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Anvendelse af musikterapi og Dementia Care Mapping I EN LÆRINGSMODEL til udvikling af musiske og interpersonelle kompetencer hos omsorgsgivere til personer med demens. ET CASESTUDIE MED EN ETNOGRAFISK TILGANG

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**THE USE OF MUSIC THERAPY AND DEMENTIA CARE MAPPING
IN A LEARNING MODEL
FOR THE DEVELOPMENT OF MUSICAL AND INTERPERSONAL COMPETENCES
IN CARE PROVIDERS OF PERSONS WITH DEMENTIA

A CASE STUDY WITH AN ETHNOGRAPHIC APPROACH**

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Summary

Thesis Submitted for the Degree of Doctor of Philosophy
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Introduction

Dementia is a condition which often reveals itself in impaired mental functions such as memory, concentration, conception of space concept of space, language skills, the ability to solve problems etc. Furthermore, changes in personality and emotional life may occur, and the person's insight into own situation and illness may also be weakened. In addition to the cognitive symptoms, dementia may also be accompanied by a number of psychiatric symptoms and behavioural disturbances such as apathy, depression, agitation and hallucinations (Hasselbach et al. 2004; Waldemar & Brændgaard 2010). In 2012, WHO published a report on dementia illnesses documenting that they represent a serious and increasing health problem and an economic concern almost worldwide. According to the report, the costs of dementia illnesses are already more than US\$ 604 billion per year. WHO (2012) estimates, that, health authorities, worldwide are facing massive challenges as the costs of dementia will increase faster than the number of persons with dementia. Therefore, WHO is urging all countries to give high priority to efforts in the area of dementia care. The report also estimates that 35.6 million persons are living with dementia at present, and that with an aging world population, the figure will double every 20 years to 65.7 million in 2030 and 115.4 million in 2050; it is estimated that the total number of new cases every year will be 7.7 million.

In Denmark in 2014 there are approx. 90,000 older people (60 + years) with dementia. Nationally, it is expected that the number of elderly people with dementia will be increased by approx. 50% around 2030. Prevalence of dementia increases rapidly with age. Dementia occurs slightly more often in women than in men in the age group of 60-64 years to 85-89 years, after which the disease occurs significantly more frequently in women aged 95 and over. The prevalence of dementia in persons below the age of 60 is estimated between 1,200 and 6,000. It is estimated that the number of new cases of dementia every year is between 13,000 and 14,000 persons (Danish Dementia Research Centre 2014).

Persons with dementia are completely or partially deprived of the ability to remember the past and to imagine the future. The present is therefore of vital importance to their existence. To have a relation with persons with dementia constitutes a special challenge because the loss of skills and functions makes it difficult for persons with dementia to express their actual needs. Situations where the dialogue and cooperation between the care providers and the person with dementia does not succeed may very easily occur. At times, persons with dementia find it difficult to understand what is happening; they often find themselves in situations where they feel at loss and alone, or in situations they cannot cope with or recognise.

For persons with dementia, the *meeting* with a care provider may be an ambiguous experience unless the care provider possesses knowledge and competences to handle such a meeting (Miller & Scholdager 2012; Nors et al. 2009; Ottesen & Weberskov 2007; Ottesen 2009).

The research project is based on the basic assumption that professional care providers are *responsible* for the Quality of their relation to the person with dementia. It is therefore decisive that care providers are in possession of the personal and professional competences required to engage in the

relational meeting with the person with dementia. The focus of the research project is the relational meeting between the person with dementia and the care provider in which music therapy is the shared platform for establishing and developing the relation. The research project is concerned with a learning model for care providers in the dementia area. The Dementia Care Mapping method is included in the learning model, together with the development of cross-disciplinary cooperation between a music therapist, care providers in the dementia area and the researcher.

Objective

The objective of the project is, through a learning model for care providers in dementia care, to promote the advancement of communication and care methods which will contribute to increasing the quality of life and wellbeing of persons with dementia.

Research questions of the project

1. How can a learning model for care providers in dementia care, which has the group music therapy course as its focal area and using Dementia Care Mapping as an observation and feedback method contribute to developing the interpersonal and musical competences of care providers for the purpose of improving/enhancing their relational meeting with persons with dementia?
2. How can the musical and interpersonal competences of the individual care provider be developed so as to enable care providers, in their relational meeting with persons with dementia, to develop and transfer new knowledge and acquired skills to their daily nursing and care practices through the application of concrete experience and tools from the music therapy sessions?
3. What impact does the targeted focus on the development of the care provider's musical and interpersonal competences have on the everyday quality of life and wellbeing of persons suffering from dementia?

Learning model for care providers in the dementia area

The research project is aimed at developing a learning model for care providers in the dementia area focusing on the relational meeting between the person with dementia and the care provider where 1) a group music therapy course is the focal point for the learning of the care providers; where 2) Dementia Care Mapping is used as an observation and feedback method; and where 3) the implementation of the learning model will be carried out through the development of cross-disciplinary cooperation between the music therapist, the care providers and the researcher, who is also responsible for the learning process. In the cross-disciplinary cooperation between the music therapist, the care providers and the researcher, practice and practice development, will focus on their joint application of knowledge and theory in clinical practice and the further development of communication and care methods which will contribute to

increasing the everyday quality of life and wellbeing of persons with dementia living in a dementia care home.

The learning model is based on the dementia researcher Tom Kitwood's (2003) theory and set of values on person-centred care. To create a framework for learning, four care providers and four persons with dementia have participated in a group music therapy course comprising nine music therapy sessions, which took place in a large common room of a dementia care home. The music therapy was undertaken by a music therapist. All music therapy sessions were recorded on video from four different angles in the room, allowing the recordings to become part of the care providers' learning process.

The participating care providers received an introduction to the theories behind the course, including theory on person-centred dementia care and Dementia Care Mapping (Brooker & Surr 2007; Kitwood 2003); senses of self, domain of relatedness, forms of vitality and the present moment (Stern 2000, 2004, 2010); retrogenesis (Reisberg et al. 1999); and mirror neurons (Bauer 2006; Rizzolatti et al. 2006).

In his research, Kitwood (2003) has developed Dementia Care Mapping (DCM), and this was used in the care providers' learning process to shed light on the relational meetings that occurred during the group music therapy course. In combination with the theoretical frame of reference and the video recordings, DCM was also used as the pedagogical approach and method for providing care providers with feedback.

During the feedback process, the researcher worked on providing the care providers with the tools needed to use music actively in their interaction with persons with dementia in different contact situations. During the feedback process, the researcher (who was also responsible for the learning process) and care providers also worked together to establish and implement action plans. The focus of the action plans was on the implementation of the care providers' new knowledge and skills in the specific care and nursing – and in care and nursing for the four participating residents as well as for all residents and care providers in the dementia care home. Furthermore, the action plans focused on the complex conditions and the context in which the intervention for persons with dementia took place, as well as on the learning aspects connected to the interaction between the care provider and the person with dementia. During the feedback process, the music therapist contributed with knowledge and perspectives from within music therapy.

During the learning process, the four participating care providers in the group music therapy course acted as "ambassadors", and they have thus been responsible for sharing their new knowledge and skills with their colleagues so as to facilitate the translation of the knowledge and skills into action and their implementation in the everyday lives of all residents in the group home.

Method

In terms of research strategy, the project is organized as a case study with an ethnographic approach. The research questions will be answered on the basis of a multi-strategy design in which both qualitative and quantitative data are included.

The quantitative data used includes measurements before and after the music therapy course carried out with the measurement instruments ADRQL (Alzheimer Disease-Related Quality of Life) and CMAI (Cohen-Mansfield Agitation Inventory). The objective of these measurements is to assess the influence of the residents' quality of life and wellbeing as well as changes in their behaviour. Furthermore, DCM was used as observation and feedback methods providing both quantitative and qualitative data. DCM-observations were carried out before and after the group music therapy course as well as at the third and seventh sessions.

The qualitative data comprises extensive data from the group music therapy course and the care providers' learning process, which has enabled data triangulation and careful analysis of the development of both the musical and interpersonal competences in care providers and the impact on the residents' quality of life and wellbeing.

The qualitative data material also comprises information on the participating residents' backgrounds, situations and life stories; video recordings of the nine music therapy sessions; DCM-observations; two DCM-feedback sessions; concluding meeting and five follow-up meetings; transcription of all video recordings; the music therapist's records, the researcher's field notes on the preliminary field observations in the dementia care home; information on the educational backgrounds and competences of the care providers prior to the research project and other data material, e.g. various summaries and material prepared during the research project process.

The overall analysis of the data was undertaken on the basis of a hermeneutic interpretation approach. The analysis and processing of data have been based on the following three areas:

- Quality of life and wellbeing of persons with dementia.
- The learning and development of musical and interpersonal competences of the care providers.
- Implementation and translation of new knowledge and acquired skills to the daily nursing and care practices through the application of concrete tools from the music therapy sessions.

In the area of quality of life and wellbeing of persons with dementia, the following analysis methods have been used: DCM analysis according to the standards of University of Bradford¹ (Brooker & Surr 2007; University of Bradford 2007); meaning condensation, narrative meaning structuring and creation of meaning through ad hoc methods (Kvale 1997; Kvale & Brinkmann 2009; Launsøe & Rieper 2005); and triangulation (Creswell & Clark 2011; Holstein 2003). The analyses of the areas of the learning and development of musical and interpersonal competences in the care providers and the implementation and translation of new knowledge and acquired skills are based on the analysis method of meaning condensation (Kvale 1997; Kvale & Brinkmann 2009; Launsøe & Rieper 2005).

¹ The data analysis standard of the University of Bradford is described in sections 5 and in annex 10 in the thesis.

Conclusions

Research questions 1 and 2

The care providers have obtained new perspectives on their relational meetings with the residents, which can be seen in that they have acquired new patterns of behaviour because they have learned to apply various musical/music therapeutic elements, which has changed their ways of viewing, understanding and acting as regards their relational meetings with the residents, contact situations and difficult nursing and care practices. These results are reflected in the following:

- a) The care providers have found new venues for “the meeting” with the residents, for instance using music for validation of feelings in residents with aggressive or agitated behaviour.
- b) The care providers have become aware of the significance of music as a non-verbal means of communication as well as of their own manners of expression, and have found that *musical presence* may assist them in calming down residents with agitated or aggressive behaviour, or in coping with difficult care situations (the concept of *musical presence* was coined during the care providers’ learning process; it covers the care providers’ practices of applying musical/music therapeutic elements in the relational meeting).
- c) The care providers have become more aware of adjusting their behaviour in relation to the residents; they have become more expectant, which have caused the residents to be more likely to act on their own terms and to show initiative.
- d) The care providers have become aware of the significance of “being” and presence as well as using non-verbal means of communication when spending time with residents.
- e) The care providers have realised the significance of their own pitch and tone of voice when they sing, and that humming a tune can be a useful approach to the meeting with the residents.
- f) The care providers use music and singing in a targeted manner in their interplay with residents; for instance through using *musical presence* in their relational meetings with residents or in unforeseen situations where singing can be used as a means of creating contact with residents, for distracting residents or for calming agitated residents.
- g) By using knowledge on arousal regulation, the care providers may assist agitated residents in lowering their arousal level or to stimulate residents in increasing their attention thresholds.
- h) The care providers’ attention to accommodating and allowing space for the residents’ emotional expressions, for example while listening to music, has been increased.
- i) By using their knowledge and experience on the four steps of a music therapy course, the care providers have learned to frame a care providing action and to work with structure and predictability in terms of non-verbal elements and cues in order to assist residents in coping with concrete difficult care situations.
- j) The care providers organise weekly music sessions based on their knowledge and experience from the four steps of a music therapy course.

- k) Furthermore, the material “*Musikalsk nærvær*”- *Musiske elementer omsat til praksis* [Musical presence – musical elements translated into practice], which was prepared during the learning process, provides an insight into the care providers’ overall toolbox of musical elements that can be translated and implemented in their practices, for instance using “care and nursing songs”.
- l) In addition, the care providers have reported that music and singing have become a natural element during the time they spend with residents.
- m) The care providers have realised that they are the most important instrument in terms of creating presence and positive relations with the residents.

With regard to the development of the competences in the care providers and the elements that have affected this process, it is evident that the competences in the care providers have been developed through a learning environment/community of practice that has allowed the possibility for new modes of awareness to be realised and that has enabled transformation of knowledge. For example, new modes of awareness have been realised through a learning environment/community of practice where shared professional reflections have been accommodated and care providers have been challenged; furthermore, these have been realised through the shared professional reflections in which the care providers have articulated their shared practices and repertoire in the community of practice, for instance by using their new knowledge in practice.

Knowledge transformation has occurred in situations where care providers have been challenged to act as one another's opponents in the analysis of video clips as well as in situations where care providers individually presented situations from their practice and argued on the basis of their new knowledge/their shared theoretical frame of reference.

In both the individual and shared reflection processes, new insight, knowledge and understanding have been gained by care providers through the application of the accommodative and transformative learning approach.

The organization of the learning context has also affected the development of the care providers’ competences; for instance, the care providers expressed that they learned much from working with the video sequences and linking these to the theoretical frame of reference and the DCM results. Furthermore, the following aspects have had a positive impact on the development of the care providers’ competences: the music therapist acting as a role model for the care providers; the person responsible for the learning process in the feedback process basing discussions on successful situations; the person responsible for the learning process, the music therapist or the manager giving the care providers positive feedback on their development processes; and the manager having actively participated and contributed to the care providers’ learning processes, which also had a positive impact on the level of involvement and motivation of the care providers.

The four care providers have managed to engage and motivate their colleagues by acting as role models and by involving their colleagues in concrete attempts to use music and singing, for instance in difficult nursing and care situations, but also in music sessions.

During the implementation process, the care providers have faced challenges and barriers, which they do not believe to be due to lack of motivation or interest. On the contrary, the challenges and barriers have been caused by external factors such as reorganization, pressure of work and illness in the dementia care home. Motivating the other care providers in the dementia care home who have not attended the music therapy sessions and thus have not had a strong and clear sense and experience of the new way of using musical elements in the relational meeting with the residents has been an issue. However, the four participating care providers' roles as "ambassadors" have contributed positively to involving and motivating colleagues in the translation and implementation of the new knowledge and skills into practice.

During the work with an action plan, 15 concrete initiatives for translating and implementing the new knowledge and skills in the entire group were launched:

1. Ensuring that the four participating care providers would act as ambassadors for translating and implementing the new knowledge and skills in the entire group of care providers at the dementia care home.
2. Having the person responsible for the learning process participate in the group meetings at the dementia care home.
3. Having the use of music and singing in relation to residents as a recurrent item on the dementia care home meeting agenda.
4. Working on the relational meeting with residents, and, likewise, testing and finding solutions for difficult care situations by using music and singing.
5. Working on *musical presence* in the relational meeting.
6. Organising weekly music sessions.
7. Organizing music sessions during evening shifts in future.
8. Focusing on articulating and acknowledging one another/colleagues when positive situations occur during the workday.
9. Purchasing music instruments for residents/giving residents instruments for Christmas.
10. Organising monthly violin concerts.
11. Recording positive experiences in a book on "Magic moments".
12. Focusing on harmful noise and sound stimuli.
13. Establishing an action plan for *musical presence* for all residents in the electronic nursing and care system Care for the purposes of documenting and disseminating ways in which music and singing can contribute in improving the residents' quality of life and wellbeing.
14. Carrying out a workshop for all care providers in order to ensure future implementation in the dementia care home.

15. Preparing posters and leaflets for informing on the project both internally and externally.

Research question 3

The analyzes showing signs, that the project has had a positive impact on the residents' behaviour, quality of life and wellbeing, that the development of musical and interpersonal competences in the care providers has been a focus point. This positive impact on the quality of life and wellbeing of residents has appeared when residents have been seen to be happier and more attentive in their daily lives, and have participated more actively when socializing with other residents. The difficult care situations have either been diminished or do not occur at all anymore. Furthermore, the following observations on the positive impact on the quality of life and wellbeing of residents have been registered:

1. The residents have become more capable of acting on their own initiative, expressing themselves as well as showing their resources and abilities due to the appreciative approach, presence and "being" of the care providers and the music therapist.
2. When an individual resident was invited into the "relational space" by the care provider or the music therapist, either through direct and attentive face-to-face contact, non-verbally or through music and singing, and the resident accepted this invitation, "present moments" occurred.
3. When the residents' preferences for particular songs and music were accepted.
4. When the care providers used positive elements from the residents' life stories during their interaction.
5. When the care providers used music or singing in the preliminary contact during the care tasks and for establishing a shared pulse and tempo, the residents coped better during difficult care situations.
6. Residents with agitated behaviour were calmed down through the care providers using validation and *musical presence* in their relational meeting.
7. The residents' attention was stimulated or regulated through music, which was used as a non-verbal focus or means of communication.
8. When the residents experienced moments of wellbeing, for instance during listening to music and when playing instruments, and they enjoyed being part of a community during the group music therapy course and the music sessions organized by the care providers on the basis of their experience harvested in the group music therapy course.
9. When the residents were given time to react in their interaction with care providers (due to a long latency period).

Overall conclusion

The implementation of the learning model has contributed to the development of the interpersonal and musical competences in care providers. The care providers have obtained new perspectives on their relational meeting with the residents, and they have acquired new patterns of behaviour and learned to apply various musical/music therapeutic elements; this has changed their ways of viewing, understanding

and acting as regards their relational meeting with the residents, interaction and difficult nursing and care practices.

In terms of the development of competences in care providers and the factors that have impacted this process, it can be concluded that the competences in the care providers have been developed through a learning environment/community of practice that has enabled the possibility for shared professional reflections and the challenging of one another. Another important factor was the learning context, which was based on successful situations and continuous feedback on the care providers' development processes. Additionally, working with the video sequences and linking these to the theoretical frame of reference and the DCM results have also contributed to the development of competences in the care providers.

During the learning process, the care providers worked on an action plan, and 15 initiatives for translating and implementing the new knowledge and skills in the daily nursing and care have been launched. One of the 15 initiatives comprises the fact that the four participating care providers have acted as ambassadors in the implementation process; this has contributed positively to translating and implementing the new knowledge and skills in the entire group of care providers at the dementia care home.

There are conclusions showing signs that the focus on developing the musical and interpersonal competences in the care providers has had a positive impact on the quality of life and wellbeing of the residents. The positive impact on the quality of life and wellbeing of residents has appeared when residents have been seen to be happier and more attentive in their daily lives, and have participated more actively when socializing with other residents. The difficult care situations have either been diminished or do not occur at all anymore.

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