living at the Home A or Home B. Music therapists and care home staff will be asked to fill in rating sheets. We will also keep a record of feedback from the residents attending music therapy.

3. We will then collate all the information together, analyse the results and inform the outcome of the project to participants and family members.

Why have I been approached?

You are a family member of a resident.

What happens if my family member decides to participate?

We will arrange a time to meet with them to explain a little more about the project and answer questions they may have.

When does the project start, and how long do they need to commit themselves to take part?

- We plan to hold Focus Groups in December 2011/January 2012.
- Music therapy sessions will be offered to Home A and Home B residents in autumn-winter 2012.

What happens if they decide not to participate, or if they decide to withdraw from the project?

It is entirely acceptable if they decide not to participate or decide to withdraw from the project at any point. Their legal rights or the quality of the service they receive will not be affected.

Consent

We will seek permission from the project participants for us to use the data we collect for research purposes.

If you would like further information, please contact:

Orii McDermott, Music Therapist
 UCL Department of Mental Health Sciences
 Charles Bell House
 67-73 Riding House Street
 London W1W 7EJ
 mobile: 07876 734496
 email: orii.mcdermott@nhs.net



Information Sheet for Staff

We hope this Information Sheet provides enough information for you to decide whether you would like to participate in the project. However, if you would like to ask further questions or discuss any aspects of the project, please refer to the contact details at the end of this document.

Music therapy for the wellbeing of people with dementia

People living with dementia, carers and families have long acknowledged the importance of music for the psychological wellbeing of residents in care homes. The National Dementia Strategy published by the Department of Health, England and Wales, in February 2009, states that there should be a: 'Provision of therapeutic activities within care homes such as art therapy, music therapy or drama therapy, may have a useful role in enabling a good quality social environment and the possibility for self expression where the individuality of the resident is respected'.

Active music therapy offers a space for a client to explore various melodic and percussion instruments and to improvise freely with a music therapist. The musical style will vary depending on needs and preference of the client. The client will be encouraged to interact through joint music-making and develop a musical relationship with the therapist.

More information on music therapy can be found at Association of Professional Music Therapists website (<http://www.apmt.org/>).

What is 'Music and Me'?

'Music and Me' is a music therapy project for residents and their care-home staff at the Home A and Home B.

We are interested to find out: 'Is music therapy beneficial for the well-being of care home residents?' - and if it is, 'Have you noticed any changes in the residents after participating in music therapy sessions?'

In order to achieve this;

1. We will hold Focus Groups to gather your views on why music might be helpful to maintain the well-being of the residents.
2. We will offer music therapy sessions to residents living at the Home A or Home B in autumn-winter 2012. Music therapists and care home staff will be asked to fill in rating sheets. We will also keep a record of feedback from the residents attending music therapy.

3. We will then collate all the information together, analyse the results and inform the outcome of the project to you.

Why have I been approached?

You are a staff member at the Home A or Home B.

What happens if I decide to participate?

We will arrange a time to meet with you to explain a little more about the project and answer questions you may have.

When does the project start, and how long do I need to commit myself to take part?

- We aim to hold Focus Groups in November/December 2011.
- If you work closely with one of the residents attending music therapy, a research team member will arrange an individual time to meet with you and explain how to complete rating sheets. We are aware you have work commitments, so will try to arrange a mutually convenient time to meet.

What happens if I decide not to participate, or if I decide to withdraw from the project?

It is entirely acceptable if you decide not to participate or decide to withdraw from the project at any point. Your legal rights will not be affected.

Consent

We will seek permission from the project participants for us to use the data we collect for research purposes.

If you would like further information, please contact:

Orii McDermott, Music Therapist
 UCL Department of Mental Health Sciences
 Charles Bell House
 67-73 Riding House Street
 London W1W 7EJ
 mobile: 07876 734496
 email: orii.mcdermott@nhs.net

Version 1. 30/09/2011

'Music and Me'



Information Sheet for Study Participants

What is 'Music and Me'?

'Music and Me' is a music therapy project for residents and their care-home staff at the Home A and Home B.

We are interested to find out: 'Is music therapy beneficial in the maintaining of the well-being of care home residents?' - and if it is, 'Have they noticed any changes after participating in music therapy sessions?'

In order to achieve this;

1. We will interview people attending CNWL day services and also hold Focus Groups at Home A and Home B to gather your views on why music might be helpful to maintain your well-being.
2. We will offer music therapy sessions to people living at the Home A or Home B, and ask music therapists and care home staff to fill in feedback forms. We will also keep a record of feedback from the residents attending music therapy.
3. We will then collate all the information together, analyse the results and inform the outcome of the project to you.

Why have I been approached?

You are attending CNWL day services.

What happens if I decide to participate?

We will arrange a time to meet with you to explain a little more about the project and answer any questions you may have.

What happens next?

We plan to interview people and hold Focus Groups in December 2011/January 2012. Music therapy sessions will be offered to 15-20 residents at Home A and Home B in autumn/winter 2012.

What happens if I decide not to participate, or if I decide to withdraw from the project?

You can choose not to participate or withdraw from the project at any point. Your legal rights and the quality of the service you receive will not be affected.

Consent

We will seek permission from all the project participants for us to use the data we collect for research purposes.

If you would like further information, please contact:

Orii McDermott
 UCL Mental Health Sciences Unit
 Charles Bell House
 67-73 Riding House Street
 London W1W 7EJ
 mobile: 07876 734496
 email: orii.mcdermott@nhs.net

Version 2. 02/06/2011

'Music and Me'**CONSENT FORM for Residents**

Please indicate you have understood each point.

1	I confirm that I have understood the information sheet and have been given the opportunity to ask questions about the 'Music and Me' project.	
2	I understand that my participation is voluntary and that I am free to withdraw at any time without affecting my care.	
3	I give permission for focus groups and music therapy sessions to be audio recorded. I understand all identifying information will be anonymised.	
4	I understand that some of music therapy sessions will be video recorded for educational and research purposes.	
5	I give permission for any written or verbal views I express to be anonymised and used for research purposes.	
6	I give permission for the research team to contact me in relation to taking part in this project.	

Name of Resident_____
Date_____
Signature_____
Name of Family Carer
(if applicable)_____
Date_____
Signature_____
Name of person taking consent_____
Date_____
Signature

There are two copies of this form: the first is for you; the second is for our research records.

Office use only:		
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Version 1. 01/06/2011

'Music and Me'**ASSENT FORM**

Please indicate you have understood each point.

1	I confirm that I have understood the information sheet and have been given the opportunity to ask questions about the 'Music and Me' project.	
2	I understand that my relative's participation is voluntary and that my relative is free to withdraw at any time without affecting his/her care.	
3	I give permission for focus groups and music therapy sessions to be audio recorded. I understand all identifying information will be anonymised.	
4	I understand that some of music therapy sessions will be video recorded for educational and research purposes.	
5	I give permission for any written or verbal views my relative expresses to be anonymised and used for research purposes.	
6	I give permission for the research team to contact me in relation to my relative taking part in this project.	
7	I agree for my relative to take part in 'Music and Me' and believe that my relative would not object to taking part in this study.	

Name of relative/next to kin
who is giving assent

Date

Signature

Name of Resident

Date

Signature (if applicable)

Name of person taking consent

Date

Signature

There are two copies of this form: the first is for you; the second is for our research records.

Office use only:		
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Version 1. 10/04/2011

'Music and Me'**CONSENT FORM for Staff Members**

Please enter your initials to confirm you have read and understood each point.

1	I confirm that I have read and understood the information sheet and have been given the opportunity to ask questions about the 'Music and Me' project.	
2	I agree to attend focus groups and fill in rating sheets as agreed with the researcher. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal rights being affected.	
3	I understand that all information given by or about me will be treated as confidential and stored securely.	
4	I give permission for focus groups to be audio recorded and used for analysis. I understand all identifying information will be anonymised and the recording will be destroyed after the transcription.	
5	I give permission for any written or verbal views I express to be anonymised and used in future analysis.	

 Name

 Date

 Signature

There are two copies of this form: the first is for you; the second is for our research records.

Office use only:		
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Version 2. 10/11/2011

'Music and Me'

CONSENT FORM for Music Therapists

Please enter your initials to confirm you have read and understood each point.

1	I confirm that I have read and understood the information sheet and have been given the opportunity to ask questions about the 'Music and Me' project.	
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal rights being affected.	
3	I understand that all information given by or about me will be treated as confidential and stored securely.	
4	I give permission for interviews to be audio recorded and used for analysis. I understand all identifying information will be anonymised and the recording will be destroyed after the transcription.	
5	I give permission for any written or verbal views I express to be anonymised and used in future analysis.	

 Name

 Date

 Signature

There are two copies of this form: the first is for you; the second is for our research records.

Office use only:		
------------------	--	--

Version 2. 02/06/2011

'Music and Me'**CONSENT FORM for Study Participants**

Please indicate you have understood each point.

1	I confirm that I have understood the information sheet and have been given the opportunity to ask questions about the 'Music and Me' project.	
2	I understand that my participation is voluntary and that I am free to withdraw at any time without affecting my care.	
3	I give permission for interviews to be audio recorded. I understand all identifying information will be anonymised.	
4	I give permission for any written or verbal views I express to be anonymised and used for research purposes.	
5	I give permission for the research team to contact me in relation to taking part in this project.	

Name of Study Participant_____
Date_____
Signature_____
Contact Address_____
Telephone (optional)_____
Name of person taking consent_____
Date_____
Signature

There are two copies of this form: the first is for you; the second is for our research records.

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