

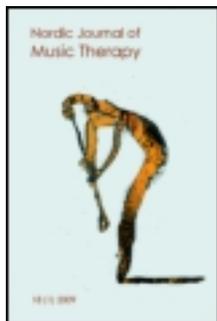
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### A pilot study on the effects of music therapy on frontotemporal dementia - developing a research protocol

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## RESEARCH ARTICLES

### A pilot study on the effects of music therapy on frontotemporal dementia – developing a research protocol<sup>1</sup>

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Some forms of dementia particularly affect the frontal parts of the brain which, in some cases, causes the onset of severe behavioural and psychological symptoms. No specific treatment for the primary diseases that cause these frontotemporal dementia conditions has yet been developed, and pharmacological treatment of the psychiatric symptoms is difficult, requiring specialist proficiency in the field.

As there is not yet sufficient research that examines the effects of non-pharmacologic treatment with this group, there is a need to develop valid and reliable research protocols. Music therapy was investigated as an example of a non-pharmacologic treatment procedure. A pilot study was carried out with the focus to develop a research protocol for a future larger population study. In two case studies a combination of data collection methods were examined with the overall goal to document changes in intersubjectivity. In this pilot study there was a specific interest in selecting a relevant and manageable dementia specific instrument for measuring quality of life and relating it with other instruments. The following three instruments were tested: the Alzheimer's Disease-Related Quality of Life (ADRQL), the Cohen–Mansfield Agitation Inventory (CMAI), and the Neuro-psychiatric Inventory (NPI), and were related to case descriptions and video analyses.

Recommendations for a mixed method research protocol focused on measuring the effect of music therapy with persons with frontotemporal dementia are presented.

**Keywords:** quality of life; agitation; neuropsychiatric symptoms; research methodology; music therapy; frontotemporal dementia; BPSD

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<sup>1</sup>This article is a shortened and edited version of a Danish article: *Udformning af en forskningsprotokol – musikterapi med frontotemporalt demensramte* in the Danish yearbook *Musikterapi i Psykiatrien* published by Aalborg University and the Psychiatric Hospital in Aalborg.

## Introduction

### *Dementia and treatment of Dementia*

It is estimated that 29.4 million people worldwide have some form of dementia. This number is expected to increase to 120 million by 2050 (Wimo 2009). In Denmark the prevalence of dementia is expected to increase by 20% during the coming years, which will lead to significantly increased expenditure for treatment and care, calculated to be approaching one thousand million euro in year 2013 (Sørensen, Gudex, & Andersen, 2006). Since 1997 pharmacologic treatment for cognitive symptoms of dementia has been available in Denmark, and in 2005 four new anti-dementia medications, that maintain cognitive functioning for a certain period, have been approved (Johannesen, 2006). Dementia is diagnosed according to the international classification systems of psychiatric diseases, DSM-IV and ICD-10, and medical treatment has two objectives; either to prevent cognitive decline or to reduce disturbing Behavioural and Psychiatric Symptoms of Dementia (BPSD) by the use of antidepressants, antipsychotics and anxiolytics (Lolk & Gulmann, 2006). Diagnostic and medical assessment procedures are carried out by general medical practitioners, at geronto-psychiatric units, or at memory clinics that have been recently established as a service for this population in Denmark. Assessment and treatment of psychiatric symptoms are the responsibility of the Danish psychiatric system. At the Memory Clinic at the Rigshospitalet in Copenhagen it is concluded that at present no specific medical treatment is available to persons with frontotemporal dementia (FTD), and therefore treatment should mainly be in the nature of psychosocial initiatives (Stokholm & Waldemar, 2003, p. 556).

### *Frontotemporal Dementia, FTD*

This article focuses on patients who suffer from certain types of dementia that lead to damages on the temporal and frontal lobes, and who, as a consequence of this, show psychiatric symptoms and need professional daily care. Medical treatment is mainly used with the intention to reduce symptoms such as “depression, anxiety, agitation, and psychosis with hallucinations and delusions” (Melin & Bang Olsen, 2006, p. 114), whereas medication aimed to prevent cognitive decline is avoided because this treatment “used to persons with FTD actually might deteriorate the condition” (Melin & Bang Olsen, 2006, p. 113). A strong need for activity and movement is often recognized as symptoms of FTD, and this is why “unfortunately it is seen that medication is given with the sole purpose to suppress the activity, independent of the cause” (Melin & Bang Olsen, 2006, p. 115). In a recently published manual on FTD, Melin & Bang Olsen (2006) suggest that, as medication may cause adverse reactions and be

contra-reported in some individuals, non-pharmacological treatment is attempted (p. 114).

### ***Non-pharmacological treatment***

A lack of evidence of benefit from the application of pharmacological treatment in FTD is complemented by an equal lack of evidence of non-pharmacological treatment methods. The Danish National Board of Social Services commissioned a literature review of what they define as newer methods of care for persons with dementia, including reminiscence therapy, life-story approaches, validation therapy, music stimulation, multi-sensory stimulation, aromatherapy, light therapy, dementia care mapping, gently teaching, retrogenesis and Marte Meo. The ensuing report concluded that there is no evidence of the effect of these more recently developed interventions. This may be due to a lack of suitable or qualified instruments for measuring effect:

The reason why no significant change is found from evaluation of the effects of these interventions might be that the *instruments that are used to measure the effects are not suited* to the aim of investigation (Lee, 2004, p. 5, authors' translation and emphasis).

The lack of evidence for effective alternatives increases pressure on medical doctors to mainly prescribe sedative pharmacological treatment in order to subdue agitated/aggressive behaviour. The ideal is an effective balance between different treatment modalities to meet the variable needs of patients/clients, and we hope that interventions in this area are strengthened and improved by further research in pharmacological as well as non-pharmacological treatment.

### ***Developing a research protocol***

In this article we describe a pilot research project carried out in collaboration with the professional healthcare studies in Northern Denmark,<sup>2</sup> Knowledge Centre of Dementia in the Northern Region of Denmark,<sup>3</sup> and the Doctoral School in Music Therapy at Aalborg University.<sup>4</sup> With the pilot study we aimed to clarify several issues in our process of developing and specifying a research protocol for later research studies. We find it relevant to carefully describe and detail these smaller steps in a process that stepwise leads to a well defined research protocol. The process of developing a research protocol is an important part of carrying

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<sup>2</sup>See <http://www.ucn.dk>

<sup>3</sup><http://www.demensportalen.dk>

<sup>4</sup><http://www.musikterapi.aau.dk>

out research. Many decisions need to be taken and we find it important not only to publish research articles disseminating effects, but also to publish research articles focusing on the research process in order to improve the research methodologies and to invite discussions and exchange in the field.

### **Aims and objectives of the pilot study**

The overall purpose of the pilot study was to develop a research protocol designed to carry out effect measures of newer, non-pharmacological methods in dementia care. Based on development and documentation of clinical practice, we aimed to evolve therapeutic approaches in dementia care concurrently with applicable research designs. Our theoretical basis was grounded in the concepts of intrinsic communicative musicality (Trevarthen, 1999; Trevarthen & Malloch, 2008), and the understanding of communicative musicality in relation to people with severe dementia who, as a consequence of cognitive deficits, experience significant difficulties in verbal communication. The development of a theoretical understanding of basic forms of communication and interaction in therapeutic settings and the integration of newer neuro-affective understandings of care are essential in current care practices for people with dementia. The pilot study addressed the field of music therapy as well as the gerontopsychiatric healthcare profession in general. For both of these fields a development of research designs and methodology is of central importance in order to be able to document research in non-pharmacological treatment procedures.

### **Ontology**

It might seem contra-reported to offer a psychotherapeutic treatment for persons with dementia, when dementia is regarded as a disease which, over time, causes dramatic changes to and confusion in a person's emotional life, personality, self and identity, as well as causing disturbed and erratic behaviour. In contrast to this standard paradigm we understand dementia as a disease or disability where the disturbance of cognitive skills gradually leads to increasingly severe difficulties in communicating and engaging appropriately in social interaction. To what degree this affects a person is determined by how daily care is carried out (Cheston & Bender, 2003; Kitwood, 1997; Ridder, 2007a). It is therefore crucial that physical as well as psychosocial needs are met in persons with dementia, and we see the way caregivers understand and contain the person's expression of insecurity, chaos and anxiety as a key to reducing what traditionally is called disturbing behaviour.

In the therapeutic treatment itself, human communication is based on an intrinsic communicative musicality (Malloch, 1999; Trevarthen, 1999;

Holck, 2002; Wigram & Elefant, 2008), which is accessible even in persons with severe dementia:

... music therapy with such patients is possible because musical perception, musical sensibility, musical emotion, and musical memory can survive long after other forms of memory have disappeared. (Sacks, 2007, p. 337)

Music provides a key for building up social interaction and communication with a person with dementia through a medium that allows understandable and empathic forms of expression other than verbal language. Well known songs familiar to the client are used with the purpose of offering a shared and understood experience, and where the person is given opportunities to sing, express him/herself vocally, interact musically, and address psychosocial needs.

Most geronto-psychiatric instruments such as the Disability Assessment for Dementia (DAD), Interview for Deterioration in Daily Living Activities in Dementia (IDDD), The Dementia Behaviour Disturbance Scale (DBD), Behavioural Pathology in Alzheimer's disease Rating Scale (BEHAVE-AD), are tools developed to register and measure those deficits and losses a dementia disease causes. By seeing quality of life as a key factor in daily care, this study identifies and prioritizes person-centred dementia care where *psychosocial needs* are in focus (Kitwood, 1997).

The concept of quality of life is about healthiness and well-being which is synonymous with a salutogenic philosophy of life rather than a pathogenic focus on illness and disease (Antonovsky, 1987). The World Health Organization defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1948). This paper positions health as a multi-dimensional and subjective concept that consists of physical, mental, social, existential, as well as spiritual dimensions (see Kaasa, 1998). In choosing a focus on health in preference to disease we want to emphasize gerontological salutogenetic care in the way it is defined by Westlund & Sjöberg (2005).

### *Epistemology*

The purpose of the pilot study was to collect knowledge about the change that happened in the therapeutic relationship, and how this was expected to lead to therapeutic effects. It was not feasible to control all the different variables that might cause such change, as there is a wealth of non-specific factors in the treatment setting as well as outside the setting that may influence the process of therapy. Nevertheless, it is more realistic to acquire knowledge about change by careful observation and documentation of all different kinds of data relating to behaviour and stimuli, and by considering the connections and patterns within and between these types of data.

In order to describe the complexity of the area of enquiry, it was decided to study two single courses of therapy in depth and integrate qualitative as well as quantitative data for a combined evaluation of the intervention. This triangulation of data was seen as necessary in order to include variables in an entirety. It was not intended to generalize results from single cases, but to use a case study to undertake and exemplify a systematic and well documented ideographical description. The knowledge gained can be then used in the development of research methodologies in a field where 'treatment' cannot be carried out in a delimited and brief intervention, but is composed of courses of longer duration that influence and are influenced by the participant and his/her context.

### *Methodology and research questions*

The study was organized at two levels with the intention of developing research methods as well as clinical methods in dementia care. From the perspective of the pilot study a combination of data collection methods was examined on two therapeutic courses of intervention. For the long-term perspective the intention is to include the findings from this triangulation procedure as part of an extended research protocol for Multiple Case Design, with a sample size that permits generalization of the results. While this may seem to be a distortion of how to understand case study research which is not aimed at generalization, the purpose is to elicit comprehensive and variable data from observations on a series of individuals who receive a treatment that cannot be standardized, and that is affected by the environment and the context in an open system (Robson, 2002).

When case study research is systematically, ethically and critically reported, it will better meet criteria for high scientific standards of reliability and validity (Ramian 2007; Robson 2002; Wheeler 2005). For this first-step pilot study the aims were formulated in the following research questions:

- (1) Which instruments specific to dementia focus on quality of life?
- (2) Which instruments for measuring quality of life are suitable for measuring the effect of music therapy on persons with FTD?
- (3) What recommendations (based on trying out the protocol in a pilot study) can be given for a protocol designed to measure the effects of music therapy?

### *Axiology*

In order to ensure ethical approval of the study an application was made to the local regions Scientific Ethics Committee, who responded that the study did not require ethical approval as they characterized it as documentation of

clinical practice and not biomedical research. Although the study therefore was not officially registered by the local Scientific Ethics Committee, general ethical principles regards in relation to research, data collection and clinical practice were incorporated. Relatives and staff were given written and verbal information about the study, and were offered the opportunity to ask questions. In addition to this, relatives gave written consent, agreeing that their relative could participate in the music therapy sessions, that video data and observation data could be collected and analysed, and that they were free to withdraw consent at any time during the study. When the course of music therapy ended, relatives and staff were shown selected video clips from the sessions and were given an opportunity to ask questions, and comment on the therapy. After having received their own copy of the selected video clips, relatives were asked to give consent for the video material to be used for teaching purposes in the future.

The music therapist, who was responsible for the clinical music therapy sessions, is a member of the Danish Association for Professional Music Therapists (MTL) and follows the ethical code for Danish music therapists.

### **Method and design**

A mixed method case study research design was used (Ramian, 2007). In a triangulation of data, both quantitative and qualitative data were collected over a period lasting six weeks. A course of music therapy was undertaken that lasted four weeks. Assessment data were collected before and after music therapy. Two participants, who followed the defined inclusion criteria, were chosen. Each took part in four music therapy sessions a week, carried out over a treatment period lasting four weeks: a total of 16 sessions. All music therapy sessions were recorded through a digital video camera. The first author, who has many years of clinical experience in relation to persons with dementia, was responsible for the clinical work. The data collection, including administering the questionnaires, undertaking the interviews, and the subsequent video analyses, was undertaken by the first author and three collaboration partners from Health Care Professional Studies in Northern Denmark (Tørring, Fock and Frølund). The project was run by Ottesen, a geriatrician in the Knowledge Centre for Dementia in Northern Denmark, and in collaboration with the head of the Doctoral Programme in Music Therapy at Aalborg University.

### ***Quantitative data***

Quantitative data were collected in the week *before* and the week *after* the music therapy course of intervention. The following instruments were used: Alzheimer Disease Related Quality of Life (ADRQL), Cohen–Mahnsfield

Agitation Inventory (CMAI) and Neuro Psychiatric Inventory (NPI). An objective of the first research question was the intention to track down dementia-specific instruments that focus on quality of life. A systematic literature review was carried out in order to find a suitable instrument.

### **Quality of life instruments relevant to research in dementia**

In order to answer research question 1, and find out which instruments specific to dementia focus on quality of life, a literature search was carried out. The purpose was to identify instruments that took into consideration means of administration, accessibility, standardization, as well as suitability for persons with dementia. As persons with severe dementia are generally unable to complete a questionnaire or to carry through an interview, instruments were searched for where contact staff or relatives could serve as proxy respondents.

### ***Search strategies***

The search of suitable quality of life instruments was carried out in international electronic search databases. Searches were made in research databases (e.g. PubMed), general search machines and subject-specific websites: International Psychogeriatric Association<sup>5</sup>, The Dementia Research Centre,<sup>6</sup> Alzheimer Europe,<sup>7</sup> MedlinePlus Dementia,<sup>8</sup> The Pick's Disease Support Group,<sup>9</sup> Nasjonalt Kompetansesenter for Aldersdemens<sup>10</sup> and Alzheimer's Worldwide.<sup>11</sup> In the search the following keywords were used: dementia/demens/mental disorders/cognitive impairment AND quality of life/QoL/well-being.

Studies and meta reviews were selected if they were seen to fulfil the criteria in their abstracts, following which full text articles were reviewed and cross-checked. Only publications from 2001–2006 were reviewed as Horsted & Christiansen's (2004) meta review gives a comprehensive evaluation of methods applied in dementia care.

The result of the search for a suitable quality of life instrument provided 15 articles/reports. In this material 16 different instruments are examined. An overview of these instruments combined with detailed comments can be found in Ridder, Ottesen, & Wigram (2006, p. 23). From this material, the

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<sup>5</sup><http://www.ipa-online.org>

<sup>6</sup><http://dementia.ion.ucl.ac.uk>

<sup>7</sup><http://www.alzheimer-europe.org>

<sup>8</sup><http://www.nlm.nih.gov/medlineplus/dementia.html>

<sup>9</sup><http://www.pdsg.org.uk>

<sup>10</sup><http://www.nordemens.no>

<sup>11</sup><http://www.geocities.com/HotSprings/3004/alzlinks.htm>

following five dementia-specific instruments were found to be applicable for people with moderately/severe dementia and for proxy responding:

- Alzheimer's disease-related Quality of Life (ADRQL) (Rabins, Kasper & Black, 1999)
- Activity and Affect Indicators of QOL (Albert et al. 1996)
- Progressive Deterioration Scale (PDS) (DeJong, Osterlund, & Roy, 1989)
- QoL for Dementia (QOL-D) (Terada et al. 2002)
- The Quality of Life in Late-Stage Dementia (QUALID) Scale (Weiner et al. 2000)

### *Alzheimer's disease-related QoL (ADRQL)*

ADRQL, developed by Rabins (1999), was selected for this study as it met the following criteria: it is used internationally, and has a standardized and validated Danish translation carried out by Gudex & Horsted (2005). The ADRQL is carried out as an interview with the proxy respondent who scores 48 true-false items divided into the following five categories: Social Interaction, Awareness of Self, Feelings and Mood, Enjoyment of Activities, and Response to Surroundings. According to Horsted (2004) the instrument is generally usable in connection with a comparison of medical and environmental treatment/interventions and is not dependent on type of dementia, even if it was originally designed for persons with Alzheimer's disease. Validity is assessed to be high even if inter-rater reliability for several sub-questions are low or non-significant. It is estimated that further examination of the instrument's psychometric qualities are necessary (Horsted, 2004).

There are certain reservations that need comments, as the instrument is very new and still needs thorough reliability and validity tests, particularly as the focus is on health related quality of life, and as it might need adjusting according to practice testing. In addition to this, Ettema et al. (2005) reported that the ADRQL score positively and significantly correlates with degree of cognitive decline. Whether this instrument is reliable in longitudinal studies where a decrease in cognitive functioning is to be expected and, as a consequence of this, a decrease in quality of life scores needs to be addressed.

### *Triangulation of quality of life measures*

In order to strengthen reliability in the pilot study and in future studies we find it necessary to compare the quality of life instrument with other instruments. Based on previous research, knowledge of Danish clinical dementia research, and with the findings from two recent reports from the

Ministry of Social Health (Horsted, 2004; Lee, 2004) two internationally recognized and frequently used measures of agitated behaviour and psychopathology in persons with dementia were also included, the Cohen-Mansfield Agitation Inventory (CMAI) and Neuro-Psychiatric Inventory (NPI).

### ***Cohen-Mansfield Agitation Inventory (CMAI)***

The CMAI is a systematic assessment of agitated behaviour in persons with cognitive impairment, and was developed by Cohen-Mansfield, Werner, and Marx (1989). The questionnaire consists of only one page and is manageable and intelligible. Twenty-nine items are assessed, e.g. “pacing”, “spitting”, “hoarding”, or “repetitive mannerisms”. Each behaviour item is explicated in detail in the form, if needed. Frequency is assessed by a seven-point rating system. Based on this, a degree of disturbance is defined through a five-point rating scale from “not at all” to “extremely”. Fifteen minutes is the normal estimated time it will take to carry out the CMAI scoring (Horsted, 2004). The questionnaire has a standardized, modified and validated Danish translation carried out by psychiatrist Kirsten Abelskov, and distributed by Lundbeck-pharma.

### ***Neuropsychiatric Inventory (NPI)***

The NPI is an assessment of psychopathology in persons with dementia, and measures psychiatric symptoms and behavioural changes. The instrument was developed by Cummings and colleagues (Cummings et al. 1994). Compared with the CMAI, the instrument is more comprehensive, and in the Danish translation it takes up 12 pages with questions and sub-questions. On each page the respondent is required to give an opinion on the following 10 behavioural and two neurovegetative areas: delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, elation/euphoria, apathy/indifference, disinhibition, irritability/lability, aberrant motor behaviour, sleep and night-time behaviour disorders, appetite and eating disorders. Questions are answered with “yes”, “no”, and only those behavioural domains with positive responses to screening questions are further evaluated, which minimizes administration time. Finally, frequency, severity and distress are determined by Likert scale ratings.

*Frequency* of symptoms is scored by rating from 1 (Occasionally – less than once per week) to 4 (Very frequently – daily or essentially continuously present). *Severity* is rated from 1–3: (1) Mild – produces little distress in the patient, (2) Moderate – more disturbing to the patient but can be redirected by the caregiver, (3) Severe – very disturbing to the patient and difficult to redirect. The distress score is an assessment of how much the specific behaviour troubles the respondent and is determined on a scale from 0 (no distress) to 5 (very severe or extreme). Ten minutes is the normal estimated

time it will take to carry out the NPI scoring (Horsted, 2004). The NPI has a standardized and validated Danish translation carried out by psychiatrist Kirsten Abelskov and gerontopsychologist Per Torpdahl.

### ***Diagnostic data/status description***

In addition to the quantitative data in the pilot study collected by means of the ADRQL, CMAI and NPI questionnaires, the interviewer and contact staff completed a descriptive summary of the current status of the participants. These data were not used as effect measures, but were used to give a precise description of the participants. The description was completed before the music therapy course of intervention started, and included a short cognitive test, the Mini-Mental State Examination, MMSE, (Folstein et al., 1975), by proxy scoring. The description of current status included following information:

- diagnosis
- general mental and somatic symptoms and state of health
- medication
- daily routines
- participation in other activities/communities
- visits/networks.

### ***Qualitative data: life story***

In the week before music therapy started, interviews with relatives were carried out. They were asked to supply information on the story of life of the participant. The interviews followed an interview guide (see Ridder et al., 2006, pp. 36–38 and Appendix 2) that was inspired by the qualitative research interview (Kvale, 1994) and the Qualitative Line of Life (Sejerøe-Szatkowski, 2002).

### ***Qualitative data: video recordings, session 15***

Each music therapy session was recorded on video. The recordings were “quantified” by marking observations in session graphs in Excel spreadsheets. The session graphs give an overview of time sequences and progress, how many songs are sung, pauses between songs, observations of the participants’ behaviour, such as “joined in singing”, “made eye contact”, as well as a transcript of verbal comments made by both the participant and therapist. A comprehensive description of the method is given in the book *Microanalysis* (Ridder, 2007b). Based on video recordings and session graphs a detailed qualitative description of one selected session was given in order to provide insight in the participation of each participant (see Ridder et al., 2006, pp. 55–62).

### ***Qualitative data: analysis of selected video clip***

A related professional (occupational therapist) carried out the video analyses. This evaluator was given no information about the participant, or the course of music therapy. She was given selected video clips that lasted all together five minutes for each participant, and was blind to the sessions from which the video clips were selected. Criteria for selecting the video clips and procedure for the video analysis are described in detail in Ridder et al. (2006, pp. 38–41).

### **Two case studies**

A psychiatric nursing home in northern Denmark accepted to take part in the pilot study, and staff pointed out two residents who met the inclusion criteria of the study; Mr A and Mrs B.

#### ***Mr A***

Mr A was diagnosed with FTD in an advanced stage with severe cognitive impairment (Global Deterioration Scale: 6, Mini-mental State Examination: 8). He had a wife, children and grandchildren, and had enjoyed a very active life. Before onset of dementia he was engaged in several strong networks of people, committed to his work as a workman, and a responsible member of local committees. Mr A had not been a practising musician or chorus singer, but he had always liked singing and was known for his skills in song writing. For all family get-togethers and celebrations he pleased the company with his funny and ingenious song texts.

#### ***Mrs B***

Mrs B had a diagnosis of FTD and suffered from severe cognitive impairment (Global Deterioration Scale: 7, Mini-mental State Examination: 0). She was a widow, and had children and grandchildren. She had been taking care of her children and at the same time ran a small business with her husband. She had enjoyed doing needlework and painting, and had been fond of second-hand dealing in markets. Mrs B never performed music, but she liked to listen to music on the radio.

### ***Music therapy methods used in the interventions***

The music therapy sessions took place in the living room of each participant and lasted between 20 and 30 minutes. The therapist chose songs designed to catch the attention of the participant and also songs that would mark the beginning and end of sessions. These songs were chosen to put the

participants at ease, make them feel comfortable and secure, allow them to concentrate on the interaction, and help them feel contained and validated by the therapist. The music therapy work is approached by a neuro-pedagogical understanding of learning (Fredens, 2004) and is dependent on the building of a close relationship for which reason each participant is offered an intense course of therapy with four sessions a week. The therapeutic objective is to meet psychosocial needs and here a humanistic, person centred culture of care for persons with dementia (Kitwood, 1997) with emphasis on psychodynamic forms of interactions such as holding and validation offers a valuable approach. The psychodynamic approach to music therapy is grounded in analytical music therapy, with its roots in the work of the British music therapist Mary Priestley (1975, 1994; Pedersen, 2005). Pedersen (2005) has further developed analytically oriented music therapy in a Danish context and even if the instrumental improvisation often employed with this approach is not a part of the therapeutic singing described here, the music is still used with a focus on the relationship between participant and therapist within a psychodynamic understanding of communication and interaction. The sessions were carried out as individual sessions in order to be able to concentrate on uniquely individual needs for arousal regulation in participants with severe cognitive decline.

Songs in this type of music therapy session are selected and used for different purposes. In the *constitutional* part of the sessions that frame the setting, the songs were used as cues in order to catch the attention of the participant. In the *regulative* part, songs were used to regulate arousal level utilizing the stimulating or calming effect of music on the human nervous system. In the *dialogical* part of the session, songs were used to enhance communication and dialogue by combining song singing with therapeutic techniques such as holding, containing, validation and empathy. Comprehensive descriptions of this integrative method are well reported in the literature (Ridder 2003, 2005a, 2005b, 2007c).

### **Analysis and results**

In order to answer research question 2 in the pilot study, the results will here be reported for each of the two case studies together with the process of analysis. Where the data in a questionnaire are based on the scoring by a carer, it will simply be termed in the text as the proxy respondent.

### **ADRQL**

ADRQL scores were analysed with help of the explicit instructions in the material "Calculating the ADRQL domain scores and the overall ADRQL

score” that were provided by Horsted. The Excel spreadsheets were used for the scoring procedure where the five subgroups of questions were recorded and subsequently entered into two columns denoting *agree* or *disagree*. The score was calculated through the following formula:  $\{\Sigma(\text{weight of the endorsed items})/\Sigma(\text{all weights})\} \times 100$ .

Figures 1 and 2 display the values of the ADRQL sub-scores. The y-axis shows the percentage score. The x-axis shows the domains with *pre* test scores at first (light shaded bars) followed by the *post* test scores (dark shaded bars). The five domains reported here are social interaction, awareness of self, feelings and mood, enjoyment of activities and response to surroundings.

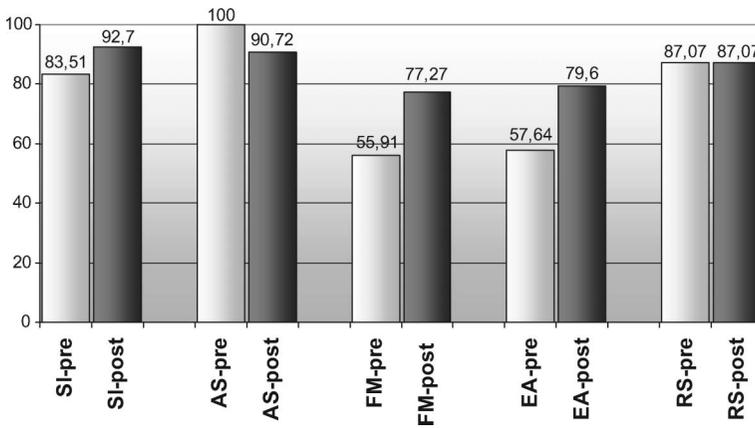


Figure 1. Increase or decrease in ADRQL sub-scores (quality of life): Mr A.

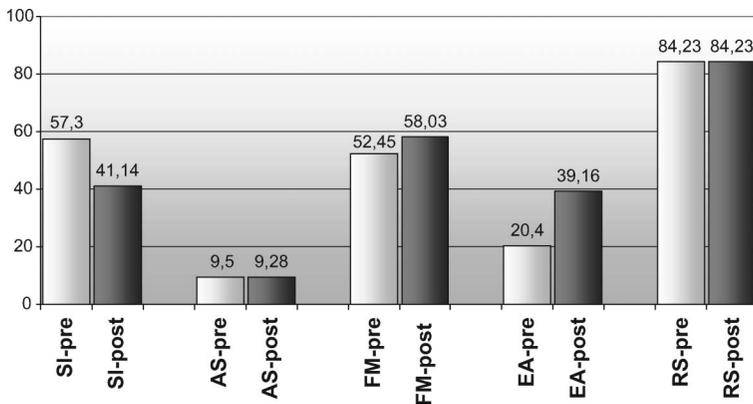


Figure 2. Increase or decrease in ADRQL sub-scores (quality of life): Mrs B.

**Mr A**

In the domain awareness of self (AS) a *decrease* was reported in quality of life score for Mr A (see Figure 1). In the following three domains of social interaction (SI), feelings and mood (FM), and enjoyment of activities (EA), an *increase* was reported. The decrease found was due to statement B4: “He becomes upset by personal limitations such as forgetting, losing things, or getting confused in familiar places”, where *disagree* was reported before music therapy, but *agree* after.

The finding of an increase in Mr A’s quality of life score was due to the following four statements, where the proxy noted *agree* before music therapy, but *disagree* after: A12: “He pushes, grabs or hits people.”<sup>12</sup> C3: “He throws, hits, kicks or bangs objects.” C4: “He calls out, yells, curses or makes accusations.” C5: “He locks or barricades himself in his room/house/apartment.” For this fifth statement, *disagree* was reported before music therapy, but *agree* after: D3: “He sits quietly and appears to enjoy the activity of others even though he is not actively participating.”

**Mrs B**

In the domain of social interaction (SI) a decrease was reported in the quality of life score (see Figure 2). In the two domains feelings and mood (FM) and enjoyment of activities (EA) an increase in quality of life score was reported.

The reported decrease in quality of life score was considered to be due to a change in following three statements. To the statements A2: “She does *not* pay attention to the presence of others” and D5: “She dozes off or does nothing most of the time” the proxy reported *disagree* before music therapy and *agree* after. To the statement A3: “She will stay around other people” the proxy reported *agree* before music therapy and *disagree* after.

The indication of an increase in Mrs B’s quality of life score was due to the following three statements. To the statements C11: “She resists help in different ways such as with dressing, eating or bathing, or by refusing to move” and D4: “She shows *no* signs of pleasure or enjoyment when taking part in leisure activities or recreation” the proxy reported *agree* before music therapy, and *disagree* after. To statement D1: “She enjoys doing activities alone such as listening to music or watching TV” the proxy reported *disagree* before music therapy and *agree* after.

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<sup>12</sup>The codes A12, C3, C5, etc. refer to the systematic numbering of the 48 statements in the questionnaire.

### *Comments to QoL scores*

There was a decrease in Mr A's quality of life score as he became upset by his own personal limitations. In Danish, the word *upset* is translated as "ked af det" which also means unhappy and sorry about. In many ways it was interesting that contact staff reported that Mr A becomes unhappy/feels sorry, as a lack of emotional response is described as being pervasive in FTD (Snowden et al., 2001; Stockholm & Waldemar, 2003). This sentence might have been scored differently if the translation would instead have been "ude af balance" (out of balance) or "chokeret" (shocked). If the reaction of Mr A was seen to be of someone who had gained deeper insight – albeit painful – into his current life status, it can be argued that he has become more aware of how his limitations have influenced his quality of life, provided that he is not overcome in a negative way by this type of insight.

Mrs B does not use verbal language; therefore it is questionable if certain items gave her a higher quality of life score than might be realistic. For example, *disagree* was reported in response to the statements: C14: "She *talks* of 'feeling sick', 'having pain' or 'being cold'", and E2: "She *talks* about feeling *unsafe* or says her belongings are *not safe*." Scoring *disagree* to these statements leads to a higher QoL score before as well as after therapy, but might not have reflected that she actually does not feel sick or unsafe. The formulation of these statements might reveal an internal validity problem in the questionnaire for participants that have lost verbal language.

A drop in Mrs B's quality of life score was seen. *Before* therapy she was reported to pay attention to the presence of others, whereas *after* therapy she was reported not to pay attention to the presence of others, and she was sometimes noted to be dozing off. During the day, Mrs B spent her time in the common room and kitchen, in a milieu with others. During the course of music therapy, and after talks with the music therapist, staff members became aware that Mrs B became more relaxed in two specific situations. In the common room, where she had previously been sitting in the centre of activities, she became calmer if she was placed in a corner of the room where it was more protected and with less stimulation. Also, staff noted she was calmer when she could spend short periods in her private living room. Paradoxically, this seemingly increased "isolation" and remoteness could suggest there would be a reduction in quality of life. However, in the case of Mrs B, we would argue that it was positive and should be understood as giving an increase in quality of life due to the fact that staff members became aware of Mrs B's needs for withdrawal and disengagement (see Cumming & Henry, 1961) allowing a possibility to relax and avoid over-stimulation and sensory overload.

### *Discussion of ADRQL*

The ADRQL is relatively easy to administer for data collection and analysis, and seems to be very relevant to use in an extended protocol for people with

dementia. However, the authors have some scepticism as to whether the instrument is able to reliably capture valid data concerning people with severe dementia who have lost verbal language and where cognitive functioning is scored zero (out of 30 points) on the Mini-mental State Examination (MMSE).

The QoL-coefficient elicits many relevant considerations about changes in everyday life of persons with dementia, but one should be hesitant about the instrument's capacity to relate to "real" observations. It may be susceptible to influence from new knowledge about each participant, in that the instrument measures to a greater degree a change in staffs attitudes and insights. There is also a propensity to measure a change that for some participants might not be very much connected to the general definition of quality of life. In our judgement, Mrs B's quality of life is increased by the renewed awareness in staff of her need for rest and disengagement. However, in the ADRQL "isolation" is seen as a negative factor and therefore a decrease in quality of life. One should also question if momentary expressions of sadness arising out of a difficult situation, such as experiencing the losses involved in having a degenerative dementia disease, is actually a negative factor of quality of life. These types of emotions are present and need a space for expression.

For the process of collecting the ADRQL data it was an advantage to have data collectors/interviewers to ensure that the questionnaires were properly filled out. Verbal interviews of proxy respondents, instead of written forms, assure optimal percentages of replies and prevent misunderstandings in the sometimes cryptic negations in some of the statements. Interviewers therefore need to have thorough knowledge of the instrument.

It is necessary that a proxy respondent knows the person well on whom they are responding. In order to relate to 48 statements it is necessary to have been together with the person with dementia in many different situations over a period of time. Since the participants in the pilot study had contact staff members that were responsible for the care for this one person and saw them every day when they were at work, they were well enough informed to respond. But for some persons with dementia we know that this is not possible, and that they do not have this continuity in the daily care.

Based on these two case studies there are relevant issues regarding the external as well as the internal validity of the ADRQL. There is no consistency in relation to certain of the statements, and some discrepancies in the assessment of single variables, such as "isolation". Concerning reliability and validity there is a need for further adjustment of the instrument. These problems raise some quite challenging questions in relation to the ambitions of developing an instrument that quantifies a concept such as quality of life. Is it possible at all to unify reactions, responses and acts to a general term and a specific score that will include all of the complex aspects related to such a delicate idea as quality of life? Or is

it necessary to link these systematic observations to further observations from every day life and daily context of every single participant – and thus accept that an unambiguous concept of quality of life does not exist?

### CMAI

Cohen-Mansfield Agitation Inventory is a score of agitated behaviours. In a factor analysis behaviours are divided into three sub-scales and from this a loading of behaviours follows. In the Danish version of CMAI no factor analysis is included in the material, and behaviour is divided into the following four sub-scales: (1) physically aggressive; (2) physically nonaggressive; (3) verbally aggressive; and (4) verbally nonaggressive. The Danish modified version was used in this study, and included the numerical values of the scoring. In the subdivision of behaviours in Figure 3 physically and verbally nonaggressive behaviours have been placed into one category.

Figure 3 shows frequency scores in the three sub-categories based on the Danish translated and modified version of CMAI. The white columns show the total of scores in each sub-category *before* therapy and the black columns show *after* therapy. The first two columns show Mr A and the sub-category nonaggressive agitated behaviour. The next two columns show Mrs B. With both Mr A and Mrs B a decrease in nonaggressive agitated behaviour is seen. In physical aggressive behaviour no change was reported in Mr A's scores, and a small decrease in Mrs B scores. The scores in physical aggression showed a minor decrease in Mr A and no change in Mrs B.

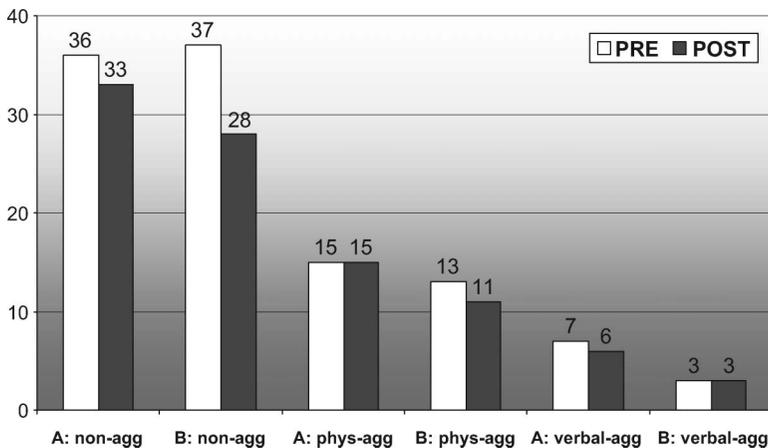


Figure 3. Numerical computation of CMAI data in three sub-categories pre/post music therapy for Mr A (A) and Mrs B (B).

**Mr A**

After the course of music therapy with Mr A, the scores indicated a *decrease* in frequency in the following behaviours: (1) pacing, aimless wandering; (4) cursing or verbal aggression; (18) complaining; and (23) hiding things. There was a pronounced decrease in (5) constant unwarranted request for attention or help, and (19) negativism.

The frequency of the following behaviours *increased* after therapy: (2) inappropriate dress or undressing; (3) spitting; (7) hitting (including self); and (29) general restlessness. The total CMAI score for Mr A was 58 before therapy and 54 after. Caregiver burdens were assessed on a 5-point scale ranging from 1 (Not at all) to 5 (Extremely) on all items in the CMAI. By summing up the numerical values from those caregiver burden scores, the totals for Mr A were 50 before therapy and 43 after, indicating that symptoms of agitated behaviour were less disturbing to staff *after* the music therapy course of intervention.

**Mrs B**

After the course of music therapy, the following behaviours *never* occurred, whereas before therapy they were occurring once or twice weekly: (5) constant unwarranted request for attention or help; (8) kicking [the dog at the unit]; (10) pushing; and (20) eating/drinking inappropriate substances.

Behaviour (16), trying to get to a different place, *decreased* in frequency from several times a day to only once or twice a day. The scores for (22) handling things inappropriately and (29) general restlessness *decreased* from occurring several times a week to not to happening at all.

Mrs B was (1) pacing/wandering aimlessly several times a day before as well as after therapy, but there was a *decrease* in (26) performing repetitious mannerisms, that was scored as happening several times a day before therapy, and only once or twice a day after therapy.

According to contact staff, a *decrease* was seen in nonaggressive, agitated behaviour after therapy, and also a minor *decrease* in physical aggressive agitated behaviour. The total CMAI score was 53 before therapy and 42 after.

From the questionnaire it is not clear how much the agitation of Mrs B proves a burden to staff. The level of disturbance was not noted in the form *before* therapy. This might mean that this behaviour is not experienced as disturbing at all, or perhaps that this part of the questionnaire was not completed. After therapy, the following behaviours were noted to disturb *a little*: (1) pace, aimless wandering; (16) trying to get to a different place; and (26) performing repetitious mannerisms.

### ***CMAI: Mr A and Mrs B***

Based on the computation of numerical values that represent the frequencies of agitated behaviour in Mr A and Mrs B, it was noted that staff experience frequency as having *decreased* after the course of music therapy, and that Mr A's expression of agitation seemed less disturbing after the therapy course of intervention.

### ***Discussion of CMAI***

The CMAI is clear, manageable and very easy to administer with only one page to complete. Several of the behavioural items are very general, for example *complaining*. But, in the instructions for administration and scoring, each of the items is explained in greater depth. The advantage of the CMAI is that it is based on very concrete behavioural patterns of which staffs seem to be able make a confident evaluation very easily. The CMAI is a relevant instrument for observing agitation, especially as a supplement to other instruments such as quality of life evaluations.

Caring for persons with dementia is additionally demanding when there are frequent symptoms of agitation. We have reported that there is a need to develop and try out new methods of treatment and care, pharmacological as well as psychosocial. In the documentation of this it is relevant to include measures of agitated behaviour, as a reduction in these behaviours would have great value both ethically and economically. But it is important to stress that this does not imply that agitated behaviours as such are unwanted, and should be subdued in all situations, especially where they externalize and represent a high level of internal anxiety. With this in mind we find it relevant to continue with further research with CMAI as a useful means in documenting the effects of therapy. For further research it is important to emphasize that the Danish version of CMAI, and the way of analysing and presenting results, follows international procedures.

### ***NPI***

The Neuropsychiatric Inventory (NPI) is used to measure psychiatric symptoms and behavioural changes as a result of treatment initiatives. We have calculated the NPI score using the following formula:  $\Sigma$  (frequency  $\times$  severity). Based on this we have calculated the distress by this formula:  $\Sigma$ (caregiver distress)/number of options.

In Figures 4 and 5 the categories are numbered as follows: (1) delusions; (2) hallucinations; (3) agitation/aggression; (4) depression/dysphoria; (5) anxiety; (6) elation/euphoria; (7) apathy/indifference; (8) disinhibition; (9) irritability/lability; (10) aberrant motor behaviour; (11) sleep and night-time behaviour disorders; and (12) appetite and eating disorders.

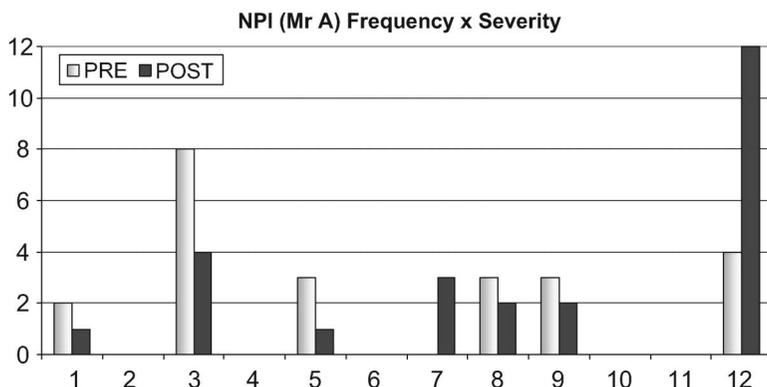


Figure 4. Mr A, NPI-score before (white bars) and after (black bars) 16 music therapy sessions.

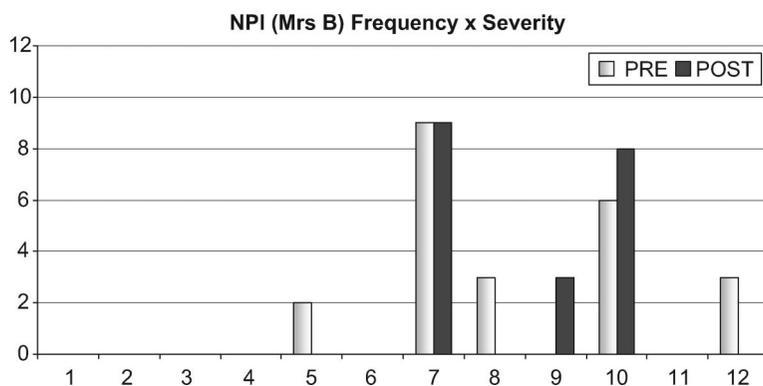


Figure 5. Mrs B, NPI-score before (white bars) and after (black bars) 16 music therapy sessions.

### *Mr A*

Mr A was reported to have symptoms in the following areas: (1) delusions, (3) agitation/aggression; (5) anxiety; (8) disinhibition; (9) irritability/lability; and (12) appetite and eating disorders. After the course of music therapy category (7) apathy/indifference is added (see white/black bars in Figure 4). Mr A's NPI score is 23 before music therapy and 25 after. This indicates an *increase* in the NPI score, where a decrease might have been expected when scores are compared with ADRQL and CMAI. As seen in Figure 4, where the white columns are the scores *before* therapy and black *after*, there is a marked increase in (12) appetite and eating disorders. Here it is reported that Mr B has increased weight (12.4). The score is 4 (*Very*

*frequently – daily or essentially continuously present*) and 3 in relation to severity (*Severe – very disturbing to the patient and difficult to redirect*). This gave a total score of 12 ( $4 \times 3$ ). Before music therapy the score was 4 ( $4 \times 1$ ). As is seen in Figure 4 this results in a pronounced shift in total weight of scores.

The average caregiver distress was calculated to 2.17 before therapy and 1.57 after. This indicates a small *decrease* in reported caregiver distress, which might be regarded as a positive drop in scores.

### **Mrs B**

In the bar chart in Figure 5, Mrs B shows neuropsychiatric symptoms in the following five categories *before* (white bars) the music therapy course of intervention: (5) anxiety; (7) apathy/indifference; (8) disinhibition; (10) aberrant motor behaviour; and (12) appetite and eating disorders. *After* music therapy (black bars) it is noted that she shows symptoms only in the following three categories: (7) apathy/indifference; (9) irritability/lability; and (10) aberrant motor behaviour.

*Apathy* was reported as Mrs B sits quietly without noticing what was going on around her. *Aberrant motor behaviour* was reported as she paced aimlessly, and she was also performing *repetitious mannerisms* (folding her hands firmly in front of her chest when she sits or walks about).

The NPI score was 23 before the music therapy sessions and 20 after. This indicated a *decrease* which could be interpreted as a positive change.

The average caregiver distress was calculated to 1.4 before therapy and 1.0 after. This indicates a small *decrease* in caregiver distress, which might be regarded as a positive drop in scores.

### **Discussion of NPI**

Mr A has gained quite a lot in weight about which he often commented, and about which he was apparently worried. This means that his NPI score increased after the 16 sessions with music therapy. The NPI score that was calculated in relation to Mrs B decreased, and for both participants caregiver distress decreased from before to after music therapy.

The NPI instrument consists of 12 pages of questions and sub-questions, and it was not as clear and easy to administer as the ADRQL and CMAI. Some questions were difficult for the proxy respondent to answer as they consisted of more questions within one statement, e.g. that *the patient has lost interest in friends and relatives*. Some statements were relatively hypothetical in character, such as following (1.3) *The patient believes his spouse had an affair*, (2.3) *The patient sees things that are not*

there, or (5.5) *The patient avoids certain places or situations that makes him/her even more nervous*. It was difficult for the respondents to give clear answers to these questions in relation to a population with severe dementia, who have specific problems with verbal communication and memory functions.

The NPI and the CMAI have a number of questions in common, for example concerning pacing, inappropriate dressing, hitting, and verbal aggression. But they differ in that the CMAI does not include psychiatric symptoms such as delusions, hallucinations, depression, anxiety, elation, irritability, sleep and eating disorders. The NPI therefore seems to be a relevant supplement to the CMAI, or actually could replace CMAI. But accurately in relation to persons with severe dementia, several questions in these categories seem irrelevant or difficult for proxy respondents to answer, and this makes one question the validity of the instrument when it is used with a population who suffers from advanced FTD.

### **Summary of findings in the two case studies**

#### ***Mr A***

Mr A participated in 16 music therapy sessions over a period of four weeks. The music therapist reported that Mr A participated actively in the music therapy sessions by singing, marking the beat, and engaging in musical dialogues. His verbal response in the sessions was very positive, and he clearly had his identity and self-worth confirmed by the experience.

Based on the video analysis it was concluded that Mr A benefited from the therapy sessions in the following ways:

- He was evidently engaged in the songs.
- He responded in a relevant way.
- He related to and understood the song texts.
- He was linguistically and verbally stimulated.
- He actively participated by contributing with his own input.
- He took the initiative and led the singing.
- He understood that the therapist was offering contact, and was aware of and appreciated the contact.
- He was able to express pleasure and contentment.
- He was confident in his musical expression.
- He was creative, playful, experimenting.
- He entered into dialogue and shared creativity.

From the video analysis it is concluded that intersubjectivity between Mr A and therapist was clearly evident.

After the music therapy sessions there was an increase in Mr A's quality of life score (ADRQL: *Pre* 75.00. *Post* 85.11), a decrease in agitated behaviour (CMAI: *Pre* 58. *Post* 54), and a decrease in disturbance (*Pre* 50. *Post* 42). An increase is seen in neuropsychiatric symptoms (NPI: *Pre* 23. *Post* 25), due to his worry about a considerable weight gain. Nevertheless, a decrease is seen in NPI distress score (*Pre* 2.17. *Post* 1.57). Contact staff members observed that Mr A, who already used to sing a lot, had extended his repertoire of songs. It is concluded that, in spite of severe FTD, Mr. A had considerable personal benefits from participating in music therapy, resulting in an increase in quality of life, reduced symptoms of agitated behaviours, and in a decrease in caregiver burden.

### **Mrs B**

Mrs B took part in 16 music therapy sessions over a period of four weeks. The music therapist reported that Mrs B never responded musically in the music therapy sessions, but that she would engage in eye contact for short periods when she was relaxed and at peace.

Based on the video analysis it was concluded that Mrs B did not participate actively, but that she was attentive to the songs, seemed to listen and calm down, and was emotionally affected by the songs. In the analysis it appeared that the songs were emotionally meaningful to Mrs B, and that the relation between therapist and participant was somewhat of the nature of a mother/infant relationship, where the songs were applied in a warm and calm feeling – akin to singing lullabies.

After the music therapy sessions there was a reported decrease in quality of life (ADRQL: *Pre* 47.17. *Post* 46.88) due to a perceived impression that Mrs B suffered increased “isolation” and remoteness. There was a reported decrease in agitation (CMAI: *Pre*: 53. *Post*: 42), in neuropsychiatric symptoms (NPI: *Pre* 23. *Post* 20), and in distress (NPI: *Pre* 1.4. *Post* 1.0). It is concluded that Mrs B, in spite of severe FTD, benefited from participating in music therapy as she was attentive to the songs and the therapist, she was calming down and showing less symptoms of agitation in the therapy, and she was showing less symptoms of agitation as after the sessions.

### **Discussion**

In order to answer research question 3 and focus on the development of a research protocol, we now want to discuss the observations from the research process. It is not intended to generalize on the basis of only two case studies. What can be drawn out is that the positive outcomes from the two case studies clarify the relevance and need for further research into the efficiency of music therapy in dementia care. It is important to study

non-pharmacological treatment procedures and develop research protocols where it is realistically possible to collect reliable data and draw valid conclusions about therapy or psychosocial initiatives.

The quality of life measures that were collected using the ADRQL were manageable and fairly easy to administer and we see them as relevant to include in an extended protocol. However, one might question the validity of the instrument in regards to persons with severe dementia, and speculate about its sensitivity to capturing slight nuances in the experience of quality of life in this population. The CMAI was easy to administer and very relevant in considering the triangulation with the ADRQL measures. The Danish version was used where no factor analysis was carried out and it is relevant in further research studies to ensure that the results will be comparable with an international use of the scores. In comparison with the NPI, the CMAI was easier to administer, and the very concrete observations of behavioural symptoms seemed to increase reliability, whereas several questions in the NPI were difficult to answer by proxy.

The analysis of selected video clips gave information of great value about the therapy process. The procedure of selecting video clips was time consuming and it would be relevant to investigate if this procedure could be more 'effective' without reducing the quality of the material. It could be sufficient with less video material, and it would also ensure greater external validity to draw on more than one professional/expert for the analysis. The contact staff, who possess valuable, pertinent and current information about the participant, could be more extensively involved. Could more specific analysis be undertaken by music therapists who are trained in assessing the nature and quality of musical interactions?

It is highly relevant to include physiological data in the quantitative measures, such as heart rate measures, reliable measurements of activity/motion, blood pressure, breathing, sleep, cortisol levels, and S-IgA levels. For persons with dementia it is necessary to use instruments that are not inconvenient and disturb free movement.

Staff and relatives expressed that they benefited from taking part in the interviews, from describing the "story of life" of the participant, seeing the video clips from the music therapy sessions, and from the comments on the therapy and on the interrelation between therapist and participant. These positive experiences are very important, as they influence the carers' and relatives' attitudes and perception of the patient, and an important question is how these factors can be integrated in a research study. For several music therapists it is a fundamental part of daily clinical practice to collaborate with relatives and staff. Nevertheless, to include such issues in research makes it even more complicated, and causes more uncontrollable and confounding variables.

A way of keeping data collection at minimum cost would be to recruit music therapists who already work with the target group, and work in close

collaboration with staff, and let them administer data collection in a clinician-based protocol. The disadvantage with this model is that one researcher/clinician alone will take a lengthy period of time to collect sufficient data. In the pilot study, Ridder was responsible for the project as well as the music therapeutic courses of intervention, but collaborators from the Health Care Studies were responsible for collecting the data. It strengthened reliability that external professionals collected most of the data, in this way releasing the clinician from this work. At the same time, this secured a high percentage of completion of answers, because each question was asked directly to the respondent by a person that was well informed about all aspects of the instrument. The collection of such extensive data is complex, and it is an advantage that a third party researcher has done this. Therefore, the idea of a clinician-based protocol where the music therapist him/herself collects and analyses data are not so efficient or effective, and for a larger study, external research professionals should be responsible for the main part of the data collection and data analysis.

### **Conclusion: recommendations for a protocol**

Developing a research protocol focused on measuring the effect of newer psychosocial initiatives for persons with FTD makes specific demands on procedures and instruments, as this population is typically not able to act as respondents. They can also be reactive to the use of intrusive physiological measures involving wires or disturbing apparatus.

In this article the authors have presented the theoretical background for a pilot study as well as the results from a small scale piece of research. This is the first step in the direction of developing a protocol designed for an extended piece of research. It is a challenge to comprehensively develop a functional protocol, and many aspects still need attention in order to ensure rigour in the method that is ready for trial with a larger sample. In order to define the limits of a project and keep it realistic, it is relevant first to focus on a protocol prepared to investigate clinical music therapy in order to gain experience in connection with one specific method.

From a literature review the ADRQL was identified as appropriate and included in the pilot study protocol that undertook a triangulation of the following data: qualitative life story, video analysis based on session graphs, video analyses carried out in a five-step procedure, and pre/post measures with the instruments NPI and CMAI. The protocol developed for the pilot study can serve as a framework for an extended protocol, but with certain reservations in relation to the ADRQL and the NPI.

The development of a protocol as well as the coordination of research trials need to be connected to a well established research milieu in collaboration with relevant professionals, specifically professionals with an expertise in dementia, or researchers with specialized knowledge in

methodology. It would be fruitful for a research leader or team to take overall responsibility for the administration and coordination of data collection, analyses, dissemination, ethical considerations as well as supervision of the clinical method used in the research.

In Denmark only a few music therapists are employed in dementia care and have the possibility to carry through individual therapy. Involvement of clinicians and researchers working with dementia from other countries would allow a larger sample through multi-centre trials. To be able to undertake such data collection, it is necessary to define a protocol that ensures standardization in order to make it possible to generalize across cases. Calculations of effect sizes (see Gold, 2004) will make this doable, even when measured on different variables. Finally, a protocol should ensure the collection of clear descriptions of background factors, such as information about the therapist (sex, education), context (institution, setting), the participant (life story, status description), and clinical method.

A description of the clinical method might be important for subsequent analyses of aspects that are relevant from the clinical work, and for pattern matching with other data. In standards for medical research it is expected that “ingredients” in a treatment, as well as the composition of these ingredients, are unified and described in detail. The same way of unifying therapeutic interrelation is not realistic if the approach is based on person-centred care, where due to the number of confounding variables it is important to give clear and precise descriptions of as many variables as possible, and in this way to focus on the value of subsequent cross-case analyses.

The triangulation of data types and data collection methods offers an opportunity to integrate the complexity of observations and documentations on therapeutic treatment from several angles. It strengthens reliability and validity that data is not only based on outcome measures, but do also include variables that are connected to the therapeutic intervention, the therapeutic relation, and the context as a whole.

As the next step in the process of the research, a mixed-method design with multiple case studies will ensure that data collection on each participant is very comprehensive, and assures validity as well as the fact that certain forms of data are not “ignored” with a risk of distorted results. Ultimately the goal will be to include sufficient participants to allow randomization where one group is assigned to receive standard treatment as a control, with the treatment group participating in an intensive course of therapy.

### **Notes on Contributors**

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