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A flexible design

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EXPLORING PERSON-ATTUNED MUSICAL INTERACTIONS IN DEMENTIA CARE

A FLEXIBLE RESEARCH DESIGN

BY
JULIE KOLBE KRØIER

DISSERTATION SUBMITTED 2022



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JULIE KOLBE KRØIER

Julie K. Krøier was born in 1984 and lives in Copenhagen, Denmark with her family. In 2010 she graduated from Aalborg University with a master's degree in music therapy and in 2014 she became a guided imagery and music therapist. She has worked as a music therapist in dementia care, palliation, and psychiatry with a focus on GIM, community practices, and indirect music therapy practice. Julie has published about psychosocial dementia care in Danish and international journals and is the co-editor of the *Danish Journal of Music Therapy*.

While writing this PhD thesis, Julie worked as a music therapist and lecturer at the music therapy education at Aalborg University in Copenhagen.

ENGLISH SUMMARY

Exploring person-attuned musical interactions in dementia care. A flexible research design

This article-based PhD thesis constitutes an exploration of person-attuned musical interaction (PAMI) with persons with advanced dementia living in nursing homes. The thesis consists of three studies all exploring PAMI or elements of PAMI from different perspectives to ensure an understanding of the concept that can be applied in an interdisciplinary context. The findings of the three studies are presented in three articles.

The thesis aims to generate knowledge concerning interdisciplinary use of PAMI in dementia care. Research has shown that music therapy and music-based activities can have a positive effect on well-being and decrease neuropsychiatric symptoms for persons with dementia. The positive effects of music therapy and music-based activities may be transferred to caregiving contexts, with music therapists to supervise the application of musical interactions. From this indirect practice, in which music therapists support and supervise caregivers in how to apply musical interactions, it is still not clear which nonverbal elements caregivers can apply in their practice, and how caregivers experience the application of musical interactions in their practice.

The concept of PAMI served as a reflexive starting point for exploring nonverbal and musical interaction between the person with dementia and caregivers. The concept is grounded in the person-centered approach to care formulated by the psychologist Tom Kitwood and the theory of communicative musicality by Colwyn Trevarthen and Stephen Malloch.

In article 1, I examine the research literature concerning attunement between caregivers and persons with dementia, with the aim of exploring how attunement is used and understood. Six studies were included in a scoping review, and a meta-ethnographic analysis revealed three interwoven themes describing attunement in dementia care. The three themes were: (1) taking the perspective of the person with dementia and the importance of a person-centered approach, (2) developing understanding through an empathic approach, and (3) using musical parameters in the interaction; tempo adjustments, timing, and the use of music. The findings in the review indicate that person-centered care and musical parameters are embedded in the application of attunement in dementia care.

In the study presented in article 2, I explore how six expert music therapists experience nonverbal interactions between themselves and persons with dementia. Explorative focus group interviews were conducted with two groups of three music therapists in each. In the focus groups, the music therapists wrote lived-experience descriptions about their nonverbal interactions with persons with dementia. The transcripts from the focus group interviews were analyzed using a phenomenological approach, and the revealed findings were elaborated and validated by two of the participating music therapists using musical improvisation as an arts-based approach. The findings describe the music therapists' experience of nonverbal interactions with persons with dementia with five interrelated themes: (1) vitality, (2) disciplined subjectivity, (3) attunement, (4) therapeutic presence, and (5) validation.

In article 3 I describe how six professional caregivers apply and understand musical interactions in their practice. Through a collaborative learning process, the caregivers and I, in the role of music therapist, explored how musical interactions can be used and understood in daily interactions between the caregiver and the person with dementia. The caregivers contributed to the data generation by validating and elaborating narratives describing their application of musical interactions in their work. The workshops from the collaborative learning process were transcribed and included as data in the study. The data was analyzed by applying a hermeneutic ethnographic approach and revealed the following four themes that illuminate how the caregivers use and understand musical interactions in dementia care: (1) Vitality and communication, (2) connectedness through attunement, (3) a life story soundtrack, (4) from anxiety to reassurance.

The linking text outlines the overall research framework and background and includes a discussion of the applicability and the limitations of PAMI as a concept in indirect music therapy practice. Based on this discussion, I conclusively propose recommendations for PAMI training for caregivers. I suggest that music therapists facilitate the PAMI training, as they are specialized in interacting nonverbally and musically.

The thesis is part of the PAMI project located at Aalborg University and is funded by the Velux Foundation and Alzheimer-forskningsfonden.

DANSK RESUME

Undersøgelse af personafstemte musikalske interaktioner i demensomsorgen. Et fleksibelt forskningsdesign

I denne ph.d.-afhandling undersøger jeg Personafstemte Musikalske Interaktioner (PAMI) med personer med fremskreden demens, der bor på plejehjem. Ph.d.-afhandlingen består af tre studier som alle undersøger PAMI eller elementer af PAMI fra forskellige perspektiver for herigennem at sikre en forståelse af begrebet, der kan anvendes i tværfaglige sammenhænge. Fundene fra de tre studier præsenteres i tre artikler.

Formålet med afhandlingen er at generere viden om interdisciplinær brug af PAMI i demensomsorgen. Forskning har vist, at musikterapi og musikbaserede aktiviteter kan have en positiv effekt på trivsel og mindske neuro-psykiatriske symptomer for personer med demens. De positive effekter af musikterapi og musikbaserede aktiviteter kan overføres til andre sammenhænge, og musikterapeuter kan støtte omsorgsgiverne i at anvende musikalske interaktioner. I denne indirekte musikterapipraksis er det stadig ikke tydeligt, hvilke nonverbale elementer omsorgsgivere kan anvende i deres praksis og hvordan de oplever anvendelsen af musikalske interaktioner i demensomsorgen.

Begrebet PAMI fungerede som et refleksivt udgangspunkt til at udforske nonverbal og musikalsk interaktion mellem personer med demens og omsorgsgivere. PAMI er baseret på den personcentreret tilgang til omsorg formuleret af psykologen Tom Kitwood samt teorien om kommunikativ musikalitet af Colwyn Trevarthen og Stephen Malloch.

I artikel 1 gennemgår jeg forskningslitteraturen om afstemning mellem omsorgsgivere og personer med demens for at undersøge, hvordan afstemning bruges og forstås. Seks studier blev inkluderet i et scoping review, og en meta-etnografisk analyse viste tre sammenvævede temaer, der beskriver afstemning i demensomsorgen. De tre temaer var (1) Personer med demens' perspektiv og vigtigheden af en personcentreret tilgang, (2) at udvikle forståelse gennem en empatisk tilgang og (3) brug af musikalske parametre i samspillet; tempojusteringer, timing og brug af musik. Fundene fra litteraturgennemgangen indikerer, at personcentreret omsorg og musikalske parametre er indlejret i forståelsen af begrebet afstemning i demensomsorgen.

I artikel 2 undersøger jeg, hvordan seks musikterapeuter med erfaring i demensomsorgen oplever nonverbale interaktioner mellem musikterapeuter og personer med demens. Eksplorative fokusgruppeinterviews blev gennemført med to grupper af hver tre musikterapeuter. I fokusgrupperne skrev musikterapeuterne oplevelsesbeskrivelser omhandlende deres nonverbale interaktioner med personer med demens. Transskriptionerne fra fokusgrupperne blev analyseret med en fænomenologisk tilgang, og de fremkomne fund blev uddybet og valideret af to af de deltagende musikterapeuterne ved at bruge musikalsk improvisation som en kunstbaseret undersøgelse. Fundene beskriver musikterapeuternes oplevelse af nonverbale interaktioner med personer med demens med fem forbundne temaer: (1) Vitalitet, (2) disciplineret subjektivitet, (3) afstemning, (4) terapeutisk nærvær og (5) validering.

I artikel 3 beskriver jeg, hvordan seks professionelle omsorgsgivere anvender og forstår musikalske interaktioner i deres praksis. Gennem en kollaborativ læringsproces udforskede omsorgsgiverne sammen med mig hvordan musikalske interaktioner kan bruges og forstås i det daglige samspil mellem omsorgsgiveren og personen med demens. Omsorgsgiverne bidrog til datagenereringen ved at validere og uddybe fortællinger, der beskrev deres anvendelse af musikalske interaktioner i deres praksis. Workshops fra den kollaborative læringsproces blev transskriberet og inkluderet som data i studiet. Data blev analyseret ved anvendelse af hermeneutisk etnografi. Gennem analyserne blev fire følgende temaer, der beskriver, hvordan pårørende bruger og forstår musikalske interaktioner i demensplejen belyst: (1) Vitalitet og kommunikation, (2) forbundethed gennem afstemning, (3) et livshistorielydspor, (4) fra angst til tryghed.

Afhandlingens kappe skitserer den overordnede forskningsramme og baggrund og indeholder en diskussion af anvendeligheden og begrænsningerne ved PAMI i indirekte musikterapipraksis. På baggrund af diskussionen præsenterer jeg afslutningsvis anbefalinger til et PAMI-undervisningsprogram for omsorgsgivere. Jeg foreslår, at musikterapeuter faciliterer PAMI undervisningen, da de er specialiserede i at interagere nonverbalt og musikalsk.

Denne Ph.d.-afhandling er en del af PAMI-projektet på Aalborg Universitet og støttet af Veluxfonden og Alzheimer forskningsfond.

*

‘There is no use in trying,’ said Alice.

‘One can’t believe impossible things.’

‘I dare say you haven’t had much practice,’ said the Queen.

‘When I was your age, I always did it for half an hour a day.

Why, sometimes I’ve believed as many as six impossible things before breakfast.’

Alice in Wonderland (Carroll, 1998).

LIST OF PHD PUBLICATIONS

Article 1

Krøier, J. K., McDermott, O., & Ridder, H. M. (2022). Conceptualizing attunement in dementia care: a meta-ethnographic review. *Arts & Health, 14*(1), 32–48. <https://doi.org/10.1080/17533015.2020.1827276>

Article 2

Krøier, J. K., Stige, B., & Ridder, H. M. O. (2021). Non-verbal interactions between music therapists and persons with dementia. A qualitative phenomenological and arts-based inquiry. *Music Therapy Perspectives, 2021*, 1–10. <https://doi.org/10.1093/mtp/miab008>

Article 3

Krøier, J. K. & Ridder, H. M. O. (2022). “When the music is on, she is there”. Professional caregivers’ perspectives and use of musical interactions in caring for the person with dementia. *Approaches: An Interdisciplinary Journal of Music Therapy*. https://approaches.gr/wp-content/uploads/2022/05/Approaches_FirstView-a20220527-kroier.pdf

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And *tusind, tusind tak!* to Hanne Mette and Brynjulf for believing in me and my writing, much more than I occasionally did myself.

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This thesis is dedicated to the wonderful people living a life with dementia in nursing homes and the loving persons who work in dementia care. You have been the driving force of this research.

Julie Kolbe Krøier
Copenhagen, July 2022.

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CHAPTER 1. INTRODUCTION AND MOTIVATION

In this article-based thesis, I explore the role of person-attuned musical interactions (PAMI) between persons with advanced dementia, professional caregivers, and music therapists. PAMI represents a conceptual framework developed in collaboration with Professor of music therapy, Hanne Mette Ridder, in a research project at Aalborg University, Denmark 2016-2022, which this thesis is part of. The defined aim of the overall study was to expand knowledge of dementia caregiving by exploring nonverbal and musical communication, including gestures, tone of voice, and implicit expressions that often spontaneously take place between persons with dementia and their caregivers. PAMI, thus, describes reciprocal, nonverbal actions embedded in caregiving practices that we are often not conscious of. The concept of PAMI served as a reflexive starting point for the research project, and the acronym explains the theoretical pre-understanding of the research topic.

In this chapter, I present my personal motivation for conducting the research and the pre-understanding by which I encounter the research phenomenon. Furthermore, I introduce the acronym PAMI and outline the structure of the doctoral study.

1.1 PERSONAL MOTIVATION

Caregiving

Before I started studying music therapy, I worked as an untrained caregiver in nursing homes and homecare for elderly people in Denmark for several years. I had a genuine interest in, and curiosity about, working with elderly people and helping them have good days in the last part of their lives. I had different work shifts and worked in different regions of the country with diverse practices and work cultures. Most of the people I worked with had cognitive impairment and needed support for personal care and everyday activities. I found the work as caregiver very meaningful, and every workday I gained new knowledge about being human, and how to communicate with and approach people and situations very unlike my own. However, sometimes working in dementia care as a caregiver was also hard. I witnessed intense despair, suffering, pain, and anger. Often, I was able to help the person, but sometimes I was not even able to establish a connection with the person I was supposed to help. I have felt helpless and powerless, and witnessed other caregivers who felt the same way. In these situations, I experienced the limitations of verbal

language. When a person was very afraid, agitated, or confused, it did not improve the situation if I started to explain or talk a lot. What helped was to be present, patient, and containing, and sometimes maybe sing or hum. Through my employment as caregiver, I experienced how very simple nonverbal interactions such as music and touch could have a positive impact on the well-being of the person with dementia. It is, thus, my personal experience that nonverbal forms of interaction can be beneficial when working with persons with advanced dementia. My embodied experiences with care work, which were occasionally challenging, motivated me to explore nonverbal and musical interaction between caregivers and persons with dementia.

Music therapy

When I became a music therapist,¹ my tasks in dementia care changed from doing care work to conducting clinical music therapy with persons with advanced dementia, as well as supervising and teaching caregivers. I taught caregivers how to use musical interaction, such as singing, humming, and dancing, to reach those nursing home residents for whom the caregivers found it challenging to provide the needed care.

Most of the time, I collaborated with caregivers in care situations and activities centered on the person with dementia. My role was to support the caregivers and demonstrate how to apply music in the interaction with the person with dementia. In these situations, I tried to attune to both the person with dementia and the caregiver's need for support and guidance, as a kind of double attunement containing many nonverbal processes. Through this work, I became curious as to how musical interactions could be beneficial, and my motivation for commencing research in interdisciplinary² dementia care grew. My motivation is driven by an intention to unfold and explore tacit practices and hereby support caregivers in caring for persons with advanced dementia.

The following vignette is from my clinical practice as a music therapist. I supervised and supported caregivers in a nursing home as to how they could

¹ In Denmark, music therapists are educated at Aalborg University. The educational program is an integrated bachelor's and master's education of five years.

² I understand interdisciplinary dementia care to be a practice in which two or more professions learn about, from, and with each other to enable effective collaboration and improve health outcomes (WHO, 2010, p. 13).

use music-based approaches in care situations. In the vignette, I am participating in the care tasks to support and encourage the caregiver, Pia,³ in implementing musical interactions. The vignette serves to illustrate the practical experiences and knowledge that I bring with me into this study and is, furthermore, an illustration of a PAMI.

Alma has an advanced state of dementia. Pia is her caregiver, and I am participating in the care situation in order to support them in how to use musical interactions when relevant. This morning Alma is lying in her bed at the nursing home, and Pia and I are helping her get up. We try to turn Alma over, so that she will be lying on her back, and we will be able to wash her, but she is so afraid of being turned over that it is impossible. She screams and her body resists movement. Pia breathes deeply, she looks at Alma, and with a soft, breathy voice she slowly starts to hum the Danish song “Jeg ved en Lærkerede”.⁴ I quietly join in the humming, and we hum one verse slowly together while Pia strokes Alma’s arm. Alma quietly starts to hum the melody herself and seems to feel safer. When Alma starts humming, Pia and I adjust the volume of our voices so that Alma can hear herself. While we continue humming, Pia and I succeed in gently turning Alma over and can wash her.

1.2 THEORETICAL STARTING POINT

In the following, I present my theoretical understanding of music, music therapy, and research to identify my pre-understanding of the research topic, in order to secure and enhance transferability and clarify the position from which I approach the research phenomenon (Fleming et al., 2003). Furthermore, the section includes an introduction to the acronym PAMI.

Music

My ontological understanding of music is strongly inspired by musicologist Christopher Small (1998), who emphasizes that music is not an object or a work, but rather a living act of humanity. At the same time, I do not totally deny that musical objects and works can create important, aesthetic meanings, and I can see a dialogically interdependent relationship between music itself and the individual's experience of it, in which musical meaning is generated (Rolvsjord, 2006; Treilter, 1999, p. 377). In this thesis, my focus will primarily

³ All names are anonymized.

⁴ Danish folk tune (Bergstedt/Nielsen).

be on music as a relational and interpersonal phenomenon taking place between two or more persons, but this focus does not exclude the aesthetic meanings of music.

I am furthermore inspired by the music sociologist Tia DeNora's (2000) work on the concepts of affordances and appropriation in relation to engaging with music. Musical affordances are the resources provided by music and its materials in situations of use. DeNora's close collaboration partner, music therapist Gary Ansdell, points out that appropriation is how the affordances are used - the "takings" and "usings" of music (Ansdell, 2004, p. 73). Music therapists working in dementia care can support the appropriations of music by providing caregivers with musical affordances that they can apply in their everyday interactions with persons with dementia.

Music therapy

According to the American Music Therapy Association (2005), music therapy is a clinical and evidence-based intervention aimed to achieve individualized goals. A professionally trained music therapist facilitates music therapy interventions, which are systematically planned (American Music Therapy Association, 2005). In the exploration of PAMI, an interdisciplinary concept, I find it relevant to apply a broader definition of music therapy which can include everyday health-related uses of music. In this doctoral study, I will therefore apply the definition suggested by Stige (2002) of music therapy as an academic discipline and area of research. "Music therapy as a discipline is the study and learning of the relationship between music and health" (Stige, 2002, p. 198).

In section 2.2 I address the concept of indirect music therapy practice in dementia care. In dementia care, indirect music therapy practice is concerned with how music therapists can support and supervise caregivers in applying music-based approaches in their work with people with dementia (McDermott et al., 2018).

Research

I have previously worked with both qualitative and quantitative methodologies and was initially open to different approaches to exploring musical interactions in dementia care. However, as the PhD project proceeded, I became aware of the importance of taking emotionality and embodiment into account in the exploration of PAMI. Aging, cognitive degeneration, nonverbal interaction, and caregiving are complex matters and I see a need for suggesting a language for approaching these phenomena. By applying an explorative, interpretivist research approach, I have attempted to incorporate contextual,

relational, and bodily dimensions of dementia care into relevant descriptions of PAMI from different perspectives.

The PAMI research group

In 2014, the research project detailing an exploration of PAMI in dementia care was submitted to the Department of Communication and Psychology at AAU, Denmark. The project was approved and selected for further application submission to the Velux Foundations' human science research. By the end of 2015, the PAMI research project was granted funding and started in 2016, including the following positions: PI, Professor Hanne Mette Ridder, Post Doc Orii McDermott, PhD fellow Margrete Bach Madsen, and PhD fellow Jens Anderson-Ingstrup. I was invited to join the project and started my PhD project in December 2017. The PAMI project contains, in addition to my thesis, a PhD thesis by Anderson-Ingstrup (2020) and several publications. For a complete list of publications, see www.pami.aau.dk. During the project period, The PAMI research group also taught caregivers musical interaction in different organizational contexts. In 2019, Bryony Waters was enrolled in the PAMI project at Nottingham University, United Kingdom, with a PhD project regarding the development of a UK version of a PAMI training program that could be culturally appropriate for UK care homes.

In 2015, PhD Aase Marie Ottesen also received funding from the Velux Foundation for an action research project aiming to construct a video manual regarding the use of song and music in dementia rehabilitation (Ottesen, 2020). As we all researched the interdisciplinary application of music in dementia care, she was invited to join the PAMI group at all research seminars, so that we could share and discuss our projects in order to enrich the process and qualify findings.

PAMI

PAMIs are interactions. I therefore do not understand PAMI as music therapy, as there is no attempt to develop a therapeutic relationship. Nor do I see PAMI as music medicine where you offer a treatment or intervention. In my understanding, PAMI describes reciprocal, nonverbal interactions embedded in daily practice. In the following, I sum up the elements of PAMI that reflect how we have described PAMI in the research group.

P- Person: The PAMI-concept is based on a humanistic, person-centered approach to care defined by the English psychologist Tom Kitwood (1997). *Person-centered* care emphasizes the perspective of the persons with dementia and the importance of meeting their psychosocial needs. The caregiver's task is to support and acknowledge the person with dementia and in this way create

meaning and improve well-being. To emphasize the person-centered understanding of care, I will, throughout the thesis, mainly use the words person/s to describe the individual/s with dementia.

A- Attuned. Attunement in the PAMI context is inspired by the developmental psychologist Daniel Stern's concept of *affective attunement* and describes the ability to respond with language, sounds, gestures, and expressive behavior that matches another person's emotional state and needs (Stern, 1985). Attunement refers to the intersubjectivity that can occur between two persons and is relevant for supporting and validating the person with dementia. We regard attuned interactions as being verbal and nonverbal. Responsiveness and empathy are required for attuned interaction to take place, and it is essential that we are constantly aware of and assured that the person gives their permission to be part of, an attuned interaction (Ridder & Krøier, 2022).

M- Musical: The understanding of music and musical in PAMI is broad and based on the theory of *communicative musicality* (Malloch & Trevarthen, 2009). Communicative musicality describes the intrinsic musical features of human interaction such as tempo, timing, rhythm, and melody. We understand musical as a metaphor describing nonverbal aspects of communication in which musical elements are embedded (Ridder & Krøier, 2022). Musical elements are inherent in daily activities and care situations, and fundamental interactional elements from music therapy sessions might therefore be relevant for caregiving. Music therapists are trained in applying, and being explicit about, musical elements in interactions, and can therefore supervise and guide caregivers in how to apply musical interactions (McDermott et al., 2018).

I- Interaction: The concept of inter-action is key to a person-centered psychosocial approach and refers to the building of personal relationships and facilitation of mutual engagement (Kitwood, 1997). As the words inter and action describe, an interaction is a communicative action that takes place between two or more persons. To be part of meaningful interactions in everyday life is crucial for human well-being (Kitwood, 1997). We regard caregivers as having an important role in supporting the person with dementia in taking part in meaningful interactions. The caregiver can pick up communicative signals from the person with dementia and respond back in a way that makes the person with dementia feel acknowledged (Ridder & Krøier, 2022).

The current thesis is based on qualitative methods of unfolding, exploring, and verbalizing what PAMI is, how the phenomenon is experienced and understood, and how PAMI can be implemented into caregivers' daily work, taking the challenges of describing nonverbal interaction into account. The focus of the thesis is to enhance the understanding of psychosocial caregiving through the exploration of PAMI between caregivers, persons with dementia, and music therapists. It is our experience that nonverbal and musical interactions can be challenging to describe with words, as they happen intuitively and are based on tacit knowledge (Ridder & Krøier, 2022, p. 20). According to Kitwood (1997), interactions are microstructures that are often grounded on a preverbal and preconscious level, which explains why it can be difficult to implement achieved knowledge and competencies regarding nonverbal interaction into care practices.

1.3 THE RESEARCH DESIGN AND STRUCTURE OF THE THESIS

This thesis consists of three interrelated studies, all examining PAMI or sub-elements of PAMI from different perspectives. The three different perspectives on PAMI are: (1) the research literature, (2) six Danish music therapists with experience in dementia care, and (3) caregivers working in the specialized Dementia Care Unit Egebjerg, Denmark. These perspectives are each explored in three studies, and the findings presented in chapter five. The knowledge that emerged from studies 1 and 2 was used to inform a collaborative learning process for caregivers, focusing on how to apply musical interactions with persons with advanced dementia. The collaborative learning process at the nursing home, Egebjerg, provided the framework for exploring how caregivers use and understand PAMI in dementia care in study 3.

In the first chapter of the thesis, I describe my personal motivation and pre-understandings for commencing this research. In the second chapter, the clinical context of the studies is introduced. The chapter includes an overview of the literature concerning dementia and caregiving, music-based interventions, music therapy, and indirect music therapy practice, and leads to a presentation of my research questions and the aims of the study in chapter 3. Thereafter follows chapter 4 in which I describe the epistemology, the applied analytical methods, and the ethical considerations regarding the studies. In chapter 5, I present the findings from the three studies, which leads to chapter 6, in which the findings are integrated. In chapter 7, I discuss relevant aspects concerning the findings, their limitations, future implications,

and present recommendations for PAMI training. Finally, chapter 8 contains the conclusion of the thesis.

Figure 1 illustrates the research design with the three interrelated studies. The numbers in brackets refer to the chapters of the thesis. The colors illustrate the chapters and the three different perspectives on PAMI in the findings section.

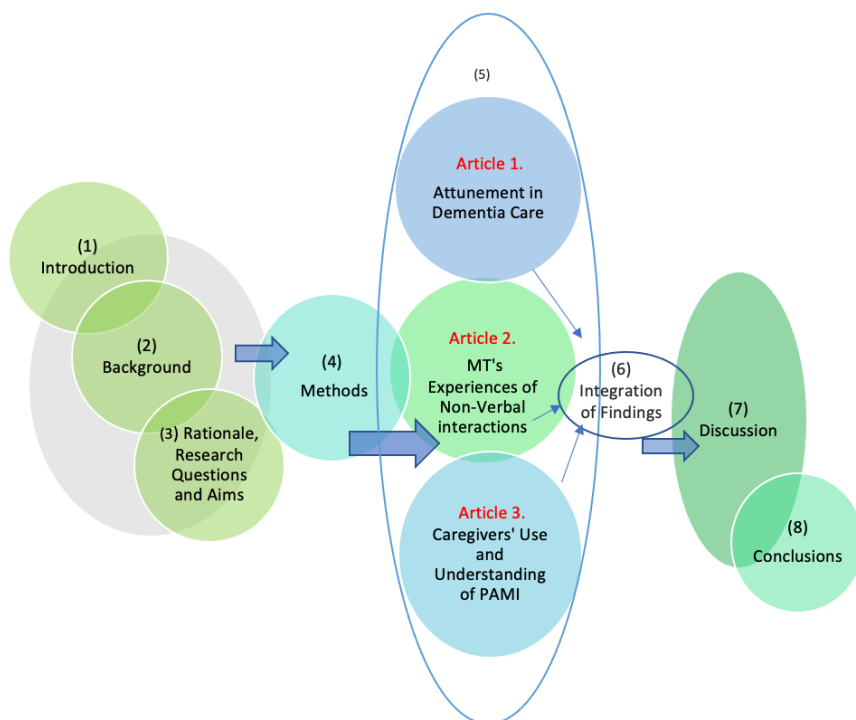


Figure 1. Overview of the research design.

CHAPTER 2. BACKGROUND

In the previous chapter, I introduced PAMI as a theoretical starting point for the thesis and presented my initial motivations and pre-understanding of concepts related to PAMI. In this chapter, I present literature and research findings concerning dementia, dementia care, and the use of music and music therapy in dementia care. I understand the need to support caregivers in applying PAMI in practice as a care team intervention. Therefore, I will also present research concerning interventions at the care team level as well as learning theory approaches that I find relevant in developing dementia caregiving. The aim of this chapter is to explain what dementia and dementia caregiving are and furthermore to outline how music and music therapy are used in this context.

2.1 DEMENTIA

According to the World Health Organization (WHO, 2021), 55 million people have dementia worldwide, and each year around 10 million cases are reported. In Denmark, 41,000 persons live in nursing homes and approximately 60 percent of the residents have dementia (DaneAge Association, 2021). There exists no cure for dementia at this point in time, and there is a need for developing and researching psychosocial interventions to address behavioral and psychosocial symptoms of dementia (McDermott et al., 2019). Persons with dementia need increasingly more care from family and friends to complete activities of daily living and to live valuable and meaningful lives throughout the course of the disease (WHO, 2021). WHO (2021) estimated the global societal cost of dementia to be 1.3 trillion US dollars in 2019, and the costs are expected to surpass 2.8 in 2030. Dementia, therefore, affects not only the individual, their families, and friends, but also has societal and economic consequences and presents an enormous worldwide health challenge (WHO, 2021).

In the diagnostic and statistical manual of mental disorders, DSM-5, dementia is described as a major neurocognitive disorder (American Psychiatric Association, APA, 2013), a syndrome due to disease in the brain, usually of chronic or progressive nature. Dementia describes a cluster of symptoms in which there are disturbances of higher cortical functions such as memory, orientation, comprehension, calculation, language, and judgment (Morris, 2008). Age is a risk factor, but dementia is a disorder that also can afflict persons below the age of 65 (Salem et al., 2012). When dementia is diagnosed, it is not possible to predict the speed or gravity of the disease, and how the

disease develops can vary (Morris, 2008). In addition to the cognitive disturbances that characterize dementia, clinical features also include clinical behavioral or psychological disturbances such as anxiety, apathy, depression, aggression, agitation, and irritability (Cerejeira et al., 2012; Morris, 2008).

Diagnosis of dementia is determined by different diagnostic tests and approaches, such as neurological and physical examinations, brain imaging and the use of the mini-mental state examination (MMSE) by Folstein et al. (1975). The MMSE is a well-established measurement that tests the cognitive functioning of a person with 30 simple questions and tasks.

The DSM-5 differentiates between subtypes of dementia with different etiologies (APA, 2013). In the following, I will briefly present the four most prevalent types of dementia, in order to give the reader a basic understanding of the pathogenesis and etiology of dementia and how the different types vary.

Alzheimer's disease

Alzheimer's disease is the most common form of dementia and is characterized by the build-up of amyloid-proteins in and around the brain cells (Freberg, 2019). As the brain cells become affected by the proteins, the number of neurotransmitters sending messages between the brain cells decrease (Danish Dementia Research Center, 2022). The most common early symptom of Alzheimer's disease is memory loss. As the disease advances through the brain, it leads to increasingly severe symptoms such as disorientation, confusion about time and space, mood and behavioral disturbances, and problems with eating, drinking, and walking (APA, 2019).

Dementias with Lewy bodies

Dementia with Lewy bodies and Parkinson's disease dementia are the second most common types of dementia in patients older than 65 (Walker et al., 2015). Dementia with Lewy bodies and Parkinson's disease dementia share the same pathophysiology and are, according to Walker et al. (2015) characterized by changes in thinking and reasoning, changes in movements, and by a high prevalence of neuropsychiatric symptoms such as visual hallucinations. Dementia with Lewy bodies has symptoms similar to Alzheimer's disease, but sleep disorders and blood pressure drops causing dizziness and falls are more common in persons with dementias with Lewy bodies as compared with persons with Alzheimer's disease (Walker et al., 2015).

Vascular dementia

Vascular dementia is caused when a stroke or thrombosis has blocked the blood flow in the brain and injured major blood vessels in the brain (O'Brien & Thomas, 2015). The symptoms of vascular dementia vary widely depending on the cause and where in the brain the injury has happened. Vascular dementia often co-exists with neurological changes linked to other types of dementia, such as Alzheimer's disease (O'Brien & Thomas, 2015).

Frontotemporal dementia

Frontotemporal dementia is diagnosed significantly earlier than Alzheimer's disease (Bang et al., 2015). The nerve cell deterioration caused by frontotemporal dementia is most prominent in areas that control behavior, empathy, social judgment, and foresight (Freberg, 2019). Other clinical features can be difficulties producing or comprehending language. Due to the changes in the personality of the person with frontotemporal dementia, this type of dementia is often very demanding for the families of the affected individual (Bang et al., 2015).

In my understanding of dementia, I am inspired by the biopsychosocial model defined by Downs et al. (2008). From the perspective of the biopsychosocial model, dementia is understood as a condition with interactive neurological and psychosocial components. Some biological and psychosocial factors are fixed, but they interact and together influence the process of dementia (Downs et al., 2008).

Psychosocial interventions

Even though there is no existing method for preventing, slowing, or treating dementia, there are medications that can help manage the symptoms (Freberg, 2019). Antipsychotic drugs are often used to treat behavioral and psychological symptoms of dementia, although research has only shown moderate beneficial effects, and serious side effects such as stroke, death, and sedation (Nørgaard et al., 2022). Social and physical activities, interventions, and support can have a beneficial influence on the symptoms caused by dementia and improve quality of life (Brooker & Latham, 2015).

McDermott et al. (2019) have examined recent reviews of systematic reviews of psychosocial interventions in dementia care published between January 2010 and February 2016. The authors conclude that there is good supporting evidence that exercise with sufficient intensity improves global physical and cognitive functions and activities of daily living skills. There is, furthermore, good evidence that group-based cognitive stimulation improves cognitive functions, social interaction, and quality of life, and that group activities can

support the social integration of people with dementia (McDermott et al., 2019).

2.2 DEMENTIA CARE

In his main work *Being and Time* (1927/2004), the German philosopher Martin Heidegger explores what it means to be human and introduces the concept of care as the fundamental core of being human. For Heidegger, the human does not exist isolated in the world,⁵ but *is-in-the-world* as an experience of connectedness where the being and the world cannot be separated. Heidegger uses language to illustrate the connectedness and unity of being-in-the-world. According to Heidegger, care is broader than just caring for other people. The concept of care is related to our attention in the context of time and pertinent to our existence (Loewy & Paulander, 2016). Human beings are not passive spectators of the world but are, from the outset, a form of existence that relates to the world in a caring way (Grelland, 2018, p. 269). Thus, the concept of care is a fundamental attitude to the world; an ontology, and from this basic attitude one can derive and develop care of a more specific nature (Grelland, 2018).

In *Being and Time*, Heidegger (1927/2004) also introduces the concept of *thrownness*. The human is thrown into the world in a particular culture at a given moment of human history. The feeling of being thrown can cause discomfort and surprise, and the human must therefore create a dwelling in which they can feel at home (Heidegger 1951/1971). Dwelling is, according to Heidegger (1951/1971), to remain and stay in place in a relationship with existence characterized by care. People with dementia can, due to the cognitive degeneration, be challenged in dwelling and need to be supported by caregivers (Jeong, 2020).

Person-centered care

The person-centered approach to care values the intrinsic worth of the individual, recognizes humans as social beings, and emphasizes the importance of mutual relationships (Kitwood, 1997). In Scandinavia, person-centered care is a well-known theoretical framework for understanding the person with dementia (Danish Dementia Research Center, 2021). The person-centered approach was established by Kitwood in the 1990s, and according to the British dementia researcher Dawn Brooker (2003), Kitwood can be considered a pioneer in the field of dementia care. Kitwood (1997) emphasizes

⁵ Heidegger does not refer to the world as a physical universe and society as such, but to the experienced world of the individual (Grelland, 2018).

the importance of developing dementia care from the perspective of the person with dementia. The theory is founded on concepts from humanistic psychology, such as unconditional positive regard, authenticity, and empathy (Rogers, 1961). According to Kitwood (1997), it is possible for persons with dementia to live a relatively good life, if they receive adequate support and help from their surroundings. Central to the theory of person-centered care is the concept of personhood. Personhood is similar to identity, but Kitwood stresses the social aspect that maintains the feeling of being a coherent individual. Sustaining personhood relies on the intersubjective relatedness created between the person with dementia and their family, friends, and caregivers (Kitwood, 1997).

Kitwood (1997) defines five basic psychological needs that are common to all human beings and important when caring for persons with dementia, as they are not always able to fulfill these needs themselves. The five basic psychological needs are comfort, identity, occupation, inclusion, and attachment. Kitwood also defines interactions that can meet these basic psychological needs and enhance the feeling of personhood. These interactions are called positive person work and could, for instance, be play, validation, and holding. In contrast, interactions that decrease personhood and do not fulfill the basic psychological needs are defined as malignancy and may include treachery, disempowerment, and infantilization (Brooker, 2007). Kitwood (1997) emphasizes that malignancy rarely occurs intentionally, but that it can become interwoven into the care culture.

Livingston et al. (2014) demonstrated in a literature review the clinical effectiveness and cost-effectiveness of the person-centered approach regarding agitation. However, even though the person-centered approach has been shown to be beneficial in reducing agitation, it can be challenging for caregivers to translate the concept of person-centered care into concrete actions in daily life in the care homes (Brooker et al., 2016; Brooker & Latham, 2015). Livingston et al. (2014), therefore recommend the development and evaluation of manual-based staff training in care homes, which should focus on changing care home culture.

Challenges in dementia care

Taking care of persons with dementia can be a demanding and complex job that requires specialized competences in nursing and psychosocial approaches to support and help the person in a relevant and respectful way (Allan & Killick, 2014). According to Lloyd et al. (2014) many caregivers only receive basic training, which might explain cases of mistreatment and calls for improving the quality of dementia care for people living in nursing homes. At

the same time, Europe is facing a huge challenge with a growing aging population, which increases the required number of employees in dementia care (Laing & Buisson, 2007). The need for improving care quality, coupled with the projected increase in the number of people with dementia entering care homes, puts pressure on caregivers to provide good care and meet complex needs (Coates & Fossey, 2016; Quince, 2013).

People working in the helping professions have been found to be vulnerable to burnout, and studies have suggested a connection between burnout and dementia care (Ballard et al., 2000; Duffy et al., 2009). Lack of meaningful reciprocal interactions between the caregiver and the person with dementia could play an important role in emotional stress and supporting caregivers in how to perform nonverbal interactions with the person with dementia is therefore relevant (Coates & Fossey, 2016).

2.3 THE USE OF MUSIC AND MUSIC THERAPY IN DEMENTIA CARE

In a report by WHO about the evidence for the role of the arts in improving health and well-being, Fancourt & Finn (2019) highlight the use of music in dementia care. Caregivers report that they use singing and music intuitively in their practice (Heiberg, 2015; Jost et al., 2010), and in several studies describing interaction and nonverbal communication between the caregiver and the person with dementia, the use of music as beneficial for the compliance of care tasks is mentioned (Hammar et al., 2011; Häggström et al., 1998; Isaksson et al., 2013; Jost et al., 2010; Palmer, 2013).

The rationale for music-based activities is well described (Laitinen et al., 2012; McDermott, 2014; Van der Steen et al., 2017; Werner et al., 2017). Even with advanced dementia, many nursing home residents can still sing, dance, and remember music with a significant value to them. Jacobsen et al. (2015) have highlighted the surprisingly well-preserved musical memory of persons with Alzheimer's disease in a review of studies of functional magnetic resonance imaging of brain responses to both new and long-known music. The review showed an overlap of musical memory regions with areas that are relatively spared in Alzheimer's disease and can thus explain the preservation of musical memory that many persons with Alzheimer's demonstrate (Jacobsen et al., 2015).

McDermott et al. (2014) have explored what music means for persons with dementia, their caregivers, families, and music therapists. The study concluded that music allows persons with dementia to "be who they are", have

“meaningful here and now experiences”, and experience “connectedness” with their surroundings (McDermott et al. 2014, p.715).

The question of why people with dementia experience meaningfulness and connectedness in relation to music may be explained by the theory of communicative musicality developed by Malloch and Trevarthen (2009). Communicative musicality is an innate capacity that allows human beings to take part in nonverbal interactions signified by pulse, pitch-contour, timbre, and rhythm. Musicality is, thus, not only linked to singing or playing an instrument, but also to how we interact nonverbally through gestures, imitation, and tone of voice (Malloch & Trevarthen, 2009). The communicative potential of musical interaction may therefore offer a relevant treatment in addressing the psychosocial needs of persons with dementia (Ridder et al., 2013; Ridder, 2016; Ridder, 2019).

Music-based activities and music therapy

According to McDermott (2014), it can be difficult to distinguish between music-based activities and music therapy interventions for persons with dementia in literature reviews. In this section, I therefore describe studies regarding both music-based activities and music therapy in dementia care.

Music-based activity studies are often included in systematic reviews on non-pharmacological and psychological treatment for behavioral and psychological symptoms of dementia (BPSD) (Douglas et al., 2004; Hulme et al., 2010; Livingston et al., 2005; O’Connor et al., 2009). Generally, these studies show that music-based activities have a positive effect on the well-being of persons with dementia. However, the music-based interventions are often poorly described, and an inconsistency exists in the researchers’ and health professionals’ understanding of music-based activities for health benefits (McDermott, 2014).

A primary goal of music therapy in dementia care is to meet the psychosocial needs of the person, and the interventions are often based on person-centered care, emphasizing the importance of validation, respect, and creating a warm welcoming atmosphere in the therapeutic setting (Janus et al., 2020; Ridder et al., 2013; Ridder, 2016). Music therapy sessions may consist of singing familiar songs, improvising on instruments, listening to music, or music and movement (Aldridge, 2000; Kvamme, 2017; Ridder, 2019). The activities are carefully attuned to the person with dementia according to the defined goals of treatment (Janus et al., 2020; Ridder, 2019).

The Danish Health Authority (2019) recommends trying music therapy in the treatment of BPSD symptoms and recent studies have demonstrated that music therapy sessions can improve emotional well-being, social engagement, and quality of life and reduce depressive symptoms associated with dementia (Janus et al., 2020; Pedersen et al., 2017; Raglio et al., 2010; Ridder et al., 2013; van der Steen et al., 2017; Vink et al., 2013; Zhang et al., 2017). According to van der Steen et al. (2017), many of the studies included in the systematic reviews are, however, of low quality and there is a lack of precise detail on the intervention offered. Li et al. (2019) conducted a systematic review including seven studies from five different countries. The findings of the systematic review revealed that music therapy of 6-12 weeks' duration significantly reduced depressive symptoms, but music therapy without a music therapist involved did not significantly reduce depression at any time (Li et al., 2019). Lam et al. (2020) conducted another systematic review on the effects of music therapy on patients with dementia. This study demonstrated that music therapy has an effect on verbal fluency and significantly reduces anxiety, depression, and apathy (Lam et al., 2020). A low number of participants and lack of standardized music therapy is, however, mentioned by Lam et al. (2020) as a major limitation. Vink & Hanser (2018) suggest that more detailed descriptions of the provided music therapy interventions could make it easier to replicate studies, which could provide a clearer conclusion on the benefits of music therapy.

Approaches using recorded individualized music, such as individualized music intervention for agitation (IMIA) (Gerdner, 2000, 2012), have shown to be relevant in terms of preventing agitation and improving quality of life for persons with dementia. However, the effect of IMIA depends on knowing the music preferences of the person with dementia, which is not always possible due to the person's cognitive decline, and depends on help from family (Gerdner, 2012). Music & Memory (2022) is another approach that instructs how to apply music in dementia care, and which has received positive media attention (Kwak et al., 2020b). However, according to a prospective randomized controlled crossover study by Kwak et al. (2020a), no statistically significant effect on agitation and BPSD could be found by the application of Music & Memory.

Findings in Danish and international contexts show that the use of music can be relevant in activities and care situations with persons with dementia and that music therapists may support the caregivers in the application of music (Beer, 2017; Beer et al., 2012; Ottesen, 2014; Ray et al., 2016). In a study on the effects of individual music therapy, Hsu et al. (2015) used video presentations to communicate elements from individual music therapy

sessions to professional caregivers. According to Hsu et al. (2015), the video presentations aimed at extending the weekly music therapy session into the caregivers' day-to-day practice. The caregivers reported that they gained enhanced interaction techniques and enhanced communication with the residents (Hsu et al., 2015).

Ray et al. (2016) describe how the reduction in agitation caused by music therapy can be sustained through the facilitation of music to aid in caregiving by professional caregivers. According to Beer (2017, p.190), the use of music in care situations is highly relevant, and caregivers may become more confident in their care abilities by learning how to listen to and mirror the melodic vocalizations of a person with dementia, for example.

Music therapeutic caregiving (MTC) is a technique in which the caregiver sings to the person with dementia during care situations (Brown et al., 2001). The goal of MTC is to improve the ability to be compliant in care situations, using songs selected by trained caregivers. According to Hammar et al. (2011), MTC can help caregivers provide better care due to the regulating influence singing can have on the person with dementia. With a search on "music therapeutic caregiving" in the databases CINAHL and SCOPUS, I found no studies after 2011 where MTC was applied, and no studies with these specific techniques have been conducted outside of Sweden.

Indirect music therapy practice

As public interest in music in dementia care has increased, the number and diversity of music-based activities has grown (International Longevity Centre-UK, 2018). Many music-based activities are offered by non-music therapists, and ways to ensure the quality and relevance for persons with dementia are not explained (McDermott et al., 2018). Music therapists can play an important role in providing help and supervision for various professionals such as caregivers, musicians, and social workers with an interest in music-based activities and interventions in dementia care. This way of working is labeled "indirect music therapy practice" (Bunt & Stige, 2014, p. 186). Indirect music therapy practice describes broader music therapy tasks such as supervision and consulting (Bunt & Stige, 2014). It is a new term that has come into the music therapy vocabulary as public interest for music-based interventions for health has increased (McDermott et al., 2018). Whereas direct music therapy practice in dementia care refers to music therapy treatment aimed, for example, at improving social engagement, indirect music therapy is concerned with how music therapists can support caregivers in applying music-based interventions in care situations or activities for the benefit of the person with dementia (McDermott et al., 2018). Indirect music

therapy practice can have many different formats and includes volunteers, families, and professional caregivers (Beer, 2017; McDermott et al., 2018; Ottesen & Kroier, 2018). A common way of intervening on a care team level is to teach and train groups of caregivers in how to apply music, but supervision and models with apprenticeship also exist (Beer, 2017; Ottesen, 2014; Stige, 2018). McDermott et al. (2018), highlight that when working with indirect music therapy practice, the music therapist must be aware of the potential harm that can be caused by using music and inform the caregivers about this risk.

Qualitative studies have demonstrated that persons with dementia remember how caregivers approach them, but not always what the caregivers did (Brooker, 2003; Brooker & Latham, 2015). According to Aldridge (2000), music therapy is essentially about the way you interact, and indirect music therapy practice could therefore be a relevant way to teach caregivers *how* to perform the qualities from person-centered care that can be difficult to implement and sustain (Brooker, 2008; McDermott et al., 2018, p. 273).

Ottesen (2014) has developed a learning model focused on improving the interaction between the person with dementia and the caregiver. The learning model was based on group music therapy sessions followed by cross-disciplinary cooperation between the music therapist, the caregivers, and the researcher who was responsible for the learning process (Ottesen, 2014). During the research project, the caregivers became more aware of how to use attuned musical interactions that met the psychosocial needs of the person with dementia. Furthermore, the persons with dementia showed signs of improved well-being because of the research project (Ottesen, 2014).

Indirect music therapy practice calls for a highlighted focus on the health systems that support the person with dementia and in which the caregiver is working (McDermott et al., 2018). Stige (2018) refers to this way of working as having an ecological perspective on music therapy practice, in which consultations and collaborations with the local context are integrated in practice and can make a difference not only for the person with dementia, but also for the community that the person is part of. In addition, Stige (2016) puts *the nursing home ecology* in a socio-cultural perspective by connecting musicking, communicative musicality, and musical traditions.

2.4 CARE TEAM INTERVENTION

Applying new ways of working requires support, training, and space to reflect on one's work (Mezirow; 2012; Schön, 1983). Organizational, psychological

interventions for care teams could be, for example, staff training, advice giving, consultancy, mentoring, or supervision (Brooker, 2008). The person doing the intervention will often be a psychologist but could, according to Brooker (2008, p. 596), be any kind of professional acting as a change agent. The caregivers impact the psychological health of the residents in care homes and, working on a team level, can support the caregivers in providing better care, which can benefit the well-being of the person with dementia (Brooker, 2008).

The person-centered approach provided in the care of the person with dementia can be seen in parallel to working with caregivers at the team level. Humanistic, psychological concepts such as unconditional positive regard and seeing the caregivers as experts about themselves and their work and “the therapist as a provider in the team’s search for self-actualization” can be a person-centered approach to care team intervention (Brooker, 2008, p. 598). The process of change is thus entrenched in the relationship that develops between the caregivers and the provider of the care team intervention.

One reason that change of practice in dementia care can be challenging is the implicit nature of care work and relational competency. As dementia progresses, verbal conversations become increasingly difficult, moving towards a loss of verbal language (Kempler, 1995). The person living with dementia therefore depends on the caregiver’s ability to comprehend nonverbal interactions with the individual with dementia. Nonverbal interactions based on facial expressions, body language, gestures, and sounds are important for the social inclusion of the person with dementia, but how we relate to and approach each other is often difficult for the caregiver to verbalize and reflect upon (Ottesen & Krøier, 2018; Ridder & Krøier, 2022; Schön, 1983). Educational researcher, Donald Schön (1983), describes practitioners’ way of doing certain actions repeatedly, and the knowledge they gain from this process as *knowing-in-action*. A risk of this way of working is that the care tasks and certain ways of relating become automatized, without reflection on when they are relevant and when they are not. However, it is possible – during the process – to reflect upon the practice and to question what is happening. This process Schön (1983) calls *reflection-in-action*, and the process of subsequently reflecting about practice, with the aim of making practice more conscious, Schön calls *reflection-on-action*. In this process, video presentation can be a relevant approach to enhance the caregivers’ reflections-on-action (Hsu et al., 2015; Ottesen & Krøier, 2018). When the caregivers are shown video clips, relevant tacit knowledge can be communicated and, when discussing the video presentation, the caregiver can build a vocabulary for expressing tacit relational practices.

Bird et al. (2016) conducted a review on the impact of care staff interventions on quality of care and the quality of life of the residents receiving the care. The review showed that the level of intervention needed depended on the aim of the care staff intervention. The studies reviewed suggested that reducing restraint and improving the interaction between the care staff and the resident could be the most promising goals. According to Bird et al. (2016), care staff intervention with didactic education alone will generally be useless if not combined with mentoring and on-site support.

2.5 LEARNING THEORY IN RELATION TO CARE TEAM INTERVENTION

Supporting caregivers in applying PAMI in their practice may, as described in the introduction of chapter 2, be understood as a care team intervention. Integrating care team intervention into care practice can, however, as mentioned be difficult, as the interactional and relational competencies often are tacit knowledge (Schön, 1983). According to Schön (1983), we may understand caregiving practices as based on knowing-in-action, and if these interactions should be used as professional reflection-on-action, learning will not occur only by reading and writing about PAMI. Becoming conscious about why, how, and when to apply PAMI calls for reflection about one's own practice and a shared professional language for describing and communicating about practice. In the following sections, I present learning theory approaches that I find relevant when aiming to increase reflexivity and communicate implicit and embodied practices in dementia caregiving.

Transformative learning is a concept developed by the North American psychologist, Jack Mezirow, in the 1990s and inspired by the Carl Rogers' concept of significant learning. According to Rogers (1980), teaching must be facilitated and not forced. Transformative learning is defined as the expansion of consciousness by transforming the learner's meaning perspectives, frames of reference, and habits of mind (Mezirow, 2006). A transformation takes place during the learning process. The transformative process involves rational thinking and understanding, but also emotions and relationships. Mezirow was inspired by the women's liberation movement in the United States in the 1970's and referred to the development of consciousness and liberation from conditions that caused societal and personal suppression of women (Illeris, 2013, pp.148-149). The theory was defined in the context of adult teaching, and even though the first definition of transformative learning is rather cognitive, Mezirow (2012) later stresses the embodied and emotional aspects of learning and the importance of creating a safe learning environment.

Critical reflection is an important part of transformative learning and supports the learner in exploring new opportunities for action and expanding their consciousness. To reflect critically on one's own experiences and try out new opportunities can transform the learners' view of themselves and the world (Musaeus & Kristensen, 2005). Learning is thus more than a cognitive and rational action but takes place through personal engaged participation that can potentially create transformation for the learners and the context they are in (Illeris, 2013). For the transformation to take place, it is crucial that the learners find it meaningful to engage themselves in learning and be supported in critical reflection, which can create new opportunities (Musaeus & Kristensen, 2005). Mezirow (2012) describes further how art, music, and dance can be alternative approaches to learning, because they facilitate experiences of inspiration and empathy.

Dutch care theorist Annemarie Mol (2010, p. 278) recommends tracing and articulating ways of caregiving that are already at work within care practices and learning from and building on these. A relevant approach could, therefore, be *experiential learning*, which, similar to transformative learning, integrates the experiences of the student into the learning process. This learning theory is defined by the North American psychologist David Kolb. According to Kolb (1984, p. 38), "Learning is the process whereby knowledge is created through the transformation of experience". Learning is a circular process with constant relearning, in which the learner reflects critically on concrete experiences, then learns from the experiences through abstract conceptualizing and finally experiments pragmatically by trying out the achieved knowledge (Kolb, 1984).

PAMI is an embodied phenomenon that can include movement, sensing, and singing. When training PAMI, embodied teaching, including embodied experiences such as movement and music, can therefore support and train the caregivers in implementing PAMI and achieving embodied PAMI experiences. Embodied learning refers to pedagogical approaches that focus on nonmental and emotional aspects of learning and include bodily expression (Paniagua & Instance, 2018). The approach can be applied in combination with transformative and experiential learning, offering teaching based on sensorial, emotional, and aesthetic experience rather than verbal reflection. Many educational programs separate mind from body, and in schools and colleges the learner sits, watches, listens, and writes (Macedonia, 2019). In embodied learning, which is based on embodied cognition, the body and mind are equally involved in the learning process. Creativity and expression are the driving forces, and artistic practices such as dance, theater, and music can be

involved and are likely to engage the learner more (Paniagua & Instance, 2018). Including embodied approaches and art in the training of caregivers might furthermore enhance creative approaches to care (Windle et al., 2019).

CHAPTER 3. RATIONALE, RESEARCH QUESTIONS AND AIMS

The context and background for the exploration of PAMI is presented in chapter two, to situate the concept and its interdisciplinary implications. Based on findings in previous research in dementia care and music-based activities and music therapy, this chapter presents the rationale, the research questions, and aim of the current PhD study.

3.1 RATIONALE OF THE STUDY

Dementia creates an enormous health challenge, with psychological, physical, social, and economic impacts on the person living with dementia, but also for people who work as caregivers and for society (WHO, 2021). Taking care of persons with dementia is a complex job and requires diverse competencies of the caregiver in psychosocial approaches (Kitwood, 1997; Ward et al., 2008; Windle et al., 2019). Many professional caregivers only receive basic training and there is a need to improve the training of caregivers and to acknowledge care work to a greater degree (Banerjee et al., 2015; Coates & Fossey, 2016; Windle et al., 2019).

According to the person-centered understanding of dementia, it is possible to decrease behavioral and psychological symptoms of dementia by meeting the psychosocial needs of the person with dementia (Ballard et al., 2018; Livingstone et al., 2014; Kitwood, 1997; Ward et al., 2008). Through meaningful and mutual interactions that strengthen personhood, psychosocial needs can be met (Hägström et al., 1998; Kitwood, 1997; Palmer, 2013; Wu et al., 2020). Kitwood (1997) defines positive interactions that caregivers can apply in their daily communication with persons living with dementia. However, it can be challenging to learn how to conduct positive and nonverbal interactions, and there is a need for training and support of caregivers (Livingstone et al., 2014; Lloyd et al., 2014; Wu et al., 2020).

Music-based activities are widely used in dementia care with a positive effect on well-being for persons with dementia (Douglas et al., 2004; Hulme et al., 2010; Livingston et al., 2005; O'Connor et al., 2009). Music therapy has shown to be beneficial in dementia care, and although methodological challenges exist, some positive effects on apathy, agitation, and depression

have been demonstrated (Lam et al., 2020; Li et al., 2019; Ridder et al., 2013, Zhang et al., 2017). The positive effects of music-based activities and music therapy can be transferred to other contexts with the support of music therapists, and this practice can be labeled as indirect music therapy practice (Beer, 2017; Bunt & Stige, 2014; Hsu et al., 2015; McDermott et al., 2018; Ottesen & Krøier, 2018). In indirect music therapy practice, the music therapist supports the caregiver in how to apply music-based intervention for the benefit of the person with dementia. The term is relatively new, and even though studies have demonstrated that music and singing can be useful in care situations, it is still not clear which elements of music therapy, and which nonverbal elements, can be transferred; how caregivers can apply musical interactions in their practice; and how the caregivers experience the application of musical interactions in dementia care (Hammar et al., 2011; Hsu et al., 2015; McDermott et al., 2018; Ottesen & Krøier, 2018).

Care team intervention can be approached in various ways. Person-centered care can be provided in parallel to care team interventions by integrating concepts from humanistic psychology, such as unconditional positive regard, into the intervention (Brooker, 2008). Often, caregiving is based on tacit, intuitive knowledge, and it can be challenging to articulate and communicate to colleagues (Ottesen & Krøier, 2018; Wu et al., 2020). This aspect calls for approaches to learning that support the caregivers in reflecting about their practice, to create a shared professional language for communicating ways of meeting the psychosocial needs of the person with dementia.

Person-attuned musical interaction (PAMI) is a conceptual framework to describe the nonverbal and often musical interactions happening spontaneously between caregivers and persons with dementia. The application of PAMI in dementia care might support the nonverbal interaction between the caregiver and the person with dementia. To access and apply musical interaction systematically in dementia care requires an exploration and verbalization of PAMI in the context of person-centered care.

3.2 RESEARCH QUESTIONS

Presentation of the clinical context, the current use of music-based activities and music therapy in dementia care, and approaches to care team intervention and learning theory leads to the research question:

Which theoretical, clinical, and methodological elements define person-attuned musical interaction (PAMI) with persons with advanced dementia living in nursing homes?

This main question is approached through the following three questions:

1. How is attunement used and understood in published dementia care research?
2. How do music therapists experience nonverbal interactions in their practice with persons with dementia?
3. How do professional caregivers use and understand person-attuned musical interactions in dementia care?

3.3 AIMS OF THE RESEARCH

The overall purpose of the research is to explore which theoretical, clinical, and methodological elements describe PAMI as applied with persons with advanced dementia living in nursing homes. Three corresponding methods are identified to answer the research questions. The results of the three studies may provide information on how caregivers integrate PAMI in care practices and contribute to recommendations on how to teach and train PAMI. The aims of the thesis are:

- To conduct a review of the research regarding attunement in dementia care (study 1)
- To explore how music therapists experience nonverbal interactions with persons with dementia (study 2).

Findings from studies 1 and 2 generate knowledge about the ontology of PAMI. This knowledge is integrated into a collaborative learning process applied in study 3. In the context of the learning process, a central aim of the thesis is to:

- explore how caregivers use and understand person-attuned musical interactions in their everyday work with persons with advanced dementia living in care homes (study 3).

By wrapping up and integrating the findings from the three studies, the discussion will lead to a set of recommendations for how to train caregivers in PAMI in a way that contributes to person-centered care in nursing homes.

CHAPTER 4. EPISTEMOLOGY, METHODOLOGY AND ETHICAL CONSIDERATIONS

The main purpose of chapter 4 is to give a meta-reflective perspective on the epistemology and the methodological approaches used to answer the research questions of this PhD study. First, I introduce the applied epistemology, the flexible design, and its implications. I then present the methods applied in the three different studies. Finally, I describe ethical considerations linked to conducting the three studies of the thesis.

4.1 EPISTEMOLOGICAL PERSPECTIVES

Epistemology originates from Greek and means knowledge, acquaintance, or understanding (Matney, 2019). In this doctoral thesis, I focus on the kind of knowledge that Aristotle called *phronesis* (Ridder & Bonde, 2019). *Phronesis* is knowledge of everyday life, “practical wisdom about being in the world” (Ridder & Bonde, 2019, p. 391). This knowledge is, however, often tacit, and the current thesis is therefore exploring and verbalizing how PAMI is used in dementia care.

Pragmatism

The three studies in the thesis are situated in practice and can be referred to as *real world research* (Robson & McCartan, 2016). I endeavor to understand PAMI as it is unfolded in the lived-in reality of music therapists and caregivers working in dementia care. According to Robson & McCartan (2016, p. 3), real world research can shape and influence the world, as well as explain why the world is in the shape that it is. This means, in the context of the current thesis, extending the understanding of PAMI and exploring how PAMI, as a reflexive, conceptual framework, can be applied to understand nonverbal, musical interactions in dementia care. Throughout the thesis, knowledge of PAMI is widened, and tacit practices are attempted to be verbalized.

Pragmatism serves as the epistemological foundation for the research conducted. Pragmatism was, according to North American philosopher and psychologist William James (1907), first introduced by philosopher Charles Peirce in the article, “How to make our ideas clear”, (Peirce, 1878/1955). In pragmatism, the focus is on what we do, instead of what we think about it (Brinkmann, 2006). Fundamental to pragmatism is an emphasis on the

practical usefulness of any statement and on how to obtain clarity (Peirce in Anderson, 2013). North American philosopher John Dewey stresses this aspect of pragmatism by stating that to discover the meaning of an idea we must ask for its consequences (Dewey, 1948, p. 132). Peirce, James, and Dewey were all interested in examining practical consequences and empirical findings to understand the implications of philosophical positions (Johnson & Onwuegbuzie, 2004). High regard is placed on the reality and influence of the human's inner world, and knowledge is seen as being both constructed and based on the reality that we live in. Traditional dualisms such as free will vs. determinism are rejected in pragmatism (Johnson & Onwuegbuzie, 2004). Instead, the pragmatic researcher seeks more moderate or commonsense solutions according to how well they function, and truth is basically defined as "what works" (Robson & McCartan, 2016, p. 28).

Pragmatism has to a great degree informed *the practice turn* in social sciences and philosophy (Gimmler, 2012; Nicolini, 2012). The concept of practice turn refers to several different theories such as science and technology studies (STS), Bourdieu's sociology of practice, and Laurent Thevenot's neopragmatism, but also reinterpretations of Heidegger's philosophy of existence (Gimmler, 2012). In these approaches, practices are highly related to the actors, routines, and habituations such as objects and tools involved in the practices. Practice turned approaches can thus be said to have "bodily anchored and materially intertwined practices which are centrally organized around common practical understandings" (Schatzki 2001, p. 12).

The research processes in the current thesis involve continuous alternation between an inductive and deductive approach and can be defined as abduction (Robson & McCartan, 2016). Abduction is often used in pragmatism and was initially described by Peirce (Burks, 1946). When working in an open system such as a nursing home (and not in a laboratory), the configurations of structures and processes are constantly changing, which makes prediction almost impossible. However, the past can still be explained by an abductive reasoning process that alternates between theory and observation (Robson & McCartan, 2016). In abduction, a case is interpreted from a theoretical central pattern that can explain the specific case. New observations and cases can then strengthen the interpretation (Alvesson & Sköldbberg, 2018).

A relevant question to ask, when applying pragmatism as epistemological meta-theory,⁶ is for whom is a certain action or intervention useful? (Mertens, 2003). The current thesis was written for music therapists supervising and training caregivers, but other professionals working or researching in dementia care might also find the conceptual framework of PAMI and the applied methods of exploration relevant.

A flexible design

A pragmatist would encourage using the philosophical or methodological approach that works best for exploring a certain phenomenon (Robson & McCartan, 2016). The applied methods in the current study were chosen according to the research questions, which focus on expanding knowledge of PAMI. I consider PAMI to be a complex human phenomenon taking place in situated contexts with a need to be explored, unfolded, and operationalized. To develop a comprehensive understanding of PAMI, I applied a flexible design with qualitative data. To describe different research approaches, Robson & McCartan (2016) use the terms *fixed* or *flexible* design instead of the terms *quantitative* or *qualitative* research that designate the type of data generated. Robson & McCartan (2016) argue that the two approaches to research no longer belong to different paradigms, and that either type of research can be carried out from different philosophical stances. Similarly, in the latest edition of *Music Therapy Research*, Murphy & Wheeler (2016) do not label the two different research positions as quantitative and qualitative, but instead use the terms *objectivist* and *interpretivist* research.

A flexible design is characterized by research strategies and approaches that are likely to change and evolve when the researcher becomes involved with the data. Similarly, the research questions may also be clarified and adapted as the data collection progresses, which again sheds light on the need for additional data (Robson & McCartan, 2016). The designs of the three studies in the current thesis did, to a high degree, evolve as both the data collection and the data analyses progressed, as the research of PAMI called for methodological creativity, which I will elaborate on in section 4.2.

Evaluation of studies with a flexible design

Trustworthiness of findings from flexible research with qualitative data can be a topic of much discussion (Robson & McCartan, 2016). The standard meanings of validity and reliability from natural sciences are often not feasible when a flexible design is applied (p. 168). Validity and reliability in fixed designs are defined in relation to the consistency of a measure and the extent

⁶ Metatheory is here understood as a theory above theory (Stige, 2002, p. 333).

to which a variable is accurately measured (Cohen, 2016). According to Robson & McCartan (2016), it is therefore important to explore other ways to ensure validity for studies with flexible designs.

One way to secure and assess the validity and quality of studies with qualitative data can be to consult existing standard checklists with recommendations for how to report research. With all three studies, I strived to adhere to the Standard for Reporting Qualitative Research (SRQR) (O'Brien et al., 2014), which is recommended for use by the *Journal of Music Therapy*. The SRQR consists of a checklist with 21 items aiming to improve the transparency of all aspects of studies applying qualitative data. SRQR was developed by identifying and reviewing existing guidelines, reporting standards, and receiving feedback on proposed guidelines by experienced qualitative researchers (O'Brien et al., 2014). I applied the SRQR when evaluating the limitations and trustworthiness of the studies and reporting the findings in the three articles.

Furthermore, I integrated the agenda for evaluation of qualitative research EPICURE (Stige et al., 2009) developed by Professor in Music Therapy, Brynjulf Stige, Professor in Medicine, Kirsti Malterud, and Professor Torjus Midtgaarden, to continuously reflect on the research quality and ethical issues related to the three studies. EPICURE is a practical approach to evaluation that acknowledges the pluralism of current qualitative research and encourages reflexive dialogue in the evaluation process (Stige et al., 2009, p. 1504). Epicure is thus not a checklist, and Stige and colleagues argue that, due to diverse paradigms and perspectives in qualitative research, the use of fixed criteria can lead to the use of inadequate criteria and evaluation based on premises that are not aligned to the specific study. Instead of providing fixed criteria, EPICURE invites dialogue. The first part (EPIC) addresses the challenge of producing rich research based on engagement, processing, interpretation and (self)critique. The second part (CURE) refers to the challenge of relating research to (social) critique, usefulness, relevance, and ethics (Stige et al., 2009). I find EPICURE highly relevant as an ethical guideline for conducting real world research as done in this thesis.

4.2 METHODS OF ANALYSIS

I here present the methods used in the three studies and elaborate on why I have chosen these three approaches in answering the research questions. As described in section 4.1, I have applied a flexible design and my decision of methods was partly made as the data collection and analyses emerged. I combined different data sources and research literature with empirical data in

the exploration of PAMI. The three studies are applied in a triangulation strategy to obtain knowledge about PAMI from the perspective of research literature, music therapists, and caregivers, respectively. Originally, triangulation was used to describe the mathematical method used to draw precise maps. For example, in Denmark, The Royal Danish Academy of Sciences and Letters (n.d.) in 1761 initiated a geographical and trigonometric mapping of the country. Later, triangulation was used by the military when multiple reference points were applied to locate the precise position of an object (Smith, 1975). In social science research, triangulation is defined as a combination of methods in the study of the same phenomenon to validate or extend existing findings (Denzin, 1978). According to Jonsen & Jehn (2009), triangulation can increase validity in flexible design research when two or more methods are used to access a given phenomenon. Triangulation can be applied as a constant, habitual cross-check on theories, explanations, methods, data, informants, and the researchers themselves (Carney, 1990). The most discussed type of triangulation is the use of multiple methods in the examination of a social phenomenon, but triangulation can take place throughout the research design (Denzin, 1978). Figure 2 illustrates the three applied methods in the triangulation strategy used to explore PAMI from different perspectives and with different methods.

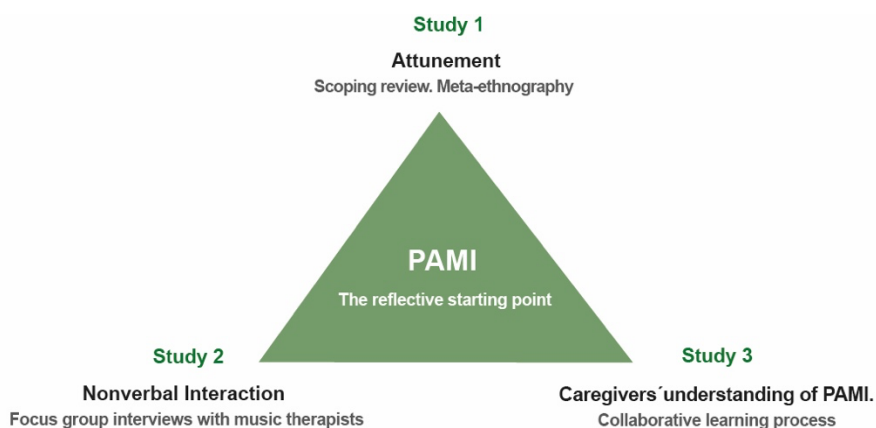


Figure 2. Triangulation strategy exploring PAMI from three different perspectives.

The three studies are concerned with practice, experience, and meaning regarding PAMI. The findings from studies 1 and 2 generate knowledge about the ontology of PAMI. Studies 1 and 2 explore attunement and nonverbal interaction, respectively, and the findings from the two studies are integrated into a collaborative learning process, with caregivers exploring PAMI in study

3. A detailed description of the methods of analysis used in each study is included in articles 1, 2, and 3 and will not be repeated here. Instead, I present the methods and reflect on why these methods were chosen.

STUDY 1. META-ETHNOGRAPHICAL SCOPING REVIEW

In study 1, we examined the research literature concerning attunement in dementia care with the aim of exploring how the concept is used and understood. Generating knowledge about how caregivers and persons with dementia attune to each other may provide new approaches in daily care tasks. To explore attunement in dementia care, we conducted a scoping review applying meta-ethnography as an analytical approach. According to Munn et al. (2018, p. 2), indicators for conducting a scoping review are to identify the types of available knowledge of a concept, identify key characteristics or factors related to the concept, and clarify the concept in the literature. Scoping reviews have been criticized for not assessing the quality of the included studies (Pham et al., 2014). We therefore consulted the PRISMA-ScR checklist for scoping reviews synthesis (Tricco et al., 2018) and developed an assessment that differentiated between four levels of thoroughness in methodological rigor and depth.

Meta-ethnography is an interpretive review method developed by Noblit & Hare (1988) that compares certain concepts in both qualitative and quantitative studies. The included studies are repeatedly read and reread to identify core themes. The findings are then compared to synthesize interpretations that are greater than the sum of their parts (Kelly et al., 2018). Meta-ethnography is widely used in health research and aims to reach a new holistic understanding of a phenomenon (Paterson, 2012). We chose meta-ethnography because it is context sensitive and comparative, which I found relevant in exploring the interdisciplinary application of attunement, a core concept in PAMI.

STUDY 2. PHENOMENOLOGY AND ARTS-BASED RESEARCH

In study 2, music therapists' experiences of nonverbal interactions with persons with dementia were explored by applying a phenomenological and arts-based analysis integrating focus groups interviews and musical improvisations. In phenomenology, lived experiences are studied to gain an understanding of a certain phenomenon (Jackson, 2016). In the context of

study 2, the focus was on generating an understanding of how music therapists experience nonverbal interactions with persons with dementia.

I am inspired by the contemporary phenomenologist Max van Manen who applies phenomenological philosophy in pedagogical and qualitative research (van Manen, 1989, 2014). I chose van Manen's approach to phenomenology because of his focus on practice and meaning, which are essential elements in PAMI (van Manen, 1990). The phenomenological *epoche* is often presented as central in phenomenological research processes (Giorgi, 2012; van Manen, 2014). Epoché is a Greek word which means abstention, to stay away from (van Manen, 2014). The German phenomenologist Husserl adopted the term epoché to indicate the act by which the natural attitude of taken-for-granted beliefs of a certain topic are suspended. Among contemporary phenomenologists, however, no consensus exists on how to conduct an epoché (Giorgi, 2012; van Manen, 2014; Zahavi, 2019). Van Manen argues for writing an epoché to gain access to the pre-reflective experience as lived, and thereby opening oneself to the research topic. As I had been a participant in the focus group interviews conducted for the study, I found it relevant to write an epoché. Before starting the data analysis, I therefore wrote one to bracket my pre-understandings and scientific expectations and at the same time regard the phenomenon that was given in my experience (van Manen, 2014, pp. 216-217). The epoché can be found in appendix A.

Van Manen (2014) highlights writing as an important method in phenomenology for accessing and externalizing internal thoughts and experiences. He describes *lived-experience descriptions* as a relevant format to explore personal human topics (van Manen, 1990). Lived-experience descriptions are subjective descriptions of human experiences in personal terms. In study 2, the music therapists explored nonverbal interactions with persons with dementia through writing lived-experience descriptions. It was difficult for the music therapists to verbalize the nonverbal interactions that often take place in music. Van Manen (2017, p. 812) stresses the challenge in transforming the lived meaning of the moment into text without turning "the lived meaning into ... objectified descriptions". Ansdell (1999) also refers to the difference between the verbal language that music therapists use to describe their practice and the musical, nonverbal language that they apply in practice.

In study 2, transcriptions of focus group interviews were analyzed by application of phenomenological microanalysis, in which key statements from the transcripts were distilled into meaning units and themes, until a distilled essence was achieved (McFerran & Grocke, 2007). The findings were

validated and elaborated on using musical improvisation as an arts-based inquiry to convey an understanding of nonverbal interactions that included embodiment as a research strategy (Beer, 2016; McNiff, 1998). According to Eisner (2004, p.7), “the arts provide access to qualities of life that literal language has no great power to access”. A strength of arts-based research is thus its capacity to elicit embodied, affective, and aesthetic knowing (Philips et al., 2022).

By exploring the emerged themes using musical improvisation, the participating music therapists discovered new elements to the experience of nonverbal interactions in dementia care.

STUDY 3. HERMENEUTIC ETHNOGRAPHY

In study 3, we explored PAMI⁷ from the perspectives of the caregivers working in a nursing home. The study contains several elements and methodological implications. In the following I start by presenting the applied method of hermeneutic ethnography, and the hermeneutic approach to research. I move on to a brief presentation of the collaborative learning process that took place in the study, and finally, I present the method of data generation, give an example of the narratives that were co-created with the caregivers, and describe musical interactions with persons with dementia.

Method

We applied hermeneutic ethnography as defined by the North American anthropologist Clifford Geertz (1973) to explore the caregivers’ understanding of musical interaction. Ethnography refers to the field work that I conducted in the nursing home Egebjerg for six months during 2019 and 2020. Together with six professional caregivers, I constructed data that I afterwards analyzed using a hermeneutic approach. Different approaches to hermeneutic research exist, and in study 3, I was inspired by hermeneutics as described by Heidegger (1927/2004). Heidegger was originally a student of Husserl and was influenced by both phenomenology and hermeneutics (Jackson, 2016). He had a great influence on hermeneutics by emphasizing the alternation between the researchers’ pre-understanding and understanding, and by focusing on existential aspects of hermeneutics (Alvesson & Sköldberg, 2018). According to Heidegger (1927/2004), humans are products of their experiences and are not born as a tabula rasa. All understanding is from the beginning colored by emotional moods and there exists no purely

⁷ Musical interactions in the context of study 3 are identical to PAMI and used synonymously.

cognitive or rational understanding (Alvesson & Skjöldberg, 2018). Alvesson & Skjöldberg (2018) are aligned with Heidegger's thoughts and argue for seeing interpretation as interplay between empirical material and the researcher's theoretical understanding.

Language, linguistic meanings, and interpretive processes have had, and continue to have, great import in hermeneutics (Loewy & Paulander, 2018). In current hermeneutic research, the way in which we use language to describe experiences influences how the experiences are understood (Hiller, 2016). Our language, as a system of symbols, thus shapes what we see and how we see our realities and interpret their meanings (Crotty, 1998, p. 88). The importance of the use of language is relevant when applying Geertz' hermeneutic ethnography, as Geertz understands and reads culture as a text.

... culture is not a power, something to which social events, behaviors, institutions, or processes can causally attributed; it is a context, something within which they can be intelligibly – that is thickly described. (Geertz, 1973, p.14).

In the context of study 3, the caregivers' daily interactions with the persons with dementia living in Egebjerg constitutes the studied culture.

A collaborative learning process

The focus of the third study was to explore and understand musical interactions in the caregivers' daily work. The musical interactions were explored in the framework of a collaborative learning process, in which ideas for how to teach PAMI were tried out. Through the collaborative learning process, the caregivers participated in workshops introducing various ways of applying musical interaction, and the importance of attuning their interactions to the person with dementia. The collaborative learning process consisted of three different learning formats. In article 3, I do not specify the content of the workshops and will therefore summarize it in the following. I include these content descriptions as the experiences gained from the collaborative learning process, and the learning theory introduced in section 2.5, inform the recommendations for a PAMI-training that I propose in section 7.6. Content of workshops included:

- 1) Power point presentations with theory on musical interaction in dementia care and video examples of how to apply music in care situations. The presentations were facilitated by me in the role of music therapist. To communicate how PAMI can be applied with different purposes in care practices, I related the findings to an established music therapy theory describing how the music therapist in the interaction focuses on framing,

regulating, or relating (hereafter FRR)⁸ (Ridder, 2007, 2019). The FRR theory was developed by Professor Hanne Mette Ridder and widely used by music therapists working in dementia care in Denmark and Norway (Holck, 2020; Kvamme, 2017; Ottesen, 2020). I did not consider integrating PAMI and FRR when I conducted studies 1 and 2 but found the FRR theory helpful to communicate the function of the music in the collaborative learning process in study 3. The FRR theory describes three interrelated main purposes of applying music in music therapy (Ridder, 2019).

Framing is understood as a way of using music to create safety and predictability, for instance by musical cueing with certain songs or sounds related to the life story of the person with dementia.

Regulating refers to using music to regulate the arousal level of the person with dementia by the application of musical parameters such as tempo, timing, and volume.

Relating describes how the use of musical interactions can facilitate experiences of connectedness and togetherness and meet the psychosocial needs of the person with dementia.

The FRR theory in particular stresses that if the person with dementia is not feeling safe and at a balanced arousal level, it is not possible to establish relational contact. This communicates the meanings music therapy can have for persons with dementia; however, I also find the theory relevant to communicate the purposes of PAMI, and I therefore applied it in the theory presentations used in the collaborative learning process.

2) Exercises including role play, musical improvisations, songs, and group discussions and reflection facilitated by me in the role of music therapist. The exercises were included to provide the caregivers with concrete experiences of PAMI and to reflect on their own relationship to music. The exercises were developed from my clinical background as a music therapist in dementia care and in collaboration with the PAMI research group.

The caregiver received a booklet with exercises and information about musical interaction. The caregivers used the booklet both during and in between the workshops.

3) Informal, individual training of the caregiver carried out under direct supervision. An important element of the collaborative learning process was my participation in daily care situations along with the caregivers. Here I

⁸ In Scandinavian languages the theory is known as “*De 3 R'er*” [the 3 R's]: *Ramme, regulering og relation* (Ridder, 2007, 2019).

could demonstrate ways to apply musical interactions in the context of the daily routines at the nursing home. The caregivers were the experts in the residents' daily routines and personal needs, and together we could apply musical interactions such as humming, singing, dancing, or listening to music in a calm and safe atmosphere. I was very aware that the situation could be stressful for the caregiver and therefore focused on communicating what we could try out before the care task, and afterwards acknowledging the caregivers' efforts to apply musical interaction in the care task.

Data generation

The data in study 3 consist of field notes, narratives describing musical interactions, and transcribed audio recordings of the workshops. The narratives describing musical interactions between caregivers and persons with dementia were co-created with the caregivers during the collaborative learning process. I wrote a narrative and the caregivers validated or amended the description. The following exemplifies a co-created narrative describing the musical interaction between the resident Katrine and the caregiver Marie:

Katrine does not like to be showered. She resists and tries to hold on to Marie. When the time has come to help Katrine to sit down, Marie begins to sing a little louder and firmer. Katrine again resists sitting down and instead leans towards Marie. For a few seconds they stand still in an embrace, while Marie sings and slowly cradles Katrine. Then Katrine gently lets go and sits down. Marie soaps her and washes her hair while humming simple melodies from children's songs. Katrine is completely relaxed and seems to enjoy the shower. A few times she opens her eyes, looks at Marie and makes some noises. Marie mirrors her sounds in her singing as if she speaks and understands Katrine's language. (Krøier & Ridder, 2022, pp. 6-7).

The validated narratives and the transcripts from the workshops were analyzed by applying Geertz's hermeneutic ethnography, and the findings were compared to the preconceptions and expectations that I initially wrote down in the field notes. The findings were finally related to practice theory to conduct abductive reasoning. Practice theory is a set of conceptual approaches that can be used for investigating and representing everyday practices (Nicolini, 2012).

4.3 ETHICAL CONSIDERATIONS

The study was registered at The Danish Data Protection Agency through Aalborg University and follows the Danish code of ethics (Ministry of Higher Education and Science, 2014). The participating music therapists and caregivers signed a consent form on the terms of participating in the study based on written and oral information provided by me. As the first part of the data collection in study 2 was conducted of Margrete Bach Madsen, I recollected consent forms after I completed the data analyses. In both studies 2 and 3, the consent form included information about anonymization of data and the possibility of withdrawing from the study at any time. The consent form was signed by the managers of Egebjerg, and the project was furthermore presented to the official managers of elderly care in the municipality of Gentofte, Denmark.

As my colleague in the PAMI research group, music therapist and PhD Jens Anderson-Ingstrup (2020), mentions, ethical considerations do not stop just because ethical approval has been obtained by the regional ethics board. The process of reflexivity continues while disseminating and discussing the findings. After the collection of data for the third study, I continuously had contact with the manager at Egebjerg to make sure that I reported the findings in a respectful and ethical way. I asked the manager if she wanted the care nursing home to be anonymized, but she preferred to release the name of the facility to provide an example of how new practices can be implemented and be beneficial to the most vulnerable persons in society.

An important ethical aspect concerns the application of musical interaction when the person with dementia is not able to adhere to the initiative (Ridder & Krøier, 2022). According to Stige & Ridder (2016, p. 235), music has fewer side effects compared to medication, but if it were harmless, it would also have no effect. The use of musical interaction to accomplish certain goals can be potentially manipulative, and therefore I find it highly relevant to support caregivers in their awareness of how they can apply musical interaction in a respectful and attuned manner.

Through my field work at Egebjerg, I became well acquainted with the caregivers involved in the study. Doing research with persons you have become acquainted with raises ethical concerns about how to disseminate data. In this process, I was inspired and guided by an article by Ellis (2007) “Telling secrets, revealing lives. Relational ethics in research with intimate others”. According to Ellis (2007, p. 25), it is worthwhile to strive to leave communities, participants, and yourself better off at the end of the research

than in the beginning. Research is never neutral, and the values, knowledge, and information that you bring into the field will influence the people involved. It was my intention during the fieldwork and the entire PhD project to approach the field, the caregivers, and the persons with dementia with respect and kindness. In other words, to research from an ethic of care (Ellis, 2007, p. 25).

CHAPTER 5. FINDINGS

In this chapter, I provide an overview of the main findings from the three studies. The findings from each study are described and summarized. Together the findings constitute a coherent elaboration of PAMI, employing multiple methodological approaches and clinical perspectives.

5.1 ATTUNEMENT IN DEMENTIA CARE

Krøier, J. K., McDermott, O., & Ridder, H. M. (2022). Conceptualizing attunement in dementia care: a meta-ethnographic review. *Arts & Health, 14*(1), 32–48.

In the first study, we examined how attunement is used and understood in published dementia care research (research question 1). To answer this question, we carried out a meta-ethnographic review (Noblit & Hare, 1988). A total of 129 studies were screened and the final dataset included six studies. One hundred and thirteen caregivers participated in these studies, and the characteristics of the included studies are summarized in Table 1 in the first article (Krøier et al., 2022). The studies were concerned with both family, volunteer, and professional caregivers, as attunement, through the search process, appeared to be a relatively unexplored topic in dementia care. An important inclusion criterion was that the study should provide perspectives on the interaction between the caregiver and the person with dementia, to shed light on how attunement is applied in dementia care.

The conducted meta-ethnographic analysis revealed three interwoven themes describing how attunement is used and understood in dementia care: (1) taking the perspective of the person with dementia and the importance of a person-centered approach, (2) developing understanding through an empathic approach, and (3) using musical parameters in the interaction; tempo adjustments, timing, and the use of music. The themes are elaborated and summarized in the following.

(1) Taking the perspective of the person with dementia and the importance of person-centered approach. All the included studies refer to the person-centered approach described by Kitwood (1997), as central in the dynamic process of attunement. For attunement to take place, the caregiver must show a genuine interest in the individual and take their perspective. The needs, wishes, and desires of the person with dementia can thus guide the caregiver on how to attune to the individual.

(2) Developing mutual understanding through an empathic approach. The second theme is divided into two interrelated subthemes: (a) care work is emotional work, and (b) reciprocity between the person with dementia and the caregiver.

(a) Care work is emotional work. According to the included studies, care work is deeply emotional work and the ability to attune to the psychosocial needs of the person with dementia requires emotional openness and awareness. When the caregivers succeed in establishing an emotional openness, attunement is a process that guides the caregiver to an understanding of the needs and feelings of the person with dementia.

(b) Reciprocity between the person with dementia and the caregiver. The feeling of reciprocity between the person with dementia and the caregiver serves as another guideline that the caregiver can follow. When attunement takes place between the person with dementia and the caregiver, it can be very pleasant for the caregiver and diminish the isolation that the individual with dementia often encounters. The reciprocal experiences can also take the reverse course, and the caregiver can experience negative feelings and stress in the interaction with the person with dementia. It is important to emphasize that attunement is a mutual process and that the person with dementia attunes to caregivers as well and senses their mood and feelings.

(3) Using musical parameters in the interaction, including tempo adjustments, timing, and the use of music. The third theme is also separated into two interrelated subthemes: (a) tempo and timing, and (b) the use of music and vocalization.

(a) Tempo and timing. Musical parameters such as tempo and timing are mentioned in the included studies as central to the interaction between the caregiver and the person with dementia, even when explicit use of song or music is not described. When the caregivers attune to the person with dementia, they adjust their tempo to match the tempo of the person. Adjusting tempo and trying to time the activities in accordance with the individual with dementia depends upon the flexibility of the caregiver. For attunement to take place, it is important that the caregiver is willing to let go of control and instead carefully and attentively listen to the person with dementia.

(b) The use of music and vocalization. By using voice and music, the caregiver can attune to the person with dementia. The included studies describe how the caregiver's emotional involvement is expressed in their vocal initiatives. A

sensitive and conscious use of voice can, furthermore, affect the mood of the person with dementia positively.

Five of the included studies mention music as a relevant approach to increasing attunement between the person with dementia and the caregiver. Music such as singing can generate synchronicity between the caregiver and the person with dementia and be a way of acknowledging the person as well as increasing compliance in care situations.

The emerged themes from the scoping review are summarized below.

- Taking the perspective of the person with dementia and the importance of person-centered care.
- Developing understanding through an empathic approach.
- Using musical parameters in the interaction. Tempo adjustments, timing, and the use of music.

Limitations

This scoping review applying meta-ethnography characterizes attunement in dementia care as a match between the expressions and behaviors of the person with dementia and the caregiver. This area is relatively unstudied, and further research is needed to develop the understanding and application of the concept. In particular, there is a need to examine attunement from the perspective of the person with dementia.

Additional findings

Since the scoping review was conducted in 2018, research in psychosocial dementia care has continued. To update the current state of research in attunement and dementia care, I repeated the literature search in January 2022 on the database SCOPUS with the search terms “nursing home,” “long term care facilities,” “dementia,” “all combined with “attun*” in any part of the article. I will mention here two relevant studies from the past three years that I found relevant for future research, clinical application, and development of attunement in dementia care.

Alsawy et al. (2020) explored how people with dementia experience communication as good and meaningful, and thus focused on the perspective

of the person with dementia, a perspective that is often not explored (Alsawy et al., 2017). Nine dyadic interactions between a family caregiver and a person with dementia were filmed. The person with dementia watched the recording and reflected on the communication in semi-structured interviews with the researcher. Through a thematic analysis, three superordinate themes emerged. The themes, “sharing moments of emotional connection” and “empowering one’s ability to communicate” describe the communicative experience of being heard and understood. The last theme “inhibitors to communication” relates to feeling disempowered and inferior (Alsawy et al., 2020). The study aligns with the findings of study 1, as the reciprocal and bidirectional dimension of communication is stressed. According to Alsawy et al. (2020), it is central that the caregiver is actively listening to the person with dementia and attuning to the thoughts and feelings of the individual. Thereby, shared moments of emotional connection are co-created.

Jeong (2020) explores attunement processes in ethical practice within a dementia context. The study brings ethnographic attention to the everyday crises of human life and outlines significant epistemological, methodological, and ethical questions that arise when conducting research in dementia care. Ethical practice is exemplified by an ethnographic case study focusing on the affective dimensions between Ayla, who has dementia and lives in a nursing home, and her daughter Tracy. Ayla wakes at night and asks the caregivers to call her daughter. Tracy has a busy life as a primary school teacher and does not want to receive phone calls during the night. Jeong (2020) outlines how the care staff, Ayla, Tracy, and the researcher experience this situation, and how they try to attend to meaning-making actions in the context they are in. Heidegger’s concept of *dwelling* is applied to disclose the process of becoming ethical. The ethical practices of Ayla, Tracy, and the care staff are attuned, responsive, and entangled in care practices. The study adds ethical and philosophical perspectives to attunement as a process that continuously takes place in dementia care.

5.2 NONVERBAL INTERACTIONS BETWEEN MUSIC THERAPISTS AND PERSONS WITH DEMENTIA

Krøier, J. K., Stige, B., & Ridder, H. M. O. (2021). Non-Verbal Interactions Between Music Therapists and Persons with Dementia. A Qualitative Phenomenological and Arts-Based Inquiry. *Music Therapy Perspectives*, 2021, 1–10.

In the second study, we explored how music therapists experience nonverbal interaction with persons with dementia (research question 2). Through a phenomenological analysis of focus group transcripts and the application of

musical improvisation for further elaboration, five themes were generated describing how music therapists experience nonverbal interaction in dementia care. The five themes were as follows.

(1) Vitality

The music therapists sense the vitality of the person with dementia and let the vitality guide the interaction with the person. They refer directly to the work of Stern (2010), who describes *forms of vitality*.

(2) Disciplined subjectivity

The music therapists describe countertransference as a central way of gaining information about the person with dementia. The term countertransference was originally introduced by Freud (1910) as the therapist's reactions to the relationship pattern that the client replicates in therapy. The participating music therapists described countertransference as bodily and emotional sensations that evoked empathic identification with the person with dementia. In the second part of the study, the music therapists agreed that the term disciplined subjectivity would be better suited to describe the theme than countertransference. Disciplined subjectivity can be defined as a state in which the music therapist is conscious about, and takes responsibility for, the emotions that they encounter in the meeting with the person with dementia (Pedersen, 2007).

(3) Attunement

The music therapists attune their interactions to the person with dementia by using musical parameters such as tempo, timing, and pitch. Attunement is a dynamic, reciprocal process in which the music therapist and the person with dementia dialogically exchange communication initiatives.

(4) Therapeutic presence

The importance of being open, present, and totally aware of the person with dementia is highlighted by all the participants. Therapeutic presence is a precondition for a successful interaction.

(5) Validation

By matching or mirroring the expression of the person with dementia, the music therapists strive to affirm that the feelings and actions of the person are worthy and acceptable. Thereby, the psychosocial needs of the person with dementia can be met, and the individual can share a mutual subjective experience.

The five themes that were constructed through the phenomenological analysis are summarized in the box.

- Vitality
- Disciplined subjectivity
- Attunement
- Therapeutic presence
- Validation

The arts-based inquiry revealed new aspects to themes 4 and 5, and these were incorporated into the final distilled essence. The participating music therapists stressed that the five emerged themes were interrelated, which supports the decision to integrate the findings into a narrative in the final distilled essence.

Limitations

Several limitations are worth addressing in this study. The participating music therapists formed a very homogenous group, being all white, middle-aged women educated at Aalborg University, Denmark. Furthermore, I had a double role as both a participant in the first part of the study and as a researcher in the second. By writing an epoche prior to the data analysis and including the arts-based elaboration on the themes, I tried to take this aspect into consideration.

5.3 CAREGIVERS' USE OF MUSICAL INTERACTIONS IN DEMENTIA CARE

Krøier, J. K. & Ridder, H. M. O. (2022). "When the music is on, she is there". Professional caregivers' perspectives and use of musical interactions in caring for the person with dementia. *Approaches: An Interdisciplinary Journal of Music Therapy*.

In the third study, we explored how caregivers use and understand person-attuned musical interactions with persons with dementia (research question 3). Through a collaborative learning process with six professional caregivers in the Danish nursing home, Egebjerg, narratives describing musical interaction were generated. The narratives and transcripts from the collaborative learning process were analyzed by applying a hermeneutic approach, which generated four themes that I present below.

(1) Vitality and communication

The application of musical interactions such as singing, dancing, humming, or listening to music can bring a positive vitality to the interaction between the caregiver and the person with dementia. The caregivers furthermore experience that the person's increased vitality can make it easier to communicate and complete care tasks.

(2) Connectedness through attunement

Musical interactions can create a feeling of connectedness between the caregiver and the person with dementia. By using singing, humming, listening to music, or dancing, and being aware of musical parameters in the interaction, the caregiver and the person with dementia can attune to each other and the psychosocial needs of the individual can be met. Additionally, musical interactions can facilitate experiences of connectedness between the residents when they participate in group music-based activities such as singing or playing together.

(3) A Life story soundtrack

According to the participating caregivers, music can serve as a soundtrack of the life of the person with dementia. For some residents, it could be relevant to play drums and for others important to listen to the music that their parents listened to. Knowing the music preferences of the individual can help the caregiver apply the music that is important for the persons with dementia and support their social identity.

(4) From Anxiety to Reassurance

Musical interactions such as singing or humming, sometimes in combination with movement or touch, can help the person with dementia feel safe and reassured if they are anxious or agitated. The caregivers were amazed at how a very simple interaction such as singing a song could have a regulating and reassuring effect.

In the article we discuss the four themes using practice theory and emphasize how the musical interactions between the caregiver and the person with dementia are inseparable from the physical context in which they take place. The four themes that emerged from study 3 are summarized in the box.

- Vitality and communication
- Connectedness through attunement
- A life story soundtrack
- From anxiety to reassurance

Challenges related to the data collection

The study faced several challenges that are not described in the article, but that I will describe here to illustrate the process of conducting research in a nursing home. Broome et al. (2017) describe how sudden changes in staff may often occur in nursing homes. In the six months that the study lasted, we faced several challenges due to organizational changes and the global COVID-19 pandemic. The leading nurse of the ward resigned as the study started and was not replaced until four months later. Having no formal management at the ward for this long period led to difficulties in organizing the workshops and the days when I participated in the care tasks. Furthermore, one of the participants resigned from Egebjerg after the second workshop. As Broome et al. (2017) conclude, practical limitations such as shortage of staff are not unusual in dementia care. This study required a high degree of flexibility and support from the manager of the nursing home to complete. We managed to complete data collection before the global COVID-19 pandemic closed all nursing homes for visits in Denmark. However, the final evaluation had to be postponed and took place two-and-a-half months later than originally scheduled.

Limitations

Several limitations are identified in the study and described in the article 3. Limitations include the challenges of translating musical interactions into text, the numerous roles that I had in the study, and the fact that only female caregivers participated.

CHAPTER 6. INTEGRATION OF FINDINGS

In this chapter, I compare the findings from the three studies with the aim of reaching a coherent understanding of PAMI, taking different clinical and methodological perspectives into consideration. The three studies explore PAMI from different perspectives. The two sub-elements of PAMI, attunement (A) and nonverbal interactions (I) are examined from the research literature (article 1) and through lived-experience descriptions from six experienced music therapists (article 2), respectively. In the third study, the caregivers' understanding of musical interactions is explored (article 3) through a collaborative learning process informed by the findings in study 1 and study 2.

The three papers generate a total of 12 themes describing PAMI or elements of PAMI. The 12 themes and their relationships to each other are presented in figure 3 and contribute to a description of the clinical and theoretical elements of PAMI.

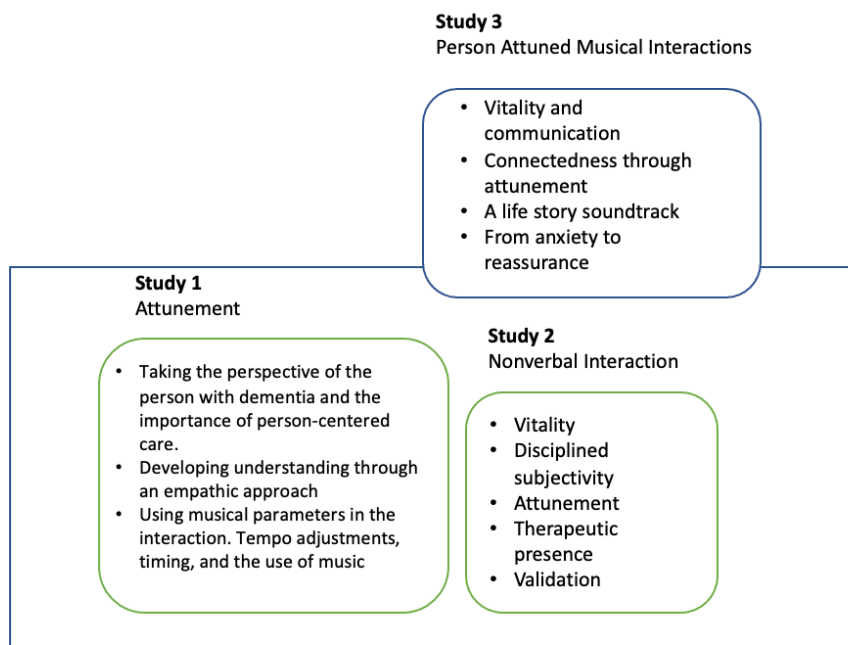


Figure 3. The findings in relation to each other.

From the beginning of the research project, PAMI was a theoretically informed concept, and the three studies contribute, through abductive reasoning, to grounding the concept in contemporary music therapy research. To deepen the understanding of the emerged themes, I integrate theory and theoretically informed concepts in the following, when I draw parallels between the studies.

Vitality

The first theme in study 3, “vitality and communication”, can be related to theme 1, “vitality” in study 2. The music therapists refer to Stern’s use of vitality in the concept forms of vitality (Stern, 2010). According to Stern, forms of vitality are “a Gestalt that emerges from the theoretically separate experiences of movement, force, time, space, and intention” (Stern, 2010, p. 5). Forms of vitality can thus be understood as multimodal expressions that unfold the dynamic manifestations of inner states (Marraffa & Meini, 2019, p. 34). They are not emotions, but structures of dynamic behavior that embrace an emotion. Musical concepts, such as crescendo, can be valuable in describing how a behavior or an emotion is being expressed, its form of vitality. In music therapy, forms of vitality are a concept that is widely used and that is relevant in describing how a music therapist relates and attunes through musical experiences (Geretsegger et al., 2012; Helle-Valle et al., 2017; Johns, 2018).

The caregivers in study 3 do not refer to the work of Stern but describe vitality as a force of life and as the energy that the individual brings into a certain behavior or action. Vitality in this context is a manifestation of life and being alive. In the workshops, the caregivers noticed that vitality is centered in the body and that increased vitality can increase bodily activity and awareness. These observations resonate with Marraffa & Meini (2019), who examined how early and basic forms of self-consciousness are experienced affectively and bodily.

Both the caregivers and the music therapists are aware of the vitality of the person with dementia, but whereas the music therapists let the vitality– or more precisely the forms of vitality– of the individual guide their interaction, the caregivers apply musical interaction to bring vitality into the interaction. The caregivers thus apply musical interactions to regulate the arousal level of the person with dementia to a higher level, whereas music therapists refer to vitality as a form of information about the person, the emotional state of the person, and the arousal level of the individual when the meeting takes place. This overlap in findings indicates that vitality plays an important role in PAMI both as a guideline for how to meet and attune to the person, and as an outcome

that can have a positive influence on arousal and enhance communication and compliance in care situations.

Attunement

The caregivers in study 3 use musical interactions to help them attune to and connect with the person with dementia. As with vitality, the caregivers experience that the musical interactions can help them attune to the person with dementia. The music therapists in study 2, however, attune their interactions to the tempo, pitch, and volume of the person with dementia as an approach in their encounter with the person. Thereby, the music therapists attune to the person with dementia by matching the forms of vitality of the individual. Thus, attunement is an outcome of musical interactions for the caregivers, whereas it is a starting point for the participating music therapists. I consider this difference as being rooted in the different foci in caregiving and music therapy. Caregivers are focused on helping the person with specific practical needs, whereas music therapists are concerned with creating (nonverbal) meetings and interactions.

Study 1 generates an understanding of attunement as a generic phenomenon in caregiving, grounded in the person-centered approach to care (Kitwood, 1997), manifested through an empathic approach and by the musical parameters. I find this understanding of attunement applicable and relevant for interdisciplinary use in dementia care.

Music

The three studies illustrate various uses of music and musical interaction in dementia care. In the acronym PAMI, we use the word *musical* instead of music to highlight our primary understanding of music as a social and communicative phenomenon referring to communicative musicality (Malloch & Trevarthen, 2009). The caregivers in study 3 understand the use of musical interaction in the framework of the person-centered approach to care (Kitwood, 1997). Each person with dementia has unique musical preferences creating a soundtrack of their life (theme 3 in study 3), and when presented with familiar music the individual might experience recognition and relate the music to certain events of their lives. In addition, the favorite songs and music pieces of the individual with dementia are aesthetic, meaningful artifacts that also influence the personal identity of the person. The caregivers' application of specifically selected types of music for specific residents in study 3 illustrates that they also understand music as a technology that can be beneficially applied to meet the personhood of the resident.

In study 1 and 2, the communicative potential of musical interaction is emphasized. In study 1, the findings illustrate how caregivers' use of music can enhance attunement and synchronicity between the caregiver and the person with dementia. The music therapists in study 2 use musical parameters such as pitch, rhythm, and timing to describe the nonverbal interaction with the individual. A broad understanding of music and musical interaction, highlighting the communicative aspects inherent in PAMI, can thus help in verbalizing and describing the nonverbal interactions with the person with dementia.

The person-centered approach

The person-centered approach to dementia care defined by Kitwood (1997) permeates the three studies. The person and personhood, and the unique preferences, feelings, and wishes of the person, are central for the way musical interactions, attunement, and nonverbal interactions are understood, experienced, and applied.

Validation is a central concept in person-centered care and referred to by the music therapists in study 2 when describing their experience of nonverbal interactions with persons with dementia. According to Ridder (2019), validation has parallels to the concept affect attunement (Stern, 2010). Both phenomena are concerned with affirming the person and communicating that the feelings and actions of the person are worthy and acceptable. In both attunement and validation, the caregiver strives to share the person's subjective experience, rather than just engage in a shared task. Referring to the findings in study 1, attunement might, however, have more reciprocal and bidirectional characteristics than validation.

6.1 CLINICAL APPLICATION OF THE FINDINGS

The 12 themes from the three studies illustrate PAMI and its sub-elements through applications, experiences, and understandings from the reflections and practices of music therapists and caregivers. The FRR theory (Ridder, 2019) presented in section 4.2 gives an overall understanding of three different ways of using musical interactions. I find the theory relevant in other contexts than music therapy, and I find that it also can describe the purpose of PAMI. As demonstrated in article 3, PAMI can have many different manifestations, and the FRR theory is therefore useful in communicating the focus and intention of PAMI when applying it in care practices. As the FRR theory seems to be well known to music therapists working in dementia care in Denmark and Norway, hereby suggesting a certain consensus, integration of PAMI and FRR could support music therapists in transforming and

communicating the aims of clinical music therapy practice into indirect music therapy practice (Kvamme, 2017; Ridder, 2016, 2019).

In figure 4, I integrate the findings from the three studies, exploring PAMI and the FRR theory. PAMI and the purposes of PAMI are indicated with bold letters. The findings are in the figure indicated with italics. I have included findings with relevance for caregivers, integrating PAMI into care practices. The themes “disciplined subjectivity” and “therapeutic presence” related to the music therapy profession from study 2 are not included in figure 4 but included as background understanding for the music therapists when working with PAMI. The two small circles indicate the caregiver and the person with dementia, who are connected through the dynamic processes in PAMI. The large arrows illustrate that the caregiver carries the responsibility for the interaction, but as PAMI is reciprocal, the dynamics will move between the caregiver and the person with dementia as illustrated with small arrows.

PAMI provides a theoretical framework for working with musical interaction, as it allows regulating and relating to take place within a safe setting. Music that is well known creates “a life story soundtrack” (study 3) for the individual and provides a safe framework that transforms “anxiety into reassurance” (study 3). The findings “vitality and communication” and “connectedness through attunement” are placed in the center of the figure to illustrate how the caregivers understand PAMI in study 3. “Validation”, “attunement” and “developing understanding through an empathic approach” are placed close to the purpose **Relation** in the right side of the figure. On the left side of the figure, close to the purpose **Regulation**, the finding “using musical parameter in the interaction: tempo adjustments, timing, and the use of music” is placed. The circle that surrounds PAMI illustrates the nursing home ecology where PAMI takes place, and which, as illustrated in study 3, will influence PAMI.

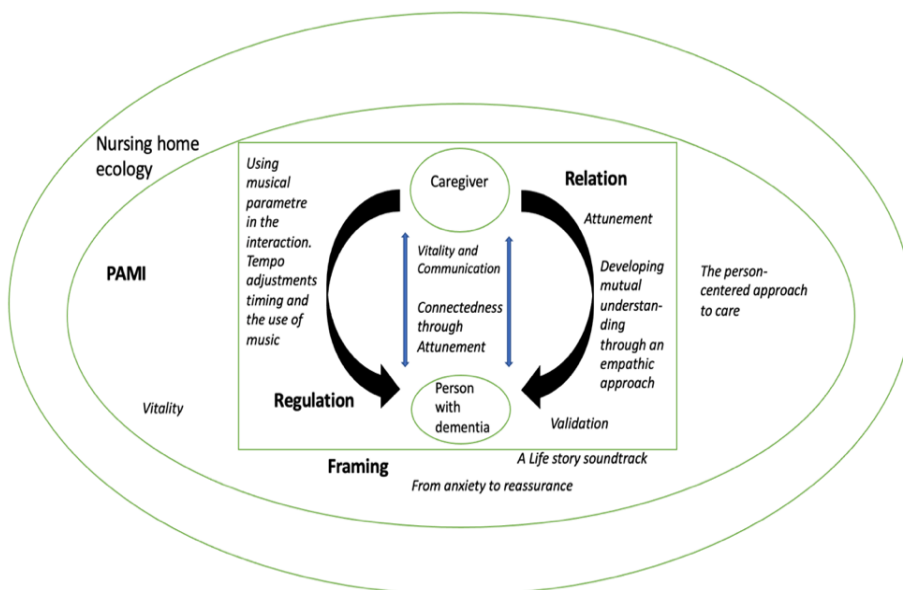


Figure 4. Integration of findings and FRR in PAMI.

CHAPTER 7. DISCUSSION

This chapter includes a discussion of the implications of PAMI and the findings that emerged from the three studies. As a starting point for the discussion, I reflect on the main research question of the thesis and discuss possible answers and new questions that have emerged through the research process. I continue by revisiting the PAMI concept and its applicability in dementia care, and then I evaluate the research process and findings by applying the evaluation agenda EPICURE (presented in section 4.1) and consider the limitations of the study. Finally, I reflect upon how this study may inform future research, and then conclude the chapter with recommendations for future PAMI training.

7.1 ANSWERS AND NEW QUESTIONS

The three studies in this thesis explore the theoretical, clinical, and methodological elements that define person-attuned musical interaction (PAMI) with persons with advanced dementia living in nursing homes (main research question). PAMI is explored from three different perspectives, and different theoretical, clinical, and methodological approaches are addressed and presented in three articles. Answers to the main research question emerge from integrating the findings from the three articles and bringing them into dialogue to elucidate perspectives, implications, and limitations of the present thesis.

The concept of PAMI served at the beginning of the project as a reflective starting point for the research. This concept was constructed as a theoretical framework to explore and understand the musical interactions between caregivers and persons with dementia that many music therapists and caregivers experience (PAMI group, n.d). An abductive approach was applied in order to unfold and enrich the concept and hereby obtain new understandings of PAMI. The three studies serve to generate knowledge about the ontology of PAMI and its sub-concepts (study 1, attunement and study 2, nonverbal interaction) and how PAMI can be applied and understood by caregivers (study 3). The three studies, thus, ground and strengthen the understanding of what constitutes PAMI.

As described in chapter 1, person-centered care served as a metatheoretical understanding of PAMI. The review of research studies regarding attunement between persons with dementia and caregivers demonstrated that person-centered care is fundamental to the understanding of attunement. Interesting

links between person-centered care, music, and attunement also emerged in study 1, where we suggest that attunement can be understood as temporal synchronizations in the interactions between the caregiver and the person with dementia.

In studies 1 and 3, the application of attunement and musical interaction is described from the perspective of the caregivers. Some themes overlap between studies 1 and 3, which can be explained by the common focus on caregiving in them. In study 2, new dimensions of PAMI are revealed by the six participating music therapists. The themes “disciplined subjectivity” and “therapeutic presence” (study 2) are concepts with a clear connection to the music therapy program at Aalborg University, Denmark, which was originally grounded on a psychodynamic approach to music therapy (Pedersen et al., (2022). “Presence” is described by the analytical music therapist Mary Priestley (1994) and “disciplined subjectivity” is a term developed by the Danish music therapy educator and researcher Inge Nygaard Pedersen (2007). I find the concepts highly relevant in nonverbal interaction, as they capture the subtle dynamics taking place between the music therapist and the person with dementia. The two themes are very specific and, as described in article 2, there is a risk of excluding other professions by using a theoretically informed discourse. The theme “disciplined subjectivity” can be related to person-centered care, in which the caregiver also needs to be aware of the perspective of the person with dementia. I understand the theme “therapeutic presence” to be a description of the special awareness of interactional signals that music therapists have achieved during their education. The findings in study 2 reveal that music therapists, through their training, have a sensitivity to musical elements of interaction and can therefore support caregivers in developing their practice, as well as providing a language for tacit relational knowledge. However, the research process in study 2 demonstrates that it can also be challenging for musical therapists to articulate nonverbal interaction, and that embodied, arts-based practices therefore may be relevant when researching PAMI.

Article 3 reveals that the caregivers can express important reflections concerning daily care practices with persons with dementia if they are given the opportunity to share their reflections. Caregivers are not necessarily included in the development of care practices, which, according to Banerjee et al. (2015), may be due to reductionist assumptions in which relational needs are not taken into account. This easily contributes to a task-based and routinized approach to care (Banerjee et al., 2015). As the caregivers have the daily contact with the person with dementia, I find their views on developing care work highly relevant and a valuable contribution to person-centered care.

The findings of the three studies indicate that an understanding of musical interactions that emphasize communicative aspects can serve both as a way of describing attunement, and of providing a language for elucidating nonverbal interaction processes, by using musical parameters such as tempo, tone of voice, and the timing between the persons in the interaction. Even though this musical understanding is embedded in music therapy, working with PAMI may be a new approach for many music therapists. Exploring and developing musical interactions that match the unique person with dementia in certain situations requires a high degree of collaboration between the music therapist and caregivers. In this context, person-centered care can create a shared framework for both music therapists and caregivers, emphasizing curiosity about the psychological needs of the person with dementia. The implementation and interdisciplinary use of PAMI may support a person-centered approach to care and delivery of comprehensive care to persons with dementia across settings (WHO, 2010). Furthermore, systematic application of and reflection on PAMI can create a shared vocabulary for the nonverbal interactions that are so crucial for the well-being of persons with dementia (Brooker & Letham, 2015; Ellis & Astell, 2017).

In terms of methodological elements, the three articles elucidate that PAMI can have various manifestations. Studies 1 and 2 focus on attunement and nonverbal interactions, respectively, but at the same time they reveal examples of PAMI that indicate that the four letters in the acronym are closely connected. PAMI can be singing, humming, dancing, or listening to music during care tasks or activities, but it can also be an increased attention to the tempo of the movements of the individual and attuning your own tempo to match the tempo of the person with dementia. It could also mean adjusting tone of voice, possibly talking less, and humming instead of talking when helping a person with dementia. Attunement is crucial in any kind of PAMI and requires that the caregivers engage themselves empathically with the person with dementia. To work relationally on a nonverbal level requires involvement from the caregivers and organizational support from managers (Ward et al., 2008). In contemporary dementia care, with challenges such as lack of labor force, an increase in the number of persons with dementia and persons with multiple diseases, it might seem unrealistic to suggest personal involvement on this scale (Lloyd et al., 2014; Quince, 2013; WHO, 2021). However, the emotional engagement of the caregivers is essential to enhancing interaction with and meeting the psychological needs of persons with dementia (Alsawy et al., 2020; Ward et al., 2008). If we want person-centered care, relational involvement in caregiving, in verbal as well as nonverbal ways, will always be present.

The three studies explore new ways of combining research methods in the exploration of caregiving in dementia care. PAMI is approached from an interpretive and co-created perspective including that of music therapists and caregivers. The findings regarding the understandings and experiences of PAMI are situated and ideographic, and studies 2 and 3 describe PAMI in a Danish context. Whether the approaches described are representative or not still needs to be further explored. Orii McDermott and Bryony Waters are researching the adaptation of PAMI into a UK context, and future research collaborations might examine cultural variations of PAMI.

7.2 REVISITING THE CONCEPT OF PAMI

As demonstrated in article 2, verbalization of nonverbal interactions can be difficult, and the constructed discourse has implications for the dissemination and practice of PAMI. Wittgenstein's later philosophy illuminates how language emerges from use in practice (1967). Therefore, I find it relevant to question whether PAMI is the appropriate concept to describe the actual phenomenon, and, in the following, I will discuss the concept.

P for person-centered care (Kitwood, 1997) is the first letter in PAMI, and the concept is based on this metatheory. Even though the application of person-centered care is widely used, there is limited knowledge on which types of interactions that constitute person-centered care (Wu et al., 2020). Wu and colleagues identify six purposes for conducting person-centered care and give suggestions for which types of interactions can support the presented purposes. Several findings regarding types of interactions are similar, according to Wu et al. (2020) and the findings of this study. Wu et al. emphasize the importance of body language, tone of voice and approaches that can reassure the individual. However, the suggested interactions do not take the nonverbal aspects of communication in dementia care into account. To communicate without verbal language requires a high degree of sensitivity and desire to communicate from the caregiver (Alsawy et al., 2020; Ellis & Astell, 2017). In this doctoral thesis, I focus on nonverbal aspects of communication and use the term interaction instead of communication to underline this dimension. However, I have had a pragmatic approach to exploring, understanding, and applying PAMI, and microphenomena of nonverbal interaction such as eye contact or tone of voice could have been examined in more detail to enhance and ground the understanding of nonverbal interaction.

The findings from articles 1 and 2 reveal that the practice of person-centered care entails attunement and sensitivity towards the person with dementia.

Throughout the thesis, attunement is understood as a dynamic process of reciprocal, empathic synchronization, in which musical elements such as tempo and timing are integrated. Based on the findings in study 1, attunement is perceived as a positive phenomenon that can bring two people closer to each other. Attunement is, nevertheless, a concept that is not very frequently used in dementia research, and the meanings of which can be very diverse, depending on the context in which the concept is applied (Ahmed, 2014; Heidegger, 1927/2004; Jeong, 2020). This diversity and the various connotations of the word can make it difficult to articulate the characteristics of attunement and to implement it into practice. Furthermore, the breadth of the concept can explain why it is not used very frequently in dementia care research. Nevertheless, attunement inhabits a musical and dynamic dimension of interaction that I find essential, and that can sometimes be overlooked in other concepts describing the phenomenon, such as bidirectional communication or synchronization. The musical connotations integrated in attunement might support the caregiver in approaching the person with dementia in a dynamic and flexible way. Working with lived-experience descriptions, in which music therapists and caregivers unfold emotional and bodily aspects of interaction could also support the understanding and application of attunement.

7.3 THE APPLICABILITY OF PAMI

In this section, I discuss implications concerning the applicability of PAMI. I address PAMI in relation to indirect music therapy practice, the interdisciplinary nature of PAMI, and I touch upon power as a consideration to be aware of in interdisciplinary contexts. Finally, I relate PAMI to the philosophers Michael Hardt and Antonio Negri's concept of affective labor.

PAMI and indirect music therapy practice

Indirect music therapy practice is a term coined by Bunt & Stige to describe the “possibilities for the music therapy profession in realizing its purpose of promoting human health” (2014, p. 186). This specific practice is increasingly used by music therapy professionals in Denmark and Norway and with a rationale based in an ecological perspective of music therapy (McDermott et al., 2018; Stige, 2016). Indirect music therapy practice has not yet been explored systematically in research. Based on limited publications, the understanding of the phenomenon is very broad, and its form of practice depends on the exact context in which it takes place (Bunt & Stige, 2014; McDermott et al., 2018; Ottesen & Krøier, 2018).

Interest in music in dementia care is increasing, and there is a need to expand music therapy practice to include system-oriented ways of working (McDermott et al., 2018; Stige, 2016). PAMI provides music therapists who work indirectly in dementia care with a framework that can support this way of practice and ground it theoretically. Indirect music therapy practice requires other skills of the music therapist than direct forms of music therapy practice. The music therapist must be highly aware of the organizational structure in which the practice takes place and attune to the needs of the person with dementia, and the caregiver (McDermott et al., 2018; Stige, 2002). It is my experience that indirect music therapy practice requires a high degree of monodisciplinary integrity, excellent communication skills, and a curiosity about other professionals and their forms of practice.

In Figure 5, I wish to illustrate PAMI in indirect music therapy practice. Whereas I integrate the findings and purposes of PAMI with the FRR theory in figure 4, this figure illustrates the relationship between the person with dementia, the caregiver, and the music therapist. PAMI is situated in a nursing home ecology with different tasks, foci, and professions, and illustrated with the oval that connects the caregiver and the person with dementia. The music therapist is supporting the caregiver in interacting with the person with dementia and PAMI is connecting them. The dynamic process of attunement is present in all meetings between individuals and illustrated with small arrows.

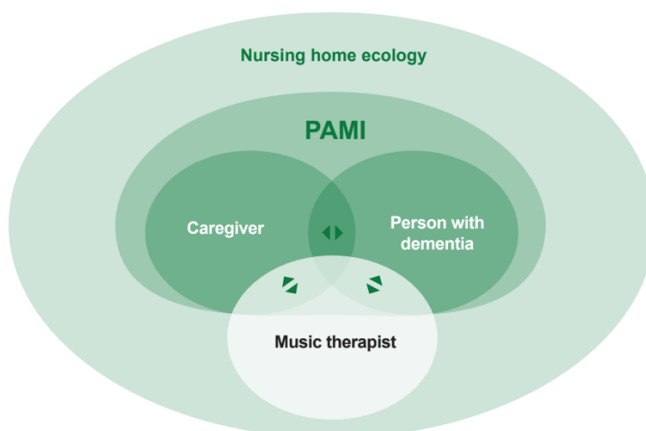


Figure 5. PAMI in indirect music therapy practice.

PAMI as an interdisciplinary phenomenon

As outlined throughout the thesis, PAMI is a relational concept that involves persons with dementia, caregivers, and other professionals. In the three articles, I focus on PAMI between professional caregivers, music therapists,

and persons with dementia living in nursing homes and, throughout the linking text, I have described how music therapists who have advanced academic training have the competence to facilitate PAMI. It is, however, important to stress that I consider PAMI to consist of interactions that can be performed by everyone, despite musical background, if the will to interact and connect is present. Research in music sociology has shown that people naturally engage with music in ways that promote their health and life quality if they are given the musical affordances such as musical training or the ability to listen to favorite music (DeNora, 2000; Ruud 2020). The diversity in the PAMIs performed in article 3 illustrates that PAMI can be adjusted and tailored in various ways and, for instance, include listening to music or of movement if the caregiver is uncomfortable with singing.

In my previous positions as music therapist, I have supported caregivers in exploring their own musicality and using it relevantly in their practice. Music therapists, however, should be sensitive to the powers of music. Music is a strong medium and can potentially be just as manipulative and harmful as it is therapeutic (Silverman, 2020). Norwegian Professor emeritus in music and health, Even Ruud (1997, p. 91), describes involvement in music as "a potential resource for obtaining a better quality of life". When facilitating PAMI, it is therefore relevant to support the caregivers in sensing and deciding when musical interactions are a potential resource for obtaining better quality of life for persons with dementia, and when not.

Power dynamics

Many power dynamics are involved in health care (Nicolini, 2012; Rolvsjord, 2010). Persons with dementia living in an institutional setting are deeply dependent on help from caregivers, and it is vital to question which kinds of practices are performed and to benefit whom. PAMI may potentially empower caregivers by giving them new nonverbal approaches to apply in their practice. As PAMI is a reciprocal phenomenon, the interaction might then have a positive influence on both the person with dementia and the caregiver whereby the use of PAMI may potentially create new opportunities for action, self-expression, and inclusion for the person with dementia.

In the same way, music therapists in indirect practice have the power to support and expand opportunities and actions for both the caregiver and the person with dementia. In the process of supervising and training caregivers in how to apply PAMI, I find it crucial to communicate the use of musical interaction with great respect towards the caregivers and their boundaries. Musical interaction on a preverbal level may reveal feelings and memories that the caregivers might not want to express and assess in the work

environment. Bruscia (2014) suggests, with inspiration from Sprague & Hayes (2000), to distinguish between *power over* something and *power to* do something. The caregivers have the power and responsibility to create well-being for the person with dementia, and the music therapist has the power and responsibility to promote the ethical application of musical interactions attuned to the unique person with dementia, and with respect for the caregiver.

When addressing issues of power and freedom, Bruscia furthermore (2014) proposes to strive for authenticity in the relationship between client and therapist. He suggests that “authenticity involves recognizing the powers and freedoms that one does and does not have and then taking responsibility to act in a way that is consistent with these powers and freedoms” (Bruscia, 2014, p. 292). The endeavor towards authenticity in both the caregiver-music therapist relationship and the relationship between the person with dementia and the caregiver can thus serve to clarify and enhance the understanding of power and empowerment in indirect music therapy practices.

PAMI as affective labor

Care is vital to daily living (Mol et al., 2010) and based on specific tasks such as assistance when showering, dressing, eating, and in activities. The influence that the professional caregivers have on individuals with dementia cannot be underestimated. Even if caregiving is often considered a low skilled job, it is complex and demanding psychologically, physically, and socially (Kitwood, 1997; Ward et al., 2008; Windle et al., 2019).

In dementia care, an essential element of caregiving is to be present and to show concern for the other (Ellis & Astell, 2017; Kitwood, 1997). Using the terminology of Heidegger, the caregiver may help the person with dementia to dwell in being-in-the-world (1927/2004), even when the person might feel alienated from their surroundings due to the symptoms of dementia (Jeong, 2020). This affective⁹ aspect of caregiving is sometimes underestimated and not considered; even though the well-being of the care recipient is highly dependent on the caregivers’ empathic engagement (Alsawy et al., 2017; Banerjee et al., 2015; Ellis & Astell, 2017; Ward et al., 2008). The lack of conceptualizing the affective aspect of caregiving can be due to challenges in operationalizing and measuring care (Det Etiske Råd, 2022). However, emotions and feelings are embedded in the practical tasks of care work, as illustrated in the narratives in study 3. To meet the psychological needs of the

⁹In this context affect refers to the experience of feeling or emotion and plays a central role in the process of the individual’s interaction with the surroundings (Zajonc, 2000).

person with dementia and to perform practical tasks are interwoven processes and both aspects are essential in caregiving.

PAMI can – as exemplified in the studies – support interaction, increase collaboration between caregiver and the person with dementia in a care situation, and meet the psychological needs of the individual. Due to the affective impact PAMI can potentially have for the person, PAMI can be understood as affective labor as described by Hardt & Negri (2004). According to Hardt & Negri, affective labor defines practices that produce, create, or manipulate affect. Affective labor is, thus, creation or production of intangible products such as well-being, satisfaction, or community feeling (Hardt, 1999, p. 96). In affective labor, subjectivities and social relations are products, and the worker's own self is given value in the work, which can blur the distinction between employment and life outside of employment. Types of affective labor could be, for instance, breast feeding consultant, therapist, wedding planner or sex worker; labor that involves body, soul, reasoning, and emotions and thus feeds on life itself in an intense way (Sharma & Dahl, 2013). Like domestic labor, caregiving can be approached as affective labor involving cleaning and cooking, but also producing affect, relationships, and communication in the facility where it takes place (Oksala, 2016). Affective labor is often required of women, but it is important to acknowledge that it is not exclusively performed by women (Oksala, 2016). Labeling caregiving as affective labor could contribute to making the affective aspect of care work visible and to recognize the impact that this work has on both caregivers and persons with dementia.

The findings in study 1 stress the importance of an empathic approach when seeking attunement between the caregiver and the person with dementia, and the narratives from study 3 reveal how certain pieces of music related to life events can induce emotional responses from the person with dementia. When applying PAMI in practice, it is essential to reflect on how to support the affective labor of the caregivers and make this way of working sustainable. As mentioned in chapter 2, caregiving for persons with dementia has been associated with burnout, and several factors might explain this fact, including lack of reciprocity and low self-efficacy (Duffy et al., 2009). Group supervision and individual supervision may therefore be relevant when supporting caregivers in applying PAMI, providing an opportunity to reflect on and develop practice. Self-efficacy may also be influenced positively in this way.

7.4 EVALUATION OF THE CONDUCTED RESEARCH

In the following section, I evaluate the research of this thesis by applying EPICURE, which is an agenda for evaluating qualitative research to strengthen reflexivity and encourage dialogue regarding the findings in the three studies (Stige et al., 2009).

Engagement

Engagement refers to the researcher's interaction and relationship with the phenomenon that is being studied (Stige et al., 2009). As described in chapter 1, I have worked in dementia care for many years and have had different roles, as both caregiver and music therapist, and have used direct as well as indirect music therapy approaches. I perceive my engagement in the context of PAMI as a resource that has given me implicit knowledge about caregiving and the working culture in Danish nursing homes. This knowledge has been relevant for interacting and collaborating with the caregivers in study 3, both verbally in the workshops and nonverbally when I took part in the care tasks. I know from my own bodily and emotional experience how demanding caregiving can be, and therefore I wish to approach the caregiving context in the role as researcher with a great deal of respect.

Processing

Processing involves producing, ordering, analyzing, and preserving empirical material (Stige et al., 2009). In the three studies, various empirical data, such as transcripts, field notes, and research literature were collected and analyzed according to the different methods applied. The data was systematized using the software program Nvivo, and several display sheets and sub-documents. Documents describing the different steps in the analysis were attached to the articles as supplementary material.

In the second study, I applied musical improvisation to elaborate on emerged themes from the phenomenological analysis. It could have been relevant to include the audio recordings of the improvisations to enhance transparency. However, it was the dialogue that developed out of the musical improvisation that influenced the elaboration of the findings and not the music itself, and I therefore chose not to include it.

In study 3, the caregivers contributed to and validated the constructed narratives. I could have chosen to involve the caregivers in the data analysis as well to enhance participation and validity of the findings. Due to the global COVID-19 pandemic and limited resources this was, however, not possible.

Interpretation

Interpretation refers to the act of creating meaning by identifying patterns and developing contexts for understanding experiences and descriptions (Stige et al., 2009). I had several roles in the studies, which calls for reflexivity and flexibility when interpreting data. In study 2, I first participated as a music therapist, and thereafter had the role of researcher in the arts-based elaboration of the initial themes and in the data analysis. In study 3, I had the dual role of being both music therapist conducting the collaborative learning process and researcher analyzing the data. In study 2, I wrote an epoche to be able to assess the influence of my pre-understandings on the data. Furthermore, the analysis processes were discussed in the PAMI research group to enhance reflexivity.

PAMI is a theoretically informed concept; a framework to describe interactions taking place in dementia care. Throughout the thesis, I have attempted to explore and unfold the concept to enhance the understanding of PAMI. I have applied abductive reasoning, and theory and empirical data have informed each other reciprocally. The abductive movement between theory and data was especially noticeable in study 2, in which the music therapists used theoretically informed language to describe their practice.

Critique

Critique in the context of EPICURE refers to both self-critique and social critique (Stige et al., 2009). An important point of critique regarding both types is the lack of persons with dementia participating in the study. The degree to which the present research study is person-centered can therefore be criticized. Studies 1 and 2 illustrate the challenges of translating nonverbal interaction into text. However, I have found it relevant to attempt to do this. By describing the examples of PAMI embedded in caregiving, it is possible to enhance interdisciplinary inspiration. I applied musical improvisation to explore additional dimensions of nonverbal interaction, but other media such as video could also have been relevant to use.

Caregiving is a profession under pressure, and caregivers often have low pay and limited prospects for professional development (Windle et al., 2019). Furthermore, there is a need for developing relational care (Banerjee et al., 2015; Wu et al., 2020). Caregivers may have a central role in the development of future caregiving. According to Philips et al. (2022, p. 407) arts-based co-production of research “furthers the heightened negotiation of knowledge across voices, and thus carries the promise of radically destabilizing traditional knowledge hierarchies and generating knowledge that can contribute to research *and* social and practice transformation”. The inclusion of practitioners – music therapists and caregivers – in exploring PAMI through

phenomenology, arts-based research, and co-production of data may thus inspire to democratic and dialogic research discourse regarding dementia care.

Usefulness

Usefulness refers to a researcher's effort to describe how the research process and products are useful in practice (Stige et al., 2009). To enhance the usefulness of this research, I presented data and analysis to peer researchers and music therapy colleagues throughout the research process and received feedback regarding the findings and the embedded concepts. Furthermore, my situatedness as a music therapist in the field and my experience with caregiving fed into my reflections as a researcher and enhanced my understanding of the interdisciplinary field and how PAMI can be applied.

The caregivers in study 3 stated that participating in the collaborative learning process and listening to the co-created narratives made them "think a lot" (Krøier & Ridder, 2022, p.11). The caregiver's participation in the research may thus have led to new professional and personal knowledge with a positive impact on future practice and understanding of practice (Philips et al., 2022).

In section 6.1, I present ideas as to how PAMI can be integrated into care work. The findings from studies 1 and 2 informed study 3, during which the caregivers found the application of PAMI useful and meaningful in their work. To ensure the usefulness of PAMI, it could have been relevant to include the perspectives of nursing homes managers who plan and lead the daily work.

Relevance

Relevance in the context of EPICURE refers to how the study contributes to development of the involved discipline(s) or interdisciplinary fields (Stige et al., 2009). Prior to the PAMI research, Ridder and I experienced that many music therapists requested guidelines on how to implement music in caregiving. Similarly, there exists a need for exploring how to conduct person-centered care and how to train caregiving in this approach (Livingston et al., 2014; Wu et al., 2020). Hsu et al. (2015) and Ray et al. (2016) present suggestions for how to prolong the positive outcome of music therapy, and Beer et al. (2012), and Ottesen (2014) provide learning formats to support the interpersonal and musical competence of the caregivers. I suggest that PAMI may provide a theoretical framework that relevantly synthesizes important aspects of applying musical interactions in dementia care interdisciplinarily. The use of a shared concept to describe the interdisciplinary application of musical interaction may improve collaboration and contribute to person-centered care.

Ethics

Ethics refers to how values and moral principles are integrated in the actions and reflections of research (Stige et al., 2009). In section 3.4, I present ethical considerations regarding the study, and each of the three articles contains sections in which I describe the ethics of the specific study.

7.5 LIMITATIONS

This PhD thesis has several notable limitations. Limitations for each of the three studies are described in the articles, and in this section, I reflect on the limitations of the overall research project and design in which a triangulation strategy was applied.

Where is the voice of the person with dementia?

PAMI is rooted in person-centered care, and musical interactions should not be applied if the person with dementia does not find them meaningful. Due to the essential role of person-centered care in PAMI, I find it relevant to address why no persons with dementia took part directly in the three studies. I consider it a significant limitation that no persons with dementia participated, but by involving the caregivers who knew the person with dementia and their daily routines well, I tried to conduct research from the perspective of caregiving, in which the person with dementia is central. According to Mol et al. (2010), academic literature puts the person that receives care in a vulnerable position, as they experience exposure of the problems related to the care that they need to receive. The persons in need of care are, in this way, represented as passive and in lack of power. The purpose of involving persons with dementia in research is to bridge the gap between current clinical research and the wishes and priorities of the persons themselves (Downs & Bowers, 2014), and, furthermore, to give the persons a more active role. Studies have shown that persons with moderate dementia can participate in research processes, but that ethical consideration is necessary to ensure a meaningful experience for the individual (Alsawy et al., 2020; McDermott et al., 2013; Thoft et al., 2020). In this thesis, I focus on PAMI with persons with advanced dementia, who are often nonverbal, and for whom it can be difficult to participate in interviews and workshops based on narratives and verbal reflection, as in studies 2 and 3. To explore how persons with advanced experience PAMI, I find it relevant to apply other methodological approaches that do not rely on verbalization of text, as do the methods applied in this thesis.

Research Design

I applied a methodological triangulation strategy and used several data collection methods to elucidate PAMI (Denzin, 1978). PAMI was approached

through: (1) the research literature, (2) music therapists, and (3) caregivers. PAMI is a concept describing cohesive actions, with different sub-elements, such as attunement and nonverbal interactions. In studies 1 and 2, attunement and nonverbal interaction were explored. Article 1 revealed that the other sub-elements in PAMI – person-centered care, nonverbal and musical interaction – were embedded in the concept of attunement. Similarly, the music therapists in study 2 referred to attunement and musical elements as central elements of the nonverbal interaction. Thus, the findings and research processes illustrate the relevance of labeling PAMI as a complex, cohesive type of interaction integrating person-centered care, attunement, and musical and nonverbal interaction in one concept.

I find it worth noting that the music therapists in article 2 have different roles and tasks than the caregivers, and that they may experience and articulate nonverbal interactions differently in music therapy than the caregivers experience them in care situations. This aspect emphasizes the need for developing and integrating a shared terminology of PAMI.

The use of triangulation made it possible to integrate different methods and data in the exploration of PAMI. Furthermore, this strategy provided the means to explore PAMI from different professional perspectives and compare the findings from articles 2 and 3 with the research literature regarding attunement. I found the integration of findings from the perspective of the caregivers, music therapists, and the research literature relevant, as PAMI is an interdisciplinary concept, and different understandings and experiences could be incorporated into one shared concept. However, I also find it problematic to apply methodological triangulation when comparing studies focusing on different sub-elements of PAMI. In relation to this problem, it is relevant to stress that the similarities between the findings indicate that the sub-elements of PAMI are closely interwoven and inform each other reciprocally.

The methodological triangulation strategy contributes to illustrating similarities and differences in the findings between the three studies in the ways that the caregivers and music therapists experience and understand PAMI. Triangulation may thus validate the findings as descriptions and understandings of PAMI on a general level, but there is a need for further examination of PAMI and its impact, and for including the person with dementia in this process.

7.6 IMPLICATIONS FOR FUTURE RESEARCH

As the findings indicate, person-centered care, attunement, and a focus on nonverbal and musical interaction are closely related in PAMI. It could be relevant to research the micro elements embedded in PAMI, such as eye contact, gestures, and tone of voice, to generate knowledge about the mechanisms of PAMI. Furthermore, I find it crucial to research the potential outcome of applying PAMI in a nursing home context. A relevant outcome to research could be quality of life for the person with dementia. By creating a PAMI training guide or manual, and training caregivers, PAMI could serve as a conceptual framework for indirect music therapy practice and be applied in research designs that ensure the possibility of replication as, for example, in randomized controlled trials examining the potential effect of working systematically with PAMI in dementia care. Future research could investigate longer-term specific outcomes of applying PAMI and consider the severity and types of dementia so as to produce knowledge concerning which kinds of PAMIs are relevant for whom.

As described throughout the discussion of the linking text, the lack of persons with dementia constitutes a significant limitation in this PhD study. To determine the relevance of PAMI, it is therefore important to include the perspective of the person with dementia in more active and direct ways than in the current three articles. The use of video analysis, Dementia Care Mapping, (Brooker, 2005) and involvement of friends and family of the person with dementia could be relevant methodological approaches for exploring the meaning of PAMI for the person. Another methodological perspective on the research process could also enhance the inclusion of persons with dementia in future research. Person-centered research (Jacobs et al., 2017) is a methodology based on person-centeredness which includes relational, contextual, and political perspectives. According to Jacobs et al. (2017, p. 52-53), person-centered research is based on connectivity, which refers to the relationship from which we as humans grow and flourish, and on the fact that knowledge is also a coaction among people. Person-centered research may be one methodology to practice person-centeredness and research *with* persons with dementia rather than doing research *about* them (Jacobs et al., 2017).

This study explored PAMI with homogeneous groups (regarding age, gender, cultural background) in local contexts. This reflects an ideographic approach to the exploration of PAMI, and I see a need for future studies that explore PAMI in a broader context and with diversity in the group of persons with

dementia, caregivers, and music therapists. Cultural adaptation will be an important aspect to integrate into future studies.

The methodological approaches outlined in this thesis elucidate the potentials of using arts-based research such as musical improvisation in exploration of complex human phenomena such as nonverbal interaction in dementia care. Like PAMI, arts-based research is an embodied and aesthetic practice that can elucidate dynamic and complex dimensions of being human.

7.7 RECOMMENDATIONS FOR PAMI TRAINING

Based on the integration of findings in chapter 6 and the discussion, I will in the following present recommendations for PAMI training for caregivers in dementia care.

The overall aim of integrating PAMI into care practices

Working systematically with PAMI can support caregivers in describing nonverbal interactions integrated into care tasks. The primary aim of PAMI training is therefore to support caregivers in new ways of practice by introducing them to PAMI with persons with dementia.

Target group

Participants. When it comes to caregivers as the target group for PAMI training, it is important to consider that caregivers are not a homogeneous group. In Denmark, there are two kinds of educational programs in caregiving at the Social and Health Care College: *Social- og sundhedshjælper* (basic level) and *social- og sundhedsassistent* (intermediate level). PAMI is targeted *social- og sundhedsassistenter*. Based on the collaboration with caregivers in article 3, I suggest that PAMI be primarily targeted professional caregivers working in dementia care, as they have the primary contact with the person with dementia, which makes it possible to work directly with reflection-on-action.

Facilitator. Based on the research processes in article 2, I consider music therapists with advanced training to be competent in communicating the content and potential of PAMIs. The findings from article 2 demonstrated that music therapists can describe and reflect upon the tacit musical elements embedded in nonverbal interaction in dementia care. Study 3 illustrated that a music therapist with experience in dementia care and with indirect music therapy can facilitate a relevant learning process for caregivers. Other studies also confirm the relevance of music therapist-led learning presentations and

learning processes for caregivers (Beer, 2017; Hsu et al., 2015; Ray et al., 2016).

Ethics regarding PAMI training

PAMI is not music therapy, and PAMI training should not be music therapy either. It is important to bear in mind that music is a strong media that can touch us in deep and nonverbal ways (McFerran & Baird, 2013; Stige & Ridder, 2016), and that working with music and singing can trigger emotional reactions in caregivers. I therefore consider it imperative that the music therapist respects the boundaries of caregivers if working with music becomes overwhelming.

Caregivers and music therapists have the duty of confidentiality regarding their experiences in applying PAMI in dementia care.

Learning theory background

When integrating PAMI into care practice, I find it important to introduce the caregiver to *what* PAMI is, *why* it can have a positive influence on people with dementia, and to support the caregiver in *how* to apply PAMI. The caregivers' ability to transfer achieved knowledge to their daily practice should be prioritized and the FRR theory may therefore be helpful in focusing the different types of PAMIs. In the following, I relate the presented learning theory introduced in section 2.5 to PAMI and present suggestions as to how PAMI can be taught and trained.

The findings from articles 1, 2, and 3 contribute to a definition and verbalization of different types of PAMI that can be presented to caregivers. Through active participation in a learning process with the facilitating music therapist, the caregivers develop a shared vocabulary for describing PAMI with persons with dementia. By critically reflecting on practice, the new concepts presented can be integrated, and the caregivers can develop their practice. It is essential that the music therapist can create a safe teaching environment, in which the caregivers feel confident enough to reflect critically on their own experiences in applying musical interactions in practice. Critical reflection (Mezirow, 2012) has, thus, the potential to transform the practice of the caregivers and, for example, help them achieve a new awareness about their use of voice when performing care tasks.

Integrating the experiences and resources of caregivers can be included in PAMI training and ensure a sustainable format, acknowledging and building on the daily efforts of the caregivers. One way to integrate the experiences of the caregivers is lived-experience descriptions and narratives as applied in

studies 2 and 3. The caregivers describe, with help and facilitation from the music therapist, experiences with music interaction. This can support the caregivers in verbalizing PAMI and integrating theory and practice. In this way, PAMI training can become a circular process in which experiences are revisited, reflected upon, and reintegrated into practice with new perspectives, competencies, and knowledge (Kolb, 1984).

PAMI is a nonverbal and bodily phenomenon, and it is therefore important that the caregivers also feel, sense, act, and sing when being introduced to PAMI, so that they have embodied experiences and, in this way, learn by doing (Paniagua & Instance, 2018). I therefore consider embodied and musical exercises to be an essential part of PAMI training.

Formats of PAMI training

Based on the presented learning theory (section 2.5), embodied experiences, and the experiences with the collaborative learning process in study 3, I describe four different PAMI training formats. In the following, I present the formats and relate them to relevant theories of learning.

Lectures on theory regarding music and dementia. The caregivers are presented with the theoretical foundations for applying PAMI in their practice and to the FRR theory. The theory is presented with PowerPoints by the involved music therapist with teaching experience. The lectures contain dialogue so as to make them relevant and practice based. The lectures provide the caregiver with knowledge about music and dementia and give examples of PAMIs and how PAMIs can be applied according to the FRR theory. I suggest four lectures of one hour each with the following themes: (1) music and dementia, (2) PAMI and framing, (3) PAMI and regulation, and (4) PAMI and relationship.

Exercises. After having had a lecture on theory, the caregivers meet four times to do exercises related to the theme of the lecture. The purpose of the exercises is to create a space for embodied learning (Paniagua & Instance, 2018) and support the caregivers in verbalizing nonverbal, bodily, and musical experiences. Through the exercises, the caregivers can reflect on their own relationship to music and singing and try out different ways of applying PAMI, as, for example, using singing for regulating arousal or applying music for reminiscence. In each workshop with exercises, the caregivers work with creating lived-experience descriptions, in order to become conscious about the aspects of their practice that already work and to train them in how to verbalize the tacit knowledge that is embedded in their application of PAMI.

Learning and working are often thought of as two separate processes (Nevalainen et al., 2018). Based on the findings from the collaborative learning process in study 3, supervision can be a way of enhancing learning and implementing the new knowledge into care practice. According to theories of experiential learning (Kolb, 1984), we learn from reflecting on previous experience and then become conscious of new ways of working. It is therefore relevant to include supervision in the practice context, as in study 3. Furthermore, meetings where caregivers can reflect on their practice are relevant, as I consider learning to be a social practice in which the caregivers can encourage and inspire each other (Lave & Wenger, 1991).

Group supervision. Group supervision gives the caregivers the opportunity to reflect on their experiences and to plan how to implement PAMI in their daily practice. Group supervision takes place four times, and each meeting is focused on a theme from the theory module. The facilitating music therapist leads the supervision process and supports the caregivers in verbalizing their experiences. The learning taking place in the group supervision is thus a circular learning process as described by Kolb (1984). The caregivers reflect on concrete experiences, conceptualize these experiences, and finally plan pragmatically how to try out new initiatives.

Individual supervision in the practice context. The music therapist participates in the care situations and demonstrates how musical interactions could be applied in daily care routines. The music therapist participates four times, for one hour each time, in the care work together with each caregiver. Individual supervision gives the caregivers the opportunity to be guided in how to apply PAMI with different intentions according to the FRR theory.

If the caregiver has never worked with musical interaction in care situations, they can feel very vulnerable about singing or humming. It might feel safer and easier to use PAMI with the music therapist and the person with dementia than in a group of colleagues.

As illustrated in figure 4, PAMIs are influenced by the nursing home ecology in which they take place. Based on the findings in study 3, I find it important that the PAMI training can be tailored flexibly to fit a given context. I therefore suggest that the precise application of PAMI training is planned and organized in close collaboration with the management of the nursing home concerned.

CHAPTER 8. CONCLUSIONS

In this article-based thesis, I explored the concept of person-attuned musical interaction (PAMI) that is rooted in the person-centered approach to dementia care. PAMI captures the implicit, attuned, often nonverbal musical interactions taking place between persons with advanced dementia and their caregivers in nursing homes, and the concept served as the reflective starting point for this research.

My doctoral research was designed around the main research question: *Which theoretical, clinical, and methodological elements define person-attuned musical interaction (PAMI) with persons with advanced dementia living in nursing homes?* The question was approached through a pragmatic and flexible research design in which the methods for the three studies emerged during the data collection and analysis. The main research question was answered through three studies, each examining different elements of PAMI from different perspectives, which were integrated in a methodological triangulation strategy. Conclusions from each of the three studies are included in three articles. I will now highlight the conclusions that can be drawn from the thesis as a whole and answer the main research question.

Study 1 centered on examining research literature concerning attunement in dementia care with the aim of exploring how the concept is used and understood. This led to a scoping review in which six studies were identified, analyzed, and synthesized. Based on a meta-ethnographic analysis of the included studies, attunement in dementia is understood and applied through the person-centered approach to care. For attunement to take place, the caregivers need to be empathically involved and able to adjust the tempo of their actions so that they are timed to the tempo of the person with dementia. These findings suggest that the four components of PAMI (the person-centered approach, attunement, musical, and interaction) are interrelated, which strengthens the understanding of PAMI as a complex concept that can describe interactions of a certain quality between the persons with dementia and their caregivers.

In study 2, I explored how music therapists working in dementia care experienced nonverbal interaction with persons with advanced dementia. This research demonstrated that the participating music therapists had a sensitivity to describing nonverbal interactions, and the findings revealed that attunement, vitality, and validation were central for the music therapists in their experience of nonverbal interaction. Additionally, the participants

emphasized therapeutic presence and disciplined subjectivity as important elements in their experience of nonverbal interaction. The use of theoretically informed language was noticeable in the findings and includes the possibility of giving precise descriptions, but at the same time the risk of excluding professionals who are not a part of this discourse.

The aim of study 3 was to investigate how professional caregivers use and understand PAMI in the framework of a collaborative learning process. The findings demonstrated that PAMI has diverse manifestations and, according to the participating caregivers, has positive relevance in care situations as well as in supporting the interaction with the persons with dementia. Similarly, to the music therapists, the caregivers also mention vitality and attunement as central elements in PAMI. Study 3 engaged the caregivers actively in the data generation process and thus integrated their views directly in the exploration of PAMI.

The findings from the three studies were compared and discussed in order to elucidate similarities and differences between the three perspectives and foci. The studies revealed that the concepts of attunement, vitality, a broad understanding of what music is, and person-centered care are central in the experience and understanding of PAMI for both the participating music therapists and caregivers. The music therapy theory of framing, regulating and relating was applied to the findings, in order to provide a direction for the application of PAMI, which was found relevant when communicating PAMI to caregivers.

Based on the findings and the research processes, I conclusively presented recommendations for PAMI training for caregivers in dementia care. Music therapists have, due to their education, a sensitivity that aids them in describing PAMIs, and training and supervising caregivers may therefore be provided by music therapists. Transformative and experiential learning can be relevant approaches from learning theory to communicate PAMI. PAMIs are embodied and mainly nonverbal, and I therefore consider the integration of embodied learning approaches with exercises with which the caregivers can apply and train PAMI as highly pertinent. Supervision both in practice and in groups may further encourage caregivers in applying PAMI and ensure ethical practice.

This thesis constitutes systematic research into interdisciplinary dementia care and the meanings that PAMI has in this context. The findings may inform training material for indirect music therapy practice and support the articulation of the nonverbal interactions in dementia care practices. The

concept of PAMI would, in the future, benefit from research that applies other methodologies and other types of data for exploring its relevance, especially from perspective of the person with dementia.

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APPENDICES

Appendix A. Epoche

The epoche was written just before I started the data analysis of transcripts of the focus group interviews in study 2. I had worked with PAMI in a research context for 18 months and it was approximately two years since I participated in the focus groups. The epoche elucidates my pre-understandings and expectations regarding nonverbal interaction between music therapists and persons with dementia. The text was originally written in Danish (A) and is in table B translated into English. The table format is applied to give an overview of the different elements of the epoche.

A

Hvad forventer jeg at finde?

Jeg forventer at Musikterapeuternes (MT) oplevelsesbeskrivelser netop er meget beskrivende, sanselige og subjektive. Jeg har også en forestilling om at sprogbruget vil være meget musikterapeutisk. Jeg er meget spændt og nysgerrig på hvordan jeg får det omsat til essenser, der evt. kan være retningsgivende i andre kontekster

Jeg forventer også at en del af sprogbruken vil relatere sig til vitalitetsdynamikken som MT er skolet i. Og at deres følsomhed på nonverbale processer vil skinne igennem.

Deres bevidsthed om grænser

En søgen efter gensidighed og synkronisitet.

Dialoger og duetter, ensembler.

Når nonverbale interaktioner er smukkeste, er de ligesom musik og flyder frit mellem to mennesker uagtet statusforskelle og diagnoser.

PAMI og nonverbal interaktion er urform for samvær rodfæstet dybt og tidligt i mennesker.

Jeg håber også at musikterapeuterne giver konkrete eksempler på nonverbale interaktioner. Nogle gange er de svære at indfange i ord. Og alt det der sker uden ord, flyver let.

Jeg forventer at oplevelsesbeskrivelserne kan sige noget generelt om afstemningsprocesser og skøn for handlinger. Hvad er det der sker? Hvorfor er det nogle gange så svært at være sammen med borgere uden ord? Jeg synes også det er svært nogle gange og nogle gange kan jeg slet ikke læse borgerens

behov. Hvad er det der går galt, hvorfor er det svært? Jeg har også brug for at øve mig 1000 gange og for at lære borgerne at kende og opbygge min tavse viden. Allervigtigst i den læringsproces er det at være barmhjertig og tålmodig med sig selv og at øve sig, gøre sig umage! Det er så vigtigt og måske forstår jeg det først rigtigt nu og ikke da jeg startede hverken i plejen eller som musikerapeut.

Jeg forholder mig åbent over for det meget fine stykke arbejde M har lavet. Jeg vil gerne vise det al respekt og prøve at lave en meningsfuld og sammenhængende analyse. Jeg har en forventning om at workshopsdata kan kaste nyt lys over musikalske parametres rolle i afstemningsprocesser. Og tydeliggøre Afstemte musikalske samhandling?

Efter kort at have skimmet data og når jeg tænker tilbage på de to år der er gået, kan jeg også mærke at der er sket rigtig meget. Jeg har haft andre ansættelser og arbejdet mere direkte med undervisning og supervision end jeg havde på det tidspunkt. Da workshopsne fandt sted, var jeg vred på systemet, besparelser og hårde arbejdsvilkår.

Med ind i dataanalysen har jeg en masse ønsker, ambitioner og intentioner, som måske kan komme til at blokere for et åbent og ærligt blik på data.

Mit blik er præget af:

- 1) Egenerfaring fra plejesektoren. I have squeezed my soul.
- 2) På trods af det en fortsat kærlighed til musikken og dens råderum og kraft. Måske fordi det i høj grad var den jeg selv overlevede på....
- 3) et politisk ønske om at gøre en forskel og om at tale SOSU op!

B

Epoche in Danish	Translated to English
<p>Hvad forventer jeg at finde?</p> <p>Jeg forventer at Mt'er oplevelsesbeskrivelser netop er meget beskrivende, sanselige og subjektive. Jeg har også en forestilling om at sprogbruget vil være meget musikerapeutisk. Jeg er meget spændt og nysgerrig på hvordan jeg får det omsat til essenser, der evt. kan være retningsgivende i andre kontekster.</p>	<p>What do I expect to find?</p> <p>I expect that the MTs' lived experience descriptions are in fact more descriptive, sensorial, and subjective. I also imagine that the language they use will be very influenced by music therapy terms. I am very excited and curious about how I can transform this language use into essences that can be a guide in other contexts.</p>

<p>Jeg forventer også at en del af sprogbrugen vil relatere sig til vitalitetsdynamikken som MT er skolet i. Og at deres følsomhed på nonverbale processer vil skinne igennem.</p> <p>Deres bevidsthed om grænser.</p> <p>En søgen efter gensidighed og synkronitet.</p> <p>Dialoger og duetter, ensembler.</p> <p>Når nonverbale interaktioner er smukkeste, er de ligesom musik og flyder frit mellem to mennesker uagtet statusforskelle og diagnoser.</p> <p>PAMI og nonverbal interaktion er urform for samvær rodfæstet dybt og tidligt i mennesker.</p>	<p>I also expect that a part of the language use will be related to the dynamics of vitality, which the MTs have knowledge of through their education. And that their sensitivity towards nonverbal processes will shine through, as will their awareness of boundaries, and of searching for reciprocity and synchronicity.</p> <p>Dialogues and duets, ensembles. When nonverbal interactions are most beautiful, they are like music and flow freely between two human beings despite differences in status and diagnoses.</p> <p>PAMI and nonverbal interaction are core forms of being together, rooted deeply and early in human beings.</p>
<p>Jeg håber også at musikterapeuterne giver konkrete eksempler på nonverbale interaktioner. Nogle gange er de svære at indfange i ord. Og alt det der sker uden ord, flyver let.</p>	<p>I also hope that the music therapists give clear examples of nonverbal interactions. Sometime this is difficult to capture with words. And everything that happens without words flies easily.</p>
<p>Jeg forventer at oplevelsesbeskrivelserne kan sige noget generelt om afstemningsprocesser og skøn for handlinger. Hvad er det der sker? Hvorfor er det nogle gange så svært at være sammen med borgere uden ord? Jeg synes også det er svært nogle gange og nogle gange kan jeg slet ikke læse borgerens behov. Hvad er det der går galt, hvorfor er det svært? Jeg</p>	<p>I expect that the lived-experience descriptions can express something general regarding processes of attunement and estimations of actions. What is it that is happening? Why is it sometimes so difficult to be together with the residents without words? I also find it difficult sometimes and sometimes I am not able to read the needs of the residents. What is it that goes wrong, why is it difficult? I also need to</p>

<p>har også brug for at øve mig 1000 gange og for at lære borgerne at kende og opbygge min tavse viden. Allervigtigst i den læringsproces er det at være barmhjertig og tålmodig med sig selv og at øve sig, gøre sig umage! Det er så vigtigt og måske forstår jeg det først rigtigt nu og ikke da jeg startede hverken i plejen eller som musikterapeut.</p>	<p>practice 1,000 times and get to know the residents and cultivate my tacit knowledge. The most important thing in that learning process is being forgiving and patient with oneself and practicing and making an effort! It is so important, and maybe I only understand it right now and not when I started working; neither as caregiver nor as a music therapist.</p>
<p>Jeg forholder mig åbent over for det meget fine stykke arbejde M har lavet. Jeg vil gerne vise det al respekt og prøve at lave en meningsfuld og sammenhængende analyse. Jeg har en forventning om at workshopsdata kan kaste nyt lys over musikalske parametres rolle i afstemningsprocesser. Og tydeliggøre Afstemte musikalske samhandlinger?</p>	<p>I am open to the fine work M has done. I want to show respect for it and try to make a meaningful and coherent analysis. I expect that the workshop data can shed new light on the role of musical parameters in processes of attunement. And clarify attuned musical interactions?</p>
<p>Efter kort at have skimmet data og når jeg tænker tilbage på de to år der er gået, kan jeg også mærke at der er sket rigtig meget. Jeg har haft andre ansættelser og arbejdet mere direkte med undervisning og supervision end jeg havde på det tidspunkt. Da workshopsne fandt sted, var jeg vred på systemet, besparelser og hårde arbejdsvilkår.</p>	<p>After having briefly skimmed data and when I think back on the two years that have passed, I can also feel that a lot has happened. I have had other positions and worked in a more focused way with teaching and supervision than I had at the time. When the workshops took place, I was angry at the system, financial cutbacks, and harsh working conditions.</p>
<p>Med ind i dataanalysen har jeg en masse ønsker, ambitioner og intentioner, som måske kan komme til at blokere for et åbent og ærligt blik på data.</p>	<p>I bring a lot of wishes, ambitions, and intentions with me into the data analysis that may block an open and honest look at data.</p> <p>My view is influenced by:</p>

<p>Mit blik er præget af:</p> <p>1) Egenerfaring fra plejesektoren. I have squeezed my soul.</p> <p>2) På trods af det en fortsat kærlighed til musikken og dens råderum og kraft. Måske fordi det i høj grad var den jeg selv overlevede på....</p> <p>3) et politisk ønske om at gøre en forskel og om at tale SOSU op!</p>	<p>1) My own experiences from the care sector. I have squeezed my soul.</p> <p>2) Despite of that, I retain a continued love of music and its flexibility and power. Maybe because it was, to a great degree, music that helped me survive.</p> <p>3) A political wish to make a difference and to show the caregivers respect!</p>
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Appendix B. Consent form

Informeret samtykke til deltagelse i forskningsprojekt

Forskningsprojektets titel:

Musik og demens

Delprojekt i "Exploring Person-attuned Musical Interactions Between caregivers and persons with severe dementia"

Erklæring fra deltager

Jeg har fået skriftlig og mundtlig information om forskningsprojektet og jeg ved nok om formål, metode, fordele og ulemper til at sige ja til at deltage.

Jeg ved, at det er **frivilligt at deltage**, og at jeg altid kan trække mit samtykke tilbage uden at jeg mister mine nuværende eller fremtidige rettigheder her på stedet.

Jeg giver samtykke til at deltage i forskningsprojektet, og har fået en kopi af dette samtykkeark samt en kopi af den skriftlige information om projektet til eget brug.

Mit navn: _____

Dato: _____ Underskrift: _____

Erklæring fra den, der afgiver informationen:

Jeg erklærer, at der er afgivet mundtlig og skriftlig information om undersøgelsen. Efter min overbevisning er der givet tilstrækkelig information til, at der kan træffes beslutning om deltagelse.

Navnet på den, der har afgivet information: _____

Dato: _____ Underskrift: _____



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