What indicators have been used to evaluate the impact of music on the health and wellbeing of people with dementia? A review using meta-narrative methods

Becky Dowson (University of Nottingham), Orii McDermott (University Of Nottingham), Justine Schneider (University Of Nottingham)

Abstract

This review considers how research into the impact of music upon people with dementia has been conducted, with a focus on the means used to measure outcomes. Although there is a rapidly-growing amount of research in this relatively new area, it has evolved fairly separately within different fields, such as psychology, music therapy and nursing. Using principles from the meta-narrative review method, this paper systematically surveys qualitative and quantitative measures which have been used in studies relating to music and dementia from 1980 to the present day. Data extracted included the outcome measures used, the type of music intervention, the setting of the studies and methodology and study design. Results showed that quantitative studies greatly outnumber qualitative studies, and that most research takes place in long term care settings. Instruments which measure neuro-psychiatric symptoms of dementia, especially agitation, were the most frequently used. Other domains that were targeted by the studies included quality of life, physiological change, music-related outcomes and cognitive skills; the inter-relations between these domains are represented as a diagram. Researchers' rationales for choosing to target these outcomes are discussed. The conclusion suggests that, although reduction of neuropsychiatric symptoms is a valuable outcome, it is important that researchers are open to the possibility of other outcomes. We suggest that measuring increase in positive responses might be an alternative to measuring reduction of negative symptoms, and highlight the importance of listening to people with dementia and carers when designing studies.

Keywords

Dementia, music, music therapy, outcome measurement, meta-narrative review

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Introduction

The value of music to people with dementia is widely acknowledged [1,2]. However, research into music and dementia is still a relatively new and developing field, and appears to have evolved fairly independently within different disciplines such as music therapy, psychology and nursing. Systematic reviews synthesise evidence about the effects of music, but tend to focus on one type of intervention or outcome variable, such as music therapy [3] or anxiety [4], and include only certain types of studies [5]. This review takes a broader view and systematically surveys a range of music and dementia studies from different disciplines and across a wide time period.

This paper has been developed from the initial findings of a meta-narrative review of research on music and dementia. Meta-narrative review [6] is founded on Kuhn's [7] idea that science evolves in paradigms which are field-specific. Researchers develop "rules and standards

which are considered self-evident by those working in a particular field, but which are not universally accepted” [6]. According to Kuhn’s theory, scientific paradigms differ in four main realms: the conceptual frameworks through which importance is assigned to certain objects of study, the theoretical dimension which is constructed to explain relationships between variables, the methodological approaches used to investigate, and the instruments which are accepted as appropriate tools for measurement [7]. The approach taken in this review places Kuhn’s fourth “domain”: the instruments which are accepted as tools for measurement at the centre of its inquiries.

The “tools for measurement” in this review are the outcome measures, observations and qualitative methods used to assess the impact of music upon people with dementia, which we have collectively termed “indicators”. In focusing on the indicators which have been chosen by researchers, the review highlights not the findings of the studies but the ontological and epistemological positions underlying research in this area. It is hypothesised that researchers from different fields may have different conceptual frameworks for the impact of music interventions upon people with dementia, and that these differences are reflected in their choices of indicators. In reviewing the indicators chosen by researchers from different fields, the aim is to gain insight into the outcomes which have been considered important within the various paradigms.

Aims

The aim of this paper is to provide the reader with a detailed picture of quantitative and qualitative indicators used in studies of music and dementia published since 1980, including important contextual data about study design, sample size, types of dementia and where music interventions take place. We then offer an interpretation of the results which presents the areas of interest for researchers in this field as a set of inter-related domains.

Methods

Electronic searches were performed in the databases PsychINFO, Medline, CINAHL, EMBASE and Web of Science using variations on the following search strategy, adapted for each database:

- 1 exp DEMENTIA/
- 2 (dement* OR alzheimer*).ti,ab.
- 3 (“nursing home*” OR “care home*” OR hospice OR hospital*).ti,ab.
- 4 #1 OR #2 OR #3
- 5 exp MUSIC/
- 6 exp MUSIC THERAPY/
- 7 (music* OR sing OR sings OR singing OR singer* OR song* OR choir* OR choral* OR playlist* OR listen* OR GIM).ti,ab.
- 8 (guided imagery adj3 music).ti,ab.
- 9 ((play* OR learn*) adj3 instrument*).ti,ab.
- 10 #5 OR #6 OR #7 OR #8 OR #9
- 11 #4 AND #10

Music therapy journals were hand-searched for relevant papers. Where systematic reviews were returned by the electronic searches, their reference lists were checked for additional papers.

Articles written in English and published in peer-reviewed journals between 1980 and March 2018 were considered for inclusion. Broad inclusion criteria were used with the aim of capturing as many different types of research as possible. Studies had to involve research with people with dementia and use live or recorded music intervention with the stated goal of promoting health and/or wellbeing. Studies were included if they used a music alongside another intervention, but only if it was possible to distinguish the results of the musical component. Where studies included both participants with and without dementia, these were included if the results for participants with dementia could be separated from the other results. Other types of articles were excluded (e.g. conference proceedings, editorials) as were articles where it was not clear which participants had dementia, or where the study combined music with another activity (e.g. dance accompanied by music).

Data including type of music intervention, study setting and methodology, outcome measures used, and details about the study sample, was extracted from each paper and tabulated. Quality assessment of the studies was not performed; since the review focuses on the indicators selected by researchers rather than the actual findings, it was considered relevant to include studies of varying methodological quality.

Results

Characteristics of the data

Figure 1: PRISMA flow chart

Figure 1 shows the flow of articles through the review process. After screening papers at title and abstract level, 2784 articles were excluded. Full texts were screened for the remaining articles and as a result of this process, 163 papers were included in the review. These

represent the findings of 154 studies, since some studies reported their findings in multiple papers. The chronology of studies included in this review clearly represents an expanding field of research; more papers have been published from 2010 onwards than in the preceding thirty years. The majority of studies included in this review (83%) used quantitative methodology, while 7% of studies were qualitative and a further 7% used a mixed methods approach. Two case studies were included (1%) while the remaining 2% of studies were categorised as “multi methods” meaning that they used some qualitative and quantitative methods, but did not integrate them. Table 1 shows a summary of the study designs included in these papers .

Table 1: Study methodology and design

Methodology	Study design	No. of studies	Sample size - mean, median (range)
Quantitative	Randomised Controlled Study	28	35.4, 24.5 (15-120)
	Controlled study	20	37, 27.5 (10-80)
	Other	80	33.6, 20 (1-212)
Qualitative		12	25.8, 24 (6-62)
Mixed methods		9	16, 11 (5-29)
Case study		2	1.5, 1.5 (1-2)
Multi methods		3	13, 10 (7-22)

A total of 101 studies took place in long-term residential care settings, with community settings (21 studies) and hospitals (10 studies) being the next most common contexts for studies. The remaining studies took place in domestic settings, day centres, dementia centres, or universities. 13 studies took place in more than one type of setting, and 11 studies did not state where they took place.

Studies were categorised by the type(s) of music intervention or activity they employed. The interventions included music therapy, defined as a psychological clinical intervention delivered by therapists who have met the standards of professional training and regulation in their country of practice. Other activities, such as listening to recorded or live music, and singing might be delivered by music therapists, care staff, community musicians, or family carers. Listening to recorded music was the most frequent activity, with 70 studies employing this in some form. 55 studies involved music therapy, representing an established research tradition. Twelve studies involved singing; the other categories are populated by small numbers of studies.

The types of dementia experienced by the participants in the studies are somewhat variably reported. 38% of studies stated that participants all had diagnosed or probable Alzheimer’s disease, whilst 23% reported a mixture of different types of dementia. Two studies focused exclusively on fronto-temporal dementia, and one on three different but specified types (Alzheimer’s, vascular dementia and Parkinson’s dementia) but the remaining 40% did not report the type of dementia at all. This may be because study authors felt that the severity of dementia was more relevant than the type, due to the difficulty of conclusive diagnosis and the prevalence of mixed dementia. Dementia severity was frequently reported, either by describing it as mild, moderate or severe, or through mean/standard deviation and range of MMSE scores.

Quantitative outcome measures

Table 2 shows all the standardised quantitative outcome measures which were used more than once in the included studies, the domain to which they relate, and the number of times that each was used. They are arranged in descending order of frequency. The Cohen-Mansfield Agitation Inventory, Mini-Mental State Examination and Neuro-Psychiatric Inventory were used more than ten times each, while the next most frequently used measures (Rating Anxiety in Dementia) was used only five times. A further 60 standardised outcome measures were used once each, while a number of other studies used outcome measures created specifically for that study.

Table 2: Frequency of standardised outcome measures

Outcome Measure	Relates to domain	Frequency
Cohen-Mansfield Agitation Inventory	Agitation	31
Mini-Mental State Examination	Cognitive function	16
Neuro-Psychiatric Inventory	Neuropsychiatric dementia symptoms	12
Cornell Scale for Depression in Dementia	Depression	6
Dementia Care Mapping	Quality of life	5
Rating Anxiety in Dementia	Anxiety	5
Geriatric Depression Scale	Depression	4
Barthel Index	Activities of Daily Living	3
Behavioral Pathology in Alzheimer's Disease Rating Scale	Behaviour	3
Observed Emotion Rating Scale	Mood	3
Quality of Life - Alzheimer's Disease	Quality of life	3
Test épisodique de mémoire du passé	Memory	3
Bedford Alzheimer Nursing Severity Scale	Dementia severity	2
Cornell-Brown Scale for Quality of Life in Dementia	Quality of Life	2
Disruptive Behaviour Rating Scale	Behaviour	2
Lawton's Modified Behaviour Stream	Mood	2
Montgomery-Åsberg Depression Rating Scale	Depression	2
Music in Dementia Assessment Scale	Musical engagement	2
Menorah park engagement scale	Engagement	2
Paper Folding and Cutting	Cognitive function	2
State-Trait Anxiety Inventory	Anxiety	2

Qualitative methods

11 studies (reported in 16 papers) used purely qualitative methods. The most commonly used methods were interviews either with caregivers and people with dementia or with caregivers alone, and qualitative analysis of video or audio material. Another 14 studies integrated qualitative methods as part of a mixed methods approach. Some of these studies investigate the pilot stage of novel interventions [8–10] or the development of new technology prototypes [11–13]. In these cases, the qualitative data provides information about participants' experience which can be integrated into the development.

Several studies have as their focus the development of theories or models which can explain the value of music to people with dementia, and consequently represent in-depth inquiries into musical experiences [14–16]. Six papers report qualitative findings from the same investigation into the effects of “music therapeutic caregiving” (caregiver singing during personal care situations); among these were qualitative content analysis of interview transcripts explored the caregivers’ own experiences [17] and their perception of the experiences of people with dementia [18].

Discussion

Within the developing field of research into music and dementia, a wide range of measures and methods have been employed. In order to summarise and explore the data, the standardised and study-specific outcome measures used in the studies were each assigned to a domain representing the variable which they measure. These domains were then reviewed and grouped together into five broader categories: neuropsychiatric symptoms, quality of life, cognitive function, physiological changes and music-related response. Figure 2 is a graphical representation of the categories and the links between domains within and across them, showing the most common domains for each category. There are clear links between categories; for example, reduction in symptoms of depression can be associated with improvement in mood. Additionally, the domain “behaviour” can be placed in either the “quality of life” or “neuropsychiatric symptoms” category, depending on whether a study is focusing on reduction of so-called “negative” behaviours (e.g. aggression, shouting) or increased in “positive” behaviours (e.g. communication, interaction).

Figure 2: Domains evaluated in studies of music and dementia

In the following section, the full texts of studies which used quantitative outcome measures for each of the five domains are examined, in order to explore the underlying theoretical and methodological assumptions which guide the choice of instrument.

Neuropsychiatric Symptoms

71 studies [9,19–88] used quantitative outcome measures to evaluate various neuropsychiatric symptoms of dementia. Of these, 58 took place in residential care settings, suggesting that the reduction of neuropsychiatric symptoms is considered to be of great importance in this context. 37 studies measured agitation, 32 of these using the Cohen-Mansfield Agitation Inventory (CMAI). The extensive prioritisation of agitation is perhaps explained by the burden it places on caregivers, and the fact that decrease in agitated behaviours is fairly straightforward to observe and measure using standard tools. Many studies cite caregiver burden [58] or the need to develop nonpharmacological interventions [89] as their reason for targeting neuropsychiatric symptoms of dementia. In other studies, decrease in neuropsychiatric symptoms is correlated with improvement in quality of life, both for people with dementia and their caregivers [49].

Quality of life/Wellbeing

28 studies were categorised only in the “quality of life” domain [90–117], while a further 22 include quality of life among other measures [9,21,26,27,30,38,46,50,55,60,61,67,71,76,87,118–125]. Studies measuring quality of life in the 1990s are often associated with music therapy; later, other types of intervention appear as well. Music therapy research in the 1990s and early 2000s tended not to use standardised quality of life scales, but instead created study-specific behavioural inventories. For example,

Pollack and Namazi [106] designed a checklist to record the frequency of social and non-social behaviours of participants, while Clair and Bernstein [20] measured the duration of specific responses such as singing, communicating and interacting with a musical instrument. In these papers, music is hypothesized to promote social engagement and purposeful activity which may be compromised by cognitive impairment.

Many later papers use standardised outcome measures but similarly cite music's potential to engage cognitively impaired and under-stimulated individuals in meaningful activity, especially by providing a means for making social contact with others [93,94,126]. Several studies draw an explicit link between boredom resulting from lack of stimulation, and disruptive behaviour [91,93]. The phrase "promoting wellness" is used in one study [127], whereas many of the others seem to explicitly link quality of life with the absence of behavioural and psychiatric symptoms. This raises questions about whether quality of life is represented by the presence of a positive state of being, or whether it is simply the absence of negative symptoms which detract from wellbeing. It is also worth noting that later studies include ratings of QoL which are given directly by people with dementia, rather than through observation or proxy [120,124].

Cognitive Function

18 studies [128–145] focused exclusively on the quantitative measurement of aspects of cognitive function, including different types of memory, visuospatial and language skills, and overall cognitive performance using measures such as the Mini-Mental State Examination. From these studies, three mechanisms can be identified through which enhanced cognition resulting from musical stimuli may be associated with positive outcomes for people with dementia. Firstly, a decrease in neuropsychiatric symptoms brought about by music is postulated to have a positive effect on cognitive function [146]. Secondly, music as a memory enhancer has practical applications for improving performance of activities of daily living which may enhance quality of life [147]. Thirdly, music may be used to preserve autobiographical memories and maintain sense of identity, which also has implications for quality of life [131,140].

Physiological Changes

Eleven studies measure only physiological variables [148–158]. Four of these focused on nutrition, one on brain activity, three on aspects of motor functioning and two on hormone levels. A further ten studies include measurement of a physiological variable alongside other measures, commonly of neuropsychiatric symptoms. In several cases an explicit link is drawn between reduction of neuropsychiatric symptoms and a favourable physiological outcome. For example, Gill & Englert [151] link agitation levels in people with dementia to an increased risk of falls, so music is explored as a means of reducing agitation and therefore reducing falls. The studies which focus on nutrition draw similar links; they hypothesise that playing background music at mealtimes could improve the environment and decrease stress and anxiety [150,154,157]. Clair and O'Konski [148] explore Rhythmic Auditory Cueing (RAC) to improve gait, linking falls and decreased mobility resulting from unsafe walking to decreases in physical health and quality of life.

Music-related outcomes

Seven studies used music-related quantitative outcome measures, generally to support the evidence provided by other outcome measures, or to explain the mechanisms by which such outcomes occur [52,60,82,85,122,159–161]. Ceccato et al. [85] used rating scales for evaluating musical competencies and relationship. They predicted that if the musical relationship improved, a decrease in neuropsychiatric symptoms would be noted. Similarly,

Raglio et al. [60] assessed change in the musical communication of a subset of patients involved in a larger trial which was primarily investigating neuropsychiatric symptoms.

Two papers [122,162] report stages in the development of a tool to address the “lack of client-specific, clinically appropriate, and psychometrically evaluated outcome measures” in music therapy [122]. The resulting measure, the Music in Dementia Assessment Scale, is intended to capture change which is individual and focused on what matters to the client, rather than just on reducing neuropsychiatric symptoms. In order to develop this scale, interviews and focus groups were conducted with people with dementia, carers and music therapists to discover why music was important to them. Analysis of the data showed that music was seen as an accessible and instantly engaging medium for people at all stages of dementia. It held great personal significance and allowed people to maintain and express their identity, whilst also providing a means for people with dementia to build and sustain relationships. Music also facilitated short-term improvements in mood [15]

Conclusions

The findings of this review indicate that certain outcomes, in particular reduction of neuropsychiatric symptoms, have been prioritised in music and dementia research, perhaps to the exclusion of other areas. These areas include positive responses such as music’s potential to support and strengthen relationships, provide “in the moment” experiences, and meet the psychosocial needs of people with dementia. This priority is understandable in light of the fact that neuropsychiatric symptoms of dementia are reported to cause more distress and burden to people with dementia and their caregivers than cognitive symptoms of dementia and results in early care home placement, increased hospital admissions, and lower quality of life for people with dementia and caregivers [163]. However, we risk ignoring part of the spectrum of benefits that music can have if we focus predominantly on symptom reduction. It may be that we need to broaden our horizons and ask more searching questions about the kinds of outcomes we look for, and some progress has already been made. Vink et al. [83] noted that the effect of music therapy on positive responses for people with dementia has been under-researched, and Music in Dementia Assessment Scales (MiDAS) were developed “to capture some of the aspects of musical experiences that people with dementia themselves would say are meaningful to measure” [122]. The items included in MiDAS were based on consultation with people with dementia and their carers about what music meant for them. The scale itself employs ratings judged by someone who knows the person with dementia well, allowing them to assess responses to music therapy according to each individual’s potential levels. Investigating positive responses may also improve understanding of the mechanisms involved in the complexities of human reaction to music.

The view that our perception of dementia has been hampered by a medical model is not new; as long ago as 1992, Cotrell and Shulz wrote that “our understanding of AD has become increasingly biomedical, with an accompanying tendency to attribute the experience of persons with dementia exclusively to a disease process” [164]. This perspective may explain the propensity to see music as a treatment which can be applied to people with dementia in much the same way as a drug, albeit one with fewer side effects. However, this reductive approach neglects the complex power of music across human societies and in our daily lives; Tia DeNora has written that music is not a “stimulus”; it does not in its essence contain all the qualities necessary to regulate someone’s mood, for example. Rather, “music’s powers are constituted by [the listener] herself; they derive from the ways she interacts with them” [165]. People with dementia must be considered to experience music in the same rich, complex and variable way, mediated by their experiences, memories and personalities. This assertion is

supported by qualitative research into the meaning of music for people with dementia [14,166].

We must listen to the perspectives of people with dementia when designing research, and ensure that the outcome variables chosen reflect changes which they acknowledge as valuable and relevant. This is an under-researched area but some important work has already been done. McDermott et al. suggest that the importance of music to people with dementia “goes beyond the idea of music as a tool to fix a behavioural problem (e.g. agitation) suggesting that it is part of a wider appreciation of life” [15]. People with dementia and their carers suggest that the key characteristics of music for them are that it facilitates social interaction, helps to maintain relationships, reinforces their sense of identity, remains meaningful and accessible through all stages of dementia, and that overall it supports the wellbeing of both people with dementia and those involved in their care [14,15,167]. It is probable that these positive outcomes have been neglected in quantitative research because they are considered more difficult to measure than outcomes which can be based on behavioural or symptomatic inventories. Before the development of any new outcome measures, further in-depth qualitative research involving consultation with people with dementia and their carers should be carried out to broaden our understanding of the mechanisms through which music can bring about change. To facilitate this, there is a need to adapt research so that it can include people with dementia, rather than excluding people with dementia from research because they cannot access the conventional methods [168]. Furthermore, we must take on board criticisms of established practice, such as dementia activist Kate Swaffer’s campaign against the term “Behavioural and Psychological Symptoms of Dementia” on the grounds that it de-humanises people with dementia and contributes to poor care by reducing them to a set of “challenging behaviours”, rather than seeing these behaviours as responses to unmet needs [169].

The process involved in choosing outcome measures is not self-evident, and reflects the values and underlying theoretical frameworks of the researchers. It is hoped that this review will encourage researchers in this new and developing field to use and develop methods which are relevant to clinicians, practitioners, carers – and to people with dementia themselves.

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